supplementary material-Wos_results_1to500

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ÔªøFN Clarivate Analytics Web of Science
VR 1.0
PT J
AU Borsch-Supan, A
   Brandt, M
   Hunkler, C
   Kneip, T
   Korbmacher, J
   Malter, F
   Schaan, B
   Stuck, S
   Zuber, S
AF Boersch-Supan, Axel
   Brandt, Martina
   Hunkler, Christian
   Kneip, Thorsten
   Korbmacher, Julie
   Malter, Frederic
   Schaan, Barbara
   Stuck, Stephanie
   Zuber, Sabrina
CA SHARE Cent Coordination Team
TI Data Resource Profile: The Survey of Health, Ageing and Retirement in
   Europe (SHARE)
SO INTERNATIONAL JOURNAL OF EPIDEMIOLOGY
LA English
DT Article
ID CHILDREN; CARE
AB SHARE is a unique panel database of micro data on health, socio-economic
status and social and family networks covering most of the European Union and
Israel. To date, SHARE has collected three panel waves (2004, 2006, 2010) of
current living circumstances and retrospective life histories (2008, SHARELIFE);
6 additional waves are planned until 2024. The more than 150 000 interviews give
a broad picture of life after the age of 50 years, measuring physical and mental
health, economic and non-economic activities, income and wealth, transfers of
time and money within and outside the family as well as life satisfaction and
well-being. The data are available to the scientific community free of charge at
ext-link-type="uri" xlink:href="http://www.share-project.org"
xmlns:xlink="http://www.w3.org/1999/xlink">www.share-project.org after
registration. SHARE is harmonized with the US Health and Retirement Study (HRS)
and the English Longitudinal Study of Ageing (ELSA) and has become a role model
for several ageing surveys worldwide. SHARE's scientific power is based on its
panel design that grasps the dynamic character of the ageing process, its
multidisciplinary approach that delivers the full picture of individual and
societal ageing, and its cross-nationally ex-ante harmonized design that permits
international comparisons of health, economic and social outcomes in Europe and
the USA.
C1 [Boersch-Supan, Axel; Brandt, Martina; Hunkler, Christian; Kneip, Thorsten;
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OI Brandt, Martina/0000-0001-9350-845X; Hunkler,
   Christian/0000-0002-1632-9834
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FU European Commission [QLK6-CT-2001- 00360, RII-CT-2006-062193, CIT5-CT-2005-028857, CIT4-CT-2006-028812, 211909, 227822]; US National Institute on Aging [U01 AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, Y1-AG-455301, OGHA 04-064, IAG BSR06-11, R21 AG025169]; German Federal Ministry of Education and Research [AZA 01UW0908]; EU Commission [261982]

FX During the first three Waves, the SHARE data collection has been primarily funded by the European Commission through the fifth framework programme (QLK6-CT-2001- 00360 in the thematic programme Quality of Life), through the sixth framework programme (SHARE-I3, RII-CT-2006-062193, COMPARE, CIT5-CT-2005-028857, SHARELIFE, CIT4-CT-2006-028812) and through the seventhth framework programme (SHARE-PREP, 211909, SHARE-LEAP, 227822). Starting with Wave 4, SHARE has changed to a decentralized funding model and became an international organization (SHARE-ERIC) funded by its member countries.; Substantial additional funding comes from the US National Institute on Aging (U01 AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, Y1-AG-455301, OGHA 04-064, IAG BSR06-11, R21 AG025169). The German Federal Ministry of Education and Research is funding the Munich-based international coordination of SHARE (AZA 01UW0908) and the EU Commission finances all coordination elsewhere (SHARE-M4, 261982). We gratefully acknowledge these as well as all national funding sources (see www.share-project.org for a full list of funding institutions).

CR Avendano M, 2009, AM J PUBLIC HEALTH, V99, P540, DOI 10.2105/AJPH.2008.139469
Blom A, 2011, RETROSPECTIVE DATA C
Borsch-Supan A, 2013, ACTIVE AGEING AND SOLIDARITY BETWEEN GENERATIONS IN EUROPE: FIRST RESULTS FROM SHARE AFTER THE ECONOMIC CRISIS, P337
Boersch-Supan A, 2013, ADV LIFE COURSE RES, V18, P1, DOI 10.1016/j.alcr.2012.10.009
Bohacek R, 2011, INDIVIDUAL AND THE WELFARE STATE: LIFE HISTORIES IN EUROPE, P271, DOI 10.1007/978-3-642-17472-8_24
Bonsang E, 2012, J HEALTH ECON, V31, P490, DOI 10.1016/j.jhealeco.2012.03.005
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Borsch-Supan A, 2005, SURVEY HLTH AGEING R
Borsch-Supan A, 2010, RES FINDINGS EC AGIN
Borsch-Supan A, 2013, SHARE WAVE
Borsch-Supan A, 2011, INDIVIDUAL WELFARE S
Borsch-Supan A., 2008, HLTH AGEING RETIREME
BorschSupan A, 2011, INDIVIDUAL AND THE WELFARE STATE: LIFE HISTORIES IN EUROPE, P1
Brandt M, 2013, J MARRIAGE FAM, V75, P235, DOI 10.1111/j.1741-3737.2012.01028.x
Brandt M, 2012, SOC SCI MED, V74, P1418, DOI 10.1016/j.socscimed.2012.01.004
Brandt M, 2011, INDIVIDUAL AND THE WELFARE STATE: LIFE HISTORIES IN EUROPE, P117, DOI 10.1007/978-3-642-17472-8_10
Brandt M, 2009, EUR SOCIOL REV, V25, P585, DOI 10.1093/esr/jcn076
Brugiavini A, 2011, INDIVIDUAL WELFARE S
Chan KS, 2012, J GERONTOL B-PSYCHOL, V67, P121, DOI 10.1093/geronb/gbr133
Crimmins EM, 2011, EUR J PUBLIC HEALTH, V21, P81, DOI 10.1093/eurpub/ckq022
De Luca G, 2005, SURVEY HLTH AGEING R
DEVILLE JC, 1992, J AM STAT ASSOC, V87, P376, DOI 10.2307/2290268
European Commission, 2011, OLD MOR NUM DIV EUR
Hank K, 2007, J MARRIAGE FAM, V69, P157, DOI 10.1111/j.1741-3737.2006.00351.x
Hank K, 2011, J GERONTOL B-PSYCHOL, V66, P230, DOI 10.1093/geronb/gbq089
Jurges H, 2007, HEALTH ECON, V16, P163, DOI 10.1002/hec.1134
Jurges H, 2008, APPL ECON LETT, V17, P87
Jusot F, 2012, EUR J AGEING, V9, P15, DOI 10.1007/s10433-011-0201-9
Kave G, 2012, J GERONTOL B-PSYCHOL, V67, P697, DOI 10.1093/geronb/gbs031

```
   Kearney PM, 2011, INT J EPIDEMIOL, V40, P877, DOI 10.1093/ije/dyr116
   Kesternich I, 2013, REV EC STAT IN PRESS
   Korbmacher J, 2013, SHARE WAVE
   Leopold T, 2011, J MARRIAGE FAM, V73, P105, DOI 10.1111/j.1741-
3737.2010.00792.x
   Lynn P, 2013, SHARE WAVE
   Malter F., 2013, SHARE WAVE
   Malter F, 2013, SHARE WAVE 4 INNOVAT
   Matsuo H, 2010, SURVEY RES METHODS, V4, P165
   Mazzonna F, 2012, EUR ECON REV, V56, P691, DOI
10.1016/j.euroecorev.2012.03.004
   Michaud P.C, 2007, FORUM HLTH EC POLICY, V10, P8
   Myck M, 2011, IZA DISCUSSION PAPER, P6130
   Rohwedder S, 2010, J ECON PERSPECT, V24, P119, DOI 10.1257/jep.24.1.119
   Schroder M., 2011, RETROSPECTIVE DATA C
   Schroder M, 2013, ADV LIFE COURSE RES, V18, P5, DOI
10.1016/j.alcr.2012.08.001
NR 43
TC 310
Z9 310
U1 4
U2 45
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 0300-5771
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J9 INT J EPIDEMIOL
JI Int. J. Epidemiol.
PD AUG
PY 2013
VL 42
IS 4
BP 992
EP 1001
DI 10.1093/ije/dyt088
PG 10
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 228EG
UT WOS:000325167800011
PM 23778574
OA Green Published, Bronze
HC Y
HP N
DA 2019-08-06
ER

PT J
AU Piwowar, HA
   Day, RS
   Fridsma, DB
AF Piwowar, Heather A.
   Day, Roger S.
   Fridsma, Douglas B.
TI Sharing Detailed Research Data Is Associated with Increased Citation
   Rate
SO PLOS ONE
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LA English
DT Article
AB Background. Sharing research data provides benefit to the general scientific community, but the benefit is less obvious for the investigator who makes his or her data available. Principal Findings. We examined the citation history of 85 cancer microarray clinical trial publications with respect to the availability of their data. The 48% of trials with publicly available microarray data received 85% of the aggregate citations. Publicly available data was significantly (p = 0.006) associated with a 69% increase in citations, independently of journal impact factor, date of publication, and author country of origin using linear regression. Significance. This correlation between publicly available data and increased literature impact may further motivate investigators to share their detailed research data.
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FU NLM [5T15-LM007059-19]
FX HAP was supported by NLM Training Grant Number 5T15-LM007059-19. The NIH had no role in study design, data collection or analysis, writing the paper, or the decision to submit it for publication. The publication contents are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.
CR Antelman K, 2004, COLL RES LIBR, V65, P372, DOI 10.5860/crl.65.5.372
Ball CA, 2005, NUCLEIC ACIDS RES, V33, pD580
Ball CA, 2004, NAT BIOTECHNOL, V22, P1179, DOI 10.1038/nbt0904-1179
Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
Brazma A, 2000, NATURE, V403, P699, DOI 10.1038/35001676
Buetow KH, 2005, SCIENCE, V308, P821, DOI 10.1126/science.1112120
Case DO, 2000, J AM SOC INFORM SCI, V51, P635, DOI 10.1002/(SICI)1097-4571(2000)51:7<635::AID-ASI6>3.0.CO;2-H
Cech T. R., 2003, SHARING PUBLICATION
Check E, 2004, NATURE, V429, P496, DOI 10.1038/429496a
DIAMOND AM, 1986, J HUM RESOUR, V21, P200
Edgar R, 2002, NUCLEIC ACIDS RES, V30, P207, DOI 10.1093/nar/30.1.207
Evangelou E, 2005, FASEB J, V19, P1943, DOI 10.1096/fj.05-4784lsf
Eysenbach G, 2006, PLOS BIOL, V4, P692, DOI 10.1371/journal.pbio.0040157
FIENBERG SE, 1985, SHARING RES DATA, pR8
Gupta D, 2004, AM J CLIN PATHOL, V121, P176, DOI 10.1309/E6K33GBPE5C27FYU
Ikeo K, 2003, CR BIOL, V326, P1079, DOI 10.1016/j.crvi.2003.09.034
Kyzas PA, 2005, JNCI-J NATL CANCER I, V97, P1043, DOI 10.1093/jnci/dji184
Liotta LA, 2005, JNCI-J NATL CANCER I, V97, P310, DOI 10.1093/jnci/dji053
MCCAIN KW, 1995, SCI COMMUN, V16, P403, DOI 10.1177/1075547095016004003
McShane LM, 2005, JNCI-J NATL CANCER I, V97, P1180, DOI 10.1093/jnci/dji237
Ntzani EE, 2003, LANCET, V362, P1439, DOI 10.1016/S0140-6736(03)14686-7
Parkinson H, 2005, NUCLEIC ACIDS RES, V33, pD553
Patsopoulos NA, 2005, JAMA-J AM MED ASSOC, V293, P2362, DOI 10.1001/jama.293.19.2362
Popat S, 2005, J NATL CANCER I, V97, P1855, DOI 10.1093/jnci/dji445
R Development Core Team, 2004, R LANG ENV STAT COMP
Rhodes DR, 2004, NEOPLASIA, V6, P1, DOI 10.1016/S1476-5586(04)80047-2
Riley RD, 2003, BRIT J CANCER, V88, P1191, DOI 10.1038/sj.bjc.6600886
Santos C, 2005, NATURE, V438, P738, DOI 10.1038/438738a
Seglen PO, 1997, BRIT MED J, V314, P498
Sherlock G, 2001, NUCLEIC ACIDS RES, V29, P152, DOI 10.1093/nar/29.1.152

```
   SPELLMAN PT, 2002, GENOME BIOL, V3, P46
   Swan A, 2004, LEARN PUBL, V17, P219, DOI 10.1087/095315104323159649
   Theologis A, 2004, PLANT PHYSIOL, V135, P4, DOI 10.1104/pp.104.043083
   Ventura B, 2005, PHYSIOL GENOMICS, V20, P153, DOI
10.1152/physiolgenomics.00264.2004
   Weale Andy R, 2004, BMC Med Res Methodol, V4, P14, DOI 10.1186/1471-2288-4-14
   1997, NUCL ACIDS RES, V15
   2003, NAT IMMUNOL, V4, P93
NR 37
TC 298
Z9 306
U1 6
U2 46
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 185 BERRY ST, STE 1300, SAN FRANCISCO, CA 94107 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD MAR 21
PY 2007
VL 2
IS 3
AR e308
DI 10.1371/journal.pone.0000308
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA V10DQ
UT WOS:000207445100010
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OA DOAJ Gold, Green Published, Green Accepted
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PT J
AU Wicks, P
   Massagli, M
   Frost, J
   Brownstein, C
   Okun, S
   Vaughan, T
   Bradley, R
   Heywood, J
AF Wicks, Paul
   Massagli, Michael
   Frost, Jeana
   Brownstein, Catherine
   Okun, Sally
   Vaughan, Timothy
   Bradley, Richard
   Heywood, James
TI Sharing Health Data for Better Outcomes on PatientsLikeMe
SO JOURNAL OF MEDICAL INTERNET RESEARCH
LA English
DT Article
DE Personal health records; data visualization; personal monitoring;
   technology; health care; self-help devices; personal tracking; social
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support; online support group; online health community
ID GLYCEMIC CONTROL; SUPPORT GROUPS; ALS PATIENTS; INFORMATION; PHYSICIANS; CARE; DISCLOSURE; ADHERENCE; COMMUNITY; MEDICINE

AB Background: PatientsLikeMe is an online quantitative personal research platform for patients with life-changing illnesses to share their experience using patient-reported outcomes, find other patients like them matched on demographic and clinical characteristics, and learn from the aggregated data reports of others to improve their outcomes. The goal of the website is to help patients answer the question: "Given my status, what is the best outcome I can hope to achieve, and how do I get there?"

Objective: Using a cross-sectional online survey, we sought to describe the potential benefits of PatientsLikeMe in terms of treatment decisions, symptom management, clinical management, and outcomes. Methods: Almost 7,000 members from six PatientsLikeMe communities (amyotrophic lateral sclerosis [ALS], Multiple Sclerosis [MS], Parkinson's Disease, human immunodeficiency virus [HIV], fibromyalgia, and mood disorders) were sent a survey invitation using an internal survey tool (PatientsLikeMe Lens).

Results: Complete responses were received from 1323 participants (19% of invited members). Between-group demographics varied according to disease community. Users perceived the greatest benefit in learning about a symptom they had experienced; 72% (952 of 1323) rated the site "moderately" or "very helpful." Patients also found the site helpful for understanding the side effects of their treatments (n = 757, 57%). Nearly half of patients (n = 559, 42%) agreed that the site had helped them find another patient who had helped them understand what it was like to take a specific treatment for their condition. More patients found the site helpful with decisions to start a medication (n = 496, 37%) than to change a medication (n = 359, 27%), change a dosage (n = 336, 25%), or stop a medication (n = 290, 22%). Almost all participants (n = 1,249, 94%) were diagnosed when they joined the site. Most (n = 824, 62%) experienced no change in their confidence in that diagnosis or had an increased level of confidence (n = 456, 34%). Use of the site was associated with increasing levels of comfort in sharing personal health information among those who had initially been uncomfortable. Overall, 12% of patients (n = 151 of 1320) changed their physician as a result of using the site; this figure was doubled in patients with fibromyalgia (21%, n = 33 of 150). Patients reported community-specific benefits: 41% of HIV patients (n = 72 of 177) agreed they had reduced risky behaviors and 22% of mood disorders patients (n = 31 of 141) agreed they needed less inpatient care as a result of using the site. Analysis of the Web access logs showed that participants who used more features of the site (eg, posted in the online forum) perceived greater benefit.

Conclusions: We have established that members of the community reported a range of benefits, and that these may be related to the extent of site use. Third party validation and longitudinal evaluation is an important next step in continuing to evaluate the potential of online data-sharing platforms.

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FU Union Chimique Beige (UCB); Novartis; Avanir
FX The authors are paid employees of PatientsLikeMe and hold stock options in the company. PatientsLikeMe has received research funding from Union Chimique Beige (UCB), Novartis, and Avanir.

CR Ahmad F, 2006, J MED INTERNET RES, V8, DOI 10.2196/jmir.8.3.e22
Barak A, 2008, COMPUT HUM BEHAV, V24, P1867, DOI 10.1016/j.chb.2008.02.004
Bessiere Katie, 2010, J Med Internet Res, V12, pe6, DOI 10.2196/jmir.1149
Braddock CH, 1999, JAMA-J AM MED ASSOC, V282, P2313, DOI 10.1001/jama.282.24.2313
Brownstein CA, 2009, NAT BIOTECHNOL, V27, P888, DOI 10.1038/nbt1009-888

Castro CM, 2007, AM J HEALTH BEHAV, V31, pS85
Crocco AG, 2002, JAMA-J AM MED ASSOC, V287, P2869, DOI 10.1001/jama.287.21.2869
Eysenbach G, 2004, J MED INTERNET RES, V6, P12, DOI 10.2196/jmir.6.3.e34
Eysenbach G, 2004, BMJ-BRIT MED J, V328, P1166, DOI 10.1136/bmj.328.7449.1166
Fiscella K, 2008, ARCH INTERN MED, V168, P1843, DOI 10.1001/archinte.168.17.1843
Fogarty L, 2002, PATIENT EDUC COUNS, V46, P93, DOI 10.1016/S0738-3991(01)00219-1
Fox S, 2009, SOCIAL LIFE HLTH INF
Fox S, 2010, CHRONIC DIS INTERNET
Frost Jeana H, 2008, AMIA Annu Symp Proc, P217
Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
Heeney C, 2011, PUBLIC HEALTH GENOM, V14, P17, DOI 10.1159/000294150
Hughes Rhidian A, 2004, J Interprof Care, V18, P80
Karter AJ, 2004, MED CARE, V42, P110, DOI 10.1097/01.mlr.0000109023.64650.73
Knapp P, 2009, DRUG SAFETY, V32, P837, DOI 10.2165/11316570-000000000-00000
Lester J, 2004, BMJ-BRIT MED J, V328, P1188, DOI 10.1136/bmj.328.7449.1188
Lieberman M, 2007, PSYCHO-ONCOL, V16, P961, DOI 10.1002/pon.1181
Lorig K, 2002, LANCET, V359, P814, DOI 10.1016/S0140-6736(02)07959-X
Mechanic D, 2001, NEW ENGL J MED, V344, P198, DOI 10.1056/NEJM200101183440307
Miller RG, 2009, ANN NEUROL, V65, pS24, DOI 10.1002/ana.21556
Robinson A, 2004, COMPLEMENT THER MED, V12, P90, DOI 10.1016/j.ctim.2004.09.006
Rozenfeld Y, 2008, AM J MANAG CARE, V14, P71
Schillinger D, 2002, JAMA-J AM MED ASSOC, V288, P475, DOI 10.1001/jama.288.4.475
Singh H, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1143
Smith Catherine Arnott, 2008, AMIA Annu Symp Proc, P682
Stevenson FA, 2007, BMC FAM PRACT, V8, DOI 10.1186/1471-2296-8-47
Swan M, 2009, INT J ENV RES PUB HE, V6, P492, DOI 10.3390/ijerph6020492
UNDERN T, 2010, CONSUMERS HLTH INFOR
Vollmer TL, 1999, INT J MS CARE, V1, P12
Wicks P, 2008, EUR J NEUROL, V15, P497, DOI 10.1111/j.1468-1331.2008.02107.x
Wicks P, 2009, EUR J NEUROL, V16, P353, DOI 10.1111/j.1468-1331.2008.02434.x
Wicks P, 2009, MOVEMENT DISORD, V24, P1085, DOI 10.1002/mds.22528
YE J, 2009, PATIENT ED COUN 1112
NR 37
TC 252
Z9 253
U1 5
U2 78
PU JMIR PUBLICATIONS, INC
PI TORONTO
PA 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA
SN 1438-8871
J9 J MED INTERNET RES
JI J. Med. Internet Res.
PD APR-JUN
PY 2010
VL 12
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AR e19
DI 10.2196/jmir.1549
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
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UT WOS:000278860800009
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OA DOAJ Gold, Green Published
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PT J
AU Borgman, CL
AF Borgman, Christine L.
TI The Conundrum of Sharing Research Data
SO JOURNAL OF THE AMERICAN SOCIETY FOR INFORMATION SCIENCE AND TECHNOLOGY
LA English
DT Review
DE research data sets; collaboration; information reuse; information
   policy; motivation
ID REPRODUCIBLE RESEARCH; SCIENCE; KNOWLEDGE; BIOLOGY; REPLICATION;
   CHALLENGES; SOCIOLOGY; METADATA; ACCESS; HEALTH
AB Researchers are producing an unprecedented deluge of data by using new
methods and instrumentation. Others may wish to mine these data for new
discoveries and innovations. However, research data are not readily available as
sharing is common in only a few fields such as astronomy and genomics. Data
sharing practices in other fields vary widely. Moreover, research data take many
forms, are handled in many ways, using many approaches, and often are difficult
to interpret once removed from their initial context. Data sharing is thus a
conundrum. Four rationales for sharing data are examined, drawing examples from
the sciences, social sciences, and humanities: (1) to reproduce or to verify
research, (2) to make results of publicly funded research available to the
public, (3) to enable others to ask new questions of extant data, and (4) to
advance the state of research and innovation. These rationales differ by the
arguments for sharing, by beneficiaries, and by the motivations and incentives
of the many stakeholders involved. The challenges are to understand which data
might be shared, by whom, with whom, under what conditions, why, and to what
effects. Answers will inform data policy and practice.
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FU National Science Foundation (NSF) [CCR-0120778, OCI0830976]
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   Modeling & Memory: Dynamics of Data and Knowledge in Scientific
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   Hopkins University. We also are grateful to Microsoft Technical
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CR Abrams S., 2009, INT J DIGIT CURATION, V4, P8, DOI [DOI 10.2218/IJDC.V4I1.72,
10.2218/ijdc.v4i1.72]
   Anderson C, 2008, END THEORY DATA DELU
```

[Anonymous], 2009, NATURE, V461, P145, DOI 10.1038/461145a
[Anonymous], 2011, SCIENCE, V331, DOI [10.1126/science.332.6035.1263-a, DOI 10.1126/SCIENCE.332.6035.1263-A]
[Anonymous], 2010, ECONOMIST
[Anonymous], 2011, EUROPEAN MARINE OBSE
Aronova E, 2010, HIST STUD NAT SCI, V40, P183, DOI 10.1525/hsns.2010.40.2.183
Association of Research Libraries, 2009, U ROL DISS RES SCHOL
Beaudouin-Lafon M, 2010, COMMUN ACM, V53, P32, DOI 10.1145/1646353.1646367
Bell G, 2009, SCIENCE, V323, P1297, DOI 10.1126/science.1170411
Berman F, 2010, SUSTAINABLE EC DIGIT
Berman HM, 2000, NUCLEIC ACIDS RES, V28, P235, DOI 10.1093/nar/28.1.235
Borgman C. L., 2009, P 9 ANN INT ACM IEEE, P353
Borgman C, 2006, LECT NOTES COMPUT SC, V4172, P170
Borgman CL, 2007, ACM-IEEE J CONF DIG, P269, DOI 10.1145/1255175.1255228
Borgman CL, 2007, INT J DIGIT LIBRARIE, V7, P17, DOI 10.1007/s00799-007-0022-9
BORGMAN Christine L, 2009, DIGITAL HUMANITIES Q, V3, P233
Borgman Christine L, 2007, SCHOLARSHIP DIGITAL
Borgman CL, 2010, RES DATA WHO WILL SH
Borgman CL, 2011, WHY ARE ATTRIBUTION
Bourne PE, 2005, PLOS COMPUT BIOL, V1, P1, DOI 10.1371/journal.pcbi.0010004
Bowker GC, 2000, SOC STUD SCI, V30, P643, DOI 10.1177/030631200030005001
Bowker Geoffrey C, 2005, MEMORY PRACTICES SCI
Boyle J., 2004, NATURAL EXPT
Boyle James, 2003, ROLE SCI TECHNICAL D, P10
British Library, 2009, PATT INF US EXCH CAS
Brumfiel G, 2002, NATURE, V419, P419, DOI 10.1038/419419b
BUCKLAND MK, 1991, J AM SOC INFORM SCI, V42, P351, DOI 10.1002/(SICI)1097-4571(199106)42:5<351::AID-ASI5>3.0.CO;2-3
Buneman P, 2000, LECT NOTES COMPUT SC, V1974, P87
Butler D, 2006, NATURE, V439, P6, DOI 10.1038/439006a
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI 10.1001/jama.287.4.473
Claerbout J., 2010, REPROD COMPUTATIONAL
Cohen Daniel, 2011, INTERNAL DOCUMENT
Collins HM, 1998, AM J SOCIOL, V104, P293, DOI 10.1086/210040
COLLINS HM, 1975, SOCIOLOGY, V9, P205, DOI 10.1177/003803857500900202
COLLINS HM, 1983, ANNU REV SOCIOL, V9, P265, DOI 10.1146/annurev.so.09.080183.001405
Consultative Committee for Space Data Systems, 2002, REF MOD OP ARCH INF
Cornell Lab of Ornithology, 2009, CIT SCI
Costello A, 2011, PHILOS T R SOC A, V369, P1866, DOI 10.1098/rsta.2011.0007
Couzin J, 2006, SCIENCE, V312, P38, DOI 10.1126/science.312.5770.38
Couzin-Frankel J, 2010, SCIENCE, V329, P614, DOI 10.1126/science.329.5992.614
Cragin MH, 2010, PHILOS T R SOC A, V368, P4023, DOI 10.1098/rsta.2010.0165
Crawford K, 2011, 6 PROVOCATIONS BIG D
Crow R., 2009, INCOME MODELS OPEN A
Dalrymple D., 2003, ROLE SCI TECHNICAL D, P35
Data Citation Standards and Practices, 2010, DAT CIT STAND PRACT
Data Conservancy, 2010, DAT CONS
David Paul A., 2004, CYBERINFRASTRUCTURE
Digital Curation Centre, 2011, DCC DAT MAN PLANS
Directory of Open Access Journals, 2009, OP SOC IN SCHOL PUBL
Drake A. J., 2011, DISCOVERY NATURE OPT
Dryad, 2011, JOINT DAT ARCH POL
Economic and Social Research Council, 2010, ESRC RES DAT POL
Edwards P. N., 2010, VAST MACHINE COMPUTE
Edwards PN, 2011, SOC STUD SCI, V41, P667, DOI 10.1177/0306312711413314

Esanu J. M., 2004, OP ACC PUBL DOM DIG
ESANU JM, 2003, ROL SCI TECHN DAT IN
Faniel IM, 2010, COMPUT SUPP COOP W J, V19, P355, DOI 10.1007/s10606-010-9117-8
Fazackerley A., 2004, TIMES HIGHER ED SUPP, V1665, P5
Fienberg S. E., 1985, SHARING RES DATA
Fischer BA, 2010, SCI ENG ETHICS, V16, P783, DOI 10.1007/s11948-010-9239-x
GenomeCanada, 2005, GEN CAN DAT REL SHAR
Gil Yolanda, 2010, PROVENANCE XG FINAL
Gleick PH, 2010, SCIENCE, V328, P689, DOI 10.1126/science.328.5979.689
Goble C., 2009, 4 PARADIGM DATA INTE
Gobler CJ, 2004, AQUAT MICROB ECOL, V35, P31, DOI 10.3354/ame035031
Graham-Rowe D, 2008, NATURE, V455, P8, DOI [10.1038/455008a, 10.1038/455001a]
Gray Jim, 2005, CT WATCH Q, P1
Haeussler C, 2011, RES POLICY, V40, P105, DOI 10.1016/j.respol.2010.08.007
Hanson B, 2011, SCIENCE, V331, P649, DOI 10.1126/science.1203354
Hey A. J. G., 2003, GRID COMPUTING MAKIN
Hey T., 2009, 4 PARADIGM DATA INTE
Hilgartner S, 2002, J MOL BIOL, V319, P943, DOI 10.1016/S0022-2836(02)00334-0
HILGARTNER S, 1994, KNOWLEDGE, V15, P355, DOI 10.1177/107554709401500401
Hilgartner Stephen, 1998, PRIVATE SCI BIOTECHN, P202
Hunter J, 2007, INT J DIGIT LIBRARIE, V7, P99, DOI 10.1007/s00799-007-0018-5
INSPIRE, 2007, EUR COMM
Ioannidis JPA, 2011, SCIENCE, V334, P1230, DOI 10.1126/science.1211811
Jasny BR, 2011, SCIENCE, V334, P1225, DOI 10.1126/science.334.6060.1225
Kaiser J, 2008, SCIENCE, V319, P266, DOI 10.1126/science.319.5861.266
Kanfer A. G., 2000, Information Systems Frontiers, V2, P317, DOI 10.1023/A:1026520728644
Kansa EC, 2010, ARCHAEOLOGIES, V6, P301, DOI 10.1007/s11759-010-9146-4
Karasti H., 2006, Computer Supported Cooperative Work: The Journal of Collaborative Computing, V15, P321, DOI 10.1007/s10606-006-9023-2
Karasti H, 2010, COMPUT SUPP COOP W J, V19, P377, DOI 10.1007/s10606-010-9113-z
Kelty CM, 2008, 2 BITS CULTURAL SIGN
Knorr-Cetina K., 1999, EPISTEMIC CULTURES S
Lagoze Carl, 2009, VALUE NEW SCI COMMUN
Latour B., 1986, LAB LIFE CONSTRUCTIO
Latour B., 1979, LAB LIFE SOCIAL CONS
Latour B., 1987, SCI ACTION FOLLOW SC
Lave J., 1991, SITUATED LEARNING LE
Lyon L., 2007, DEALING DATA ROLES R
Mayernik M. S., 2011, P 2011 ICONFERENCE, P417, DOI [10.1145/1940761.1940818, DOI 10.1145/1940761.1940818]
Mayernik M.S., 2011, THESIS UCLA LOS ANGE
Meng X. -L., 2010, INT ENCY STAT SCI
Merriam-Webster, 2005, MERR WEBST COLL DICT
MERTON RK, 1969, AM SCI, V57, P1
Merton RK, 1942, SOCIOLOGY SCI THEORE, P267
Moore AJ, 2010, J EVOLUTION BIOL, V23, P659, DOI 10.1111/j.1420-9101.2010.01937.x
MURRAYRUST P, 2004, J DIGITAL INF, V5
Naik G., 2011, WALL STREET J, VCCLVIII, pA16
Naik G, 2011, WALL STREET J, V258, pA1
National Academies of Science, 2011, DEV DAT ATTR CIT PRA
National Institutes of Health, 2005, PUBL ACC POL
National Research Council, 1999, QUEST BAL PRIV RIGHT
National Research Council, 1997, BITS POW ISS GLOB AC
National Research Council, 1995, PRES SCI DAT OUR PHY

National Research Council, 2009, ENS INT ACC STEW RES
National Science Board, 2005, LONG LIV DIG DAT COL
National Science Foundation, 2010, NSF DAT MAN PLANS
National Science Foundation, 2011, NSF PROP PREP INSTR
National Science Foundation, 2001, GRANT POL MAN
National Science Foundation, 2010, NSF DAT SHAR POL
National Science Foundation, 2010, SUST DIG DAT PRES AC
Networking and Information Technology Research and Development, 2009, HARN POW DIG DAT SCI
Normile D, 2006, SCIENCE, V311, P156, DOI 10.1126/science.311.5758.156
Office of the Federal Register, 2011, REQ INF PUBL ACC DIG
Olson G. M., 2008, SCI COLLABORATION IN
Organisation for Economic Co-operation and Development, 2007, OECD PRINC GUID ACC
Osterlund C, 2005, INFORM SOC, V21, P91, DOI 10.1080/01972240590925294
Overpeck JT, 2011, SCIENCE, V331, P700, DOI 10.1126/science.1197869
Palmer C.L., 2007, 3 INT DIG CUR C WASH
Palmer CL, 2005, J AM SOC INF SCI TEC, V56, P1140, DOI 10.1002/asi.20204
Peng RD, 2011, SCIENCE, V334, P1226, DOI 10.1126/science.1213847
Pepe A, 2010, J AM SOC INF SCI TEC, V61, P567, DOI 10.1002/asi.21263
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Piwowar HA, 2010, J INFORMETR, V4, P148, DOI 10.1016/j.joi.2009.11.010
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Porter J.H., 2010, B ECOL SOC AM, V91, P14, DOI DOI 10.1890/0012-9623-91.1.14
Pritchard Sarah M., 2004, COLLABORATION KNOWLE
REICHMAN H., 2003, LAW CONTEMP PROBL, V66, P315
Renear A.H., 2010, P AM SOC INFORM SCI, V47, P1, DOI [10.1002/meet.14504701240, DOI 10.1002/MEET.14504701240]
Renear AH, 2009, SCIENCE, V325, P828, DOI 10.1126/science.1157784
Research Information Network and the British Library, 2009, PATT INF US EXCH CAS
Ribes D., 2008, SCI INTERNET
Ribes D., 2005, P 2 ACM IEEE CS JOIN
Ribes D, 2007, GROUP'07: PROCEEDINGS OF THE 2007 INTERNATIONAL ACM CONFERENCE ON SUPPORTING GROUP WORK, P229
Rogers EM, 1995, DIFFUSION INNOVATION
Ryan MJ, 2011, SCIENCE, V334, P1229, DOI 10.1126/science.1214532
Santer BD, 2011, SCIENCE, V334, P1232, DOI 10.1126/science.1216273
Stephen Hilgartner, 1997, INTELLECTUAL PROPERT, P28
Stodden V., 2009, ENABLING REPRODUCIBL
Stodden V, 2009, COMPUT SCI ENG, V11, P35, DOI 10.1109/MCSE.2009.19
The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
Tomasello M, 2011, SCIENCE, V334, P1227, DOI 10.1126/science.1213443
Unsworth John, 2006, OUR CULTURAL COMMONW
Van House NA, 2004, ANNU REV INFORM SCI, V38, P3
Vandewalle P, 2009, IEEE SIGNAL PROC MAG, V26, P37, DOI 10.1109/MSP.2009.932122
Velden T, 2009, NAT CHEM, V1, P673, DOI 10.1038/nchem.448
Wallis J. C., 2010, DIGITAL LIB SCI DATA
Ware M., 2010, KNOWLEDGE EXCHANGE, P1
Wellcome Trust, 2005, WELLC TRUST POS STAT
Wellcome Trust, 1996, SUMM PRINC
Wellcome Trust, 2001, WELLC TRUST POL ACC
Wellcome Trust, 1997, WELLC TRUST STAT GEN
Wenger E., 1998, COMMUNITIES PRACTICE
Whitlock MC, 2011, TRENDS ECOL EVOL, V26, P61, DOI 10.1016/j.tree.2010.11.006
Whitlock MC, 2010, AM NAT, V175, pE45, DOI 10.1086/650340
Wilbanks J., 2009, 4 PARADIGM DATA INTE

```
   Witt M., 2009, INT J DIGITAL CURATI, V4, P93, DOI DOI 10.2218/IJDC.V4I3.117
   Wynholds L., 2010, LINKING SCI DATA IDE
   Wynholds L. A., 2011, P 11 ANN INT ACM IEE, P383
   Yale Law Sch Roundtable Data Code, 2010, COMPUT SCI ENG, V12, P8
   Young J. R., 2009, CHRON HIGHER EDUC, V55, pA1
   Zimmerman A, 2007, INT J DIGIT LIBRARIE, V7, P5, DOI 10.1007/s00799-007-0015-
8
NR 165
TC 220
Z9 223
U1 7
U2 163
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1532-2882
EI 1532-2890
J9 J AM SOC INF SCI TEC
JI J. Am. Soc. Inf. Sci. Technol.
PD JUN
PY 2012
VL 63
IS 6
BP 1059
EP 1078
DI 10.1002/asi.22634
PG 20
WC Computer Science, Information Systems; Information Science & Library
   Science
SC Computer Science; Information Science & Library Science
GA 943OO
UT WOS:000304133900001
OA Bronze
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HP N
DA 2019-08-06
ER

PT J
AU Grossman, RL
   Heath, AP
   Ferretti, V
   Varmus, HE
   Lowy, DR
   Kibbe, WA
   Staudt, LM
AF Grossman, Robert L.
   Heath, Allison P.
   Ferretti, Vincent
   Varmus, Harold E.
   Lowy, Douglas R.
   Kibbe, Warren A.
   Staudt, Louis M.
TI Toward a Shared Vision for Cancer Genomic Data
SO NEW ENGLAND JOURNAL OF MEDICINE
LA English
DT Editorial Material
```

```
C1 [Grossman, Robert L.; Heath, Allison P.] Univ Chicago, Ctr Data Intens Sci,
Chicago, IL 60637 USA.
   [Ferretti, Vincent] Ontario Inst Canc Res, Toronto, ON, Canada.
   [Varmus, Harold E.] Cornell Univ, Weill Cornell Med, New York, NY 10021 USA.
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20892 USA.
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RI Kibbe, Warren/B-2106-2010
OI Kibbe, Warren/0000-0001-5622-7659; Heath, Allison/0000-0002-2583-9668
FU Intramural NIH HHS [Z01 BC008905-26]
CR Larkin J, 2014, NEW ENGL J MED, V371, P1867, DOI 10.1056/NEJMoa1408868
   Lawrence MS, 2014, NATURE, V505, P495, DOI 10.1038/nature12912
   Shaw AT, 2014, NEW ENGL J MED, V371, P1963, DOI 10.1056/NEJMoa1406766
   Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
   Wilson WH, 2015, NAT MED, V21, P922, DOI 10.1038/nm.3884
NR 5
TC 190
Z9 192
U1 3
U2 10
PU MASSACHUSETTS MEDICAL SOC
PI WALTHAM
PA WALTHAM WOODS CENTER, 860 WINTER ST,, WALTHAM, MA 02451-1413 USA
SN 0028-4793
EI 1533-4406
J9 NEW ENGL J MED
JI N. Engl. J. Med.
PD SEP 22
PY 2016
VL 375
IS 12
BP 1109
EP 1112
DI 10.1056/NEJMp1607591
PG 4
WC Medicine, General & Internal
SC General & Internal Medicine
GA DW3JE
UT WOS:000383537100002
PM 27653561
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ER

PT J
AU KIECOLTGLASER, JK
   GLASER, R
AF KIECOLTGLASER, JK
   GLASER, R
TI PSYCHONEUROIMMUNOLOGY AND HEALTH CONSEQUENCES - DATA AND SHARED
   MECHANISMS
SO PSYCHOSOMATIC MEDICINE
LA English
DT Article
ID STRUCTURED PSYCHIATRIC INTERVENTION; HUMAN-IMMUNODEFICIENCY-VIRUS;
   HEPATITIS-B VACCINE; IMMUNE-RESPONSE; CHRONIC STRESS; PSYCHOLOGICAL
   STRESS; LYMPHOCYTE SUBSETS; DISTRESS; ANTIBODY; NOTIFICATION
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AB There is evidence linking psychosocially mediated immunological alterations with cancer, infectious illness, and HIV progression. The data reviewed suggest that immune modulation by psychosocial stressors and/or interventions may importantly influence health status. The research literature also suggests that the impact of chronic stressors and psychosocial factors on sympathetic nervous system and endocrine function influences the immune system, thereby providing shared mechanisms that may impact on disease susceptibility and progression across a broad spectrum of disorders. A better understanding of individual vulnerability, such as occurs with aging, may help to pinpoint those at greatest risk.

C1 OHIO STATE UNIV,PROGRAM BEHAV MED,COLUMBUS,OH 43210.
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RP KIECOLTGLASER, JK (reprint author), OHIO STATE UNIV,COLL MED,DEPT PSYCHIAT,473 W 12TH AVE,COLUMBUS,OH 43210, USA.
RI Kiecolt-Glaser, Janice K/A-3236-2009; Glaser, Ronald/E-3124-2011
OI Kiecolt-Glaser, Janice K/0000-0003-4900-9578;

FU NIMH NIH HHS [R01 MH50538, R37 MH42096]

CR ANDERSEN BL, 1994, AM PSYCHOL, V49, P389, DOI 10.1037/0003-066X.49.5.389
ANTONI MH, 1991, J CONSULT CLIN PSYCH, V59, P906, DOI 10.1037/0022-006X.59.6.906
ANTONI MH, 1980, PSYCHOSOM MED, V52, P496
BARRETT DC, 1994, JAMA-J AM MED ASSOC, V271, P1743
BAUM A, 1993, PSYCHOSOM MED, V55, P274, DOI 10.1097/00006842-199305000-00005
BURACK J, 1993, JAMA-J AM MED ASSOC, V270, P1568
BURNS EA, 1990, MECH AGEING DEV, V53, P229, DOI 10.1016/0047-6374(90)90041-D
CACIOPPO JT, 1995, PSYCHOSOM MED, V57, P154, DOI 10.1097/00006842-199503000-00008
COHEN S, 1991, NEW ENGL J MED, V325, P606, DOI 10.1056/NEJM199108293250903
ESTERLING BA, 1992, PSYCHOSOM MED, V54, P354, DOI 10.1097/00006842-199205000-00011
FAWZY FI, 1993, ARCH GEN PSYCHIAT, V50, P681
FAWZY FI, 1990, ARCH GEN PSYCHIAT, V47, P729
FLEMING I, 1987, HEALTH PSYCHOL, V6, P221, DOI 10.1037/0278-6133.6.3.221
GLASER R, 1992, PSYCHOSOM MED, V54, P22, DOI 10.1097/00006842-199201000-00005
GLASER R, 1987, Brain Behavior and Immunity, V1, P107, DOI 10.1016/0889-1591(87)90013-4
Glaser R., 1994, HUMAN HERPESVIRUS IN, P245
GOODKIN K, 1994, ARCH GEN PSYCHIAT, V51, P246
HEILIG M, 1993, BRAIN BEHAV IMMUN, V7, P154, DOI 10.1006/brbi.1993.1017
HERBERT TB, 1993, PSYCHOSOM MED, V55, P364, DOI 10.1097/00006842-199307000-00004
HOBSON D, 1972, INT S INFLUENZA VACC, P164
Ironson G, 1994, Int J Behav Med, V1, P90, DOI 10.1207/s15327558ijbm0101_6
IRWIN M, 1992, FASEB J, V5, P3100
JABAAIJ L, 1993, J PSYCHOSOM RES, V37, P361, DOI 10.1016/0022-3999(93)90138-6
KASL SV, 1979, PSYCHOSOM MED, V41, P445, DOI 10.1097/00006842-197910000-00002
KEMENY ME, HDB HUMAN STRESS IMM, P245
KIECOLTGLASER JK, 1992, PSYCHOSOM MED, V54, P680, DOI 10.1097/00006842-199211000-00008
KIECOLTGLASER JK, 1991, PSYCHOSOM MED, V53, P345, DOI 10.1097/00006842-199107000-00001
KIECOLTGLASER JK, HDB HUMAN STRESS IMM, P321
LAPERRIERE A, 1991, INT J SPORTS MED, V12, pS53, DOI 10.1055/s-2007-1024751
LAPERRIERE AR, 1990, BIOFEEDBACK SELF-REG, V15, P229, DOI 10.1007/BF01011107
LYKETSOS CG, 1993, JAMA-J AM MED ASSOC, V270, P2563, DOI 10.1001/jama.270.21.2563

```
   MANUCK SB, 1991, PSYCHOL SCI, V2, P111, DOI 10.1111/j.1467-
9280.1991.tb00110.x
   MCKINNON W, 1989, HEALTH PSYCHOL, V8, P389, DOI 10.1037//0278-6133.8.4.389
   MURASKO D M, 1988, Aging Immunology and Infectious Disease, V1, P1
   ORTS K, UNPUB RELIABILITY VA
   PERRY S, 1992, ARCH GEN PSYCHIAT, V49, P396
   PETERSON PK, 1991, REV INFECT DIS, V13, P710
   PHAIR J, 1978, J LAB CLIN MED, V92, P822
   RABKIN JG, 1991, ARCH GEN PSYCHIAT, V48, P111
   ROBERTST.IC, 1974, LANCET, V2, P368
   SCHLEIFER SJ, 1983, JAMA-J AM MED ASSOC, V250, P374, DOI
10.1001/jama.250.3.374
   SGOUTASEMCH S, 1994, PSYCHOPHYSIOLOGY, V31, P253
   SHERIDAN JF, 1991, J NEUROIMMUNOL, V31, P245, DOI 10.1016/0165-5728(91)90046-
A
   SOLOMON GF, 1969, INT ARCH ALLER A IMM, V35, P97, DOI 10.1159/000230163
   SOLOMON GF, 1991, PSYCHONEUROIMMUNOLOG, P1081
   SOLOMON GF, HDB HUMAN STRESS IMM, P341
   SPIEGEL D, 1989, LANCET, V1, P888
   UCHINO BN, 1992, J PERS SOC PSYCHOL, V63, P839, DOI 10.1037/0022-
3514.63.5.839
   WAYNE SJ, 1990, J GERONTOL, V45, P745
   YOSHIKAWA TT, 1983, J AM GERIATR SOC, V31, P34, DOI 10.1111/j.1532-
5415.1983.tb06285.x
NR 50
TC 157
Z9 162
U1 0
U2 12
PU WILLIAMS & WILKINS
PI BALTIMORE
PA 351 WEST CAMDEN ST, BALTIMORE, MD 21201-2436
SN 0033-3174
J9 PSYCHOSOM MED
JI Psychosom. Med.
PD MAY-JUN
PY 1995
VL 57
IS 3
BP 269
EP 274
DI 10.1097/00006842-199505000-00008
PG 6
WC Psychiatry; Psychology; Psychology, Multidisciplinary
SC Psychiatry; Psychology
GA RA414
UT WOS:A1995RA41400008
PM 7652127
DA 2019-08-06
ER

PT J
AU Weber, GM
   Murphy, SN
   McMurry, AJ
   MacFadden, D
   Nigrin, DJ
   Churchill, S
```

Kohane, IS
AF Weber, Griffin M.
Murphy, Shawn N.
McMurry, Andrew J.
MacFadden, Douglas
Nigrin, Daniel J.
Churchill, Susanne
Kohane, Isaac S.
TI The Shared Health. Research Information Network (SHRINE): A Prototype
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ID MEDICAL-RECORD; SYSTEM; ARCHITECTURE; CARE; WEB

AB The authors developed a prototype Shared Health Research Information Network (SHRINE) to identify the technical, regulatory, and political challenges of creating a federated query tool for clinical data repositories. Separate Institutional Review Boards (IRBs) at Harvard's three largest affiliated health centers approved use of their data, and the Harvard Medical School IRB approved building a Query Aggregator Interface that can simultaneously send queries to each hospital and display aggregate counts of the number of matching patients. Our experience creating three local repositories using the open source Informatics for Integrating Biology and the Bedside (i2b2) platform can be used as a road map for other institutions. The authors are actively working with the IRBs and regulatory groups to develop procedures that will ultimately allow investigators to obtain identified patient data and biomaterials through SHRINE. This will guide us in creating a future technical architecture that is scalable to a national level, compliant with ethical guidelines, and protective of the interests of the participating hospitals.

C1 [Weber, Griffin M.; McMurry, Andrew J.; Nigrin, Daniel J.; Kohane, Isaac S.] Harvard Univ, Sch Med, Ctr Biomed Informat, Boston, MA 02115 USA.
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Integrating Biology and the Bedside (i2b2), and 1 UL1 RR025758-01,
Harvard Catalyst, The Harvard Clinical and Translational Science Center,
from the National Center for Research Resources.

CR Drake TA, 2007, HUM PATHOL, V38, P1212, DOI 10.1016/j.humpath.2007.01.007
Halamka JD, 1999, INT J MED INFORM, V54, P1, DOI 10.1016/S1386-5056(98)00095-1
Holzbach A., 2004, MEDINFO, V21, P1519
Keator DB, 2008, IEEE T INF TECHNOL B, V12, P162, DOI 10.1109/TITB.2008.917893
Kohane IS, 1996, J AM MED INFORM ASSN, V3, P191, DOI 10.1136/jamia.1996.96310633
McMurry AJ, 2007, J AM MED INFORM ASSN, V14, P527, DOI 10.1197/jamia.M2371
MURPHY SN, 2002, P ANN FALL S AM MED

```
   MURPHY SN, 2007, P ANN FALL S AM MED
   MURPHY SN, 2003, P ANN FALL S AM MED
   NALICHOWSKI R, 2006, P ANN FALL S AM MED
   NAMINI AH, 2004, MEDINFO, V1264, P2004
   Nigrin DJ, 2000, J AM MED INFORM ASSN, V7, P152, DOI
10.1136/jamia.2000.0070152
   NIGRIN DJ, 1998, P ANN FALL S AM MED
   NIGRIN DJ, 1999, P ANN FALL S AM MED
   Oster S, 2008, J AM MED INFORM ASSN, V15, P138, DOI 10.1197/jamia.M2522
   SAFRAN C, 1989, ANN INTERN MED, V111, P751, DOI 10.7326/0003-4819-111-9-751
   Wright A, 2008, J BIOMED INFORM, V41, P962, DOI 10.1016/j.jbi.2008.03.001
NR 17
TC 145
Z9 146
U1 3
U2 37
PU HANLEY & BELFUS-ELSEVIER INC
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SN 1067-5027
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD SEP-OCT
PY 2009
VL 16
IS 5
BP 624
EP 630
DI 10.1197/jamia.M3191
PG 7
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA 493RL
UT WOS:000269755500003
PM 19567788
OA Green Published
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PT J
AU Lemke, AA
   Wolf, WA
   Hebert-Beirne, J
   Smith, ME
AF Lemke, A. A.
   Wolf, W. A.
   Hebert-Beirne, J.
   Smith, M. E.
TI Public and Biobank Participant Attitudes toward Genetic Research
   Participation and Data Sharing
SO PUBLIC HEALTH GENOMICS
LA English
DT Article
DE Biobank; Biorepository; Data sharing; Ethics; Focus groups; Genetic
   research; Genome-wide association studies; Policy; Public attitudes;
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Qualitative research; Research participation
ID COMMUNITY; PROJECT

AB Research assessing attitudes toward consent processes for high-throughput genomic-wide technologies and widespread sharing of data is limited. In order to develop a better understanding of stakeholder views toward these issues, this cross-sectional study assessed public and biorepository participant attitudes toward research participation and sharing of genetic research data. Forty-nine individuals participated in 6 focus groups; 28 in 3 public focus groups and 21 in 3 NUgene biorepository participant focus groups. In the public focus groups, 75% of participants were women, 75% had some college education or more, 46% were African-American and 29% were Hispanic. In the NUgene focus groups, 67% of participants were women, 95% had some college education or more, and the majority (76%) of participants was Caucasian. Five major themes were identified in the focus group data: (a) a wide spectrum of understanding of genetic research; (b) pros and cons of participation in genetic research; (c) influence of credibility and trust of the research institution; (d) concerns about sharing genetic research data and need for transparency in the Policy for Sharing of Data in National Institutes of Health-Supported or Conducted Genome-Wide Association Studies; (e) a need for more information and education about genetic research. In order to increase public understanding and address potential concerns about genetic research, future efforts should be aimed at involving the public in genetic research policy development and in identifying or developing appropriate educational strategies to meet the public's needs. Copyright (C) 2010 S. Karger AG, Basel

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FU National Human Genome Research Institute [U01HG004609]
FX We thank both the general public and NUgene participants who served as focus group participants, and we are grateful to the community partners at the public focus group sites for their support and assistance. We also thank the focus group moderators and assistant moderators for their contributions. Funding for this study is provided by the National Human Genome Research Institute, U01HG004609.

CR Bates BR, 2005, SOC SCI MED, V60, P331, DOI 10.1016/j.socscimed.2004.05.012
Burton PR, 2007, NATURE, V447, P661, DOI 10.1038/nature05911
Caulfield T, 2008, PLOS BIOL, V6, P430, DOI 10.1371/journal.pbio.0060073
Corbie-Smith G, 1999, J GEN INTERN MED, V14, P537, DOI 10.1046/j.1525-1497.1999.07048.x
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
Godard B, 2004, SCI ENG ETHICS, V10, P457, DOI 10.1007/s11948-004-0003-y
Godard B, 2007, COMMUNITY GENET, V10, P147, DOI 10.1159/000101756
Haddad MB, 2008, ANN EPIDEMIOL, V18, P139, DOI 10.1016/j.annepidem.2007.09.006
Henderson G, 2008, GENET MED, V10, P193, DOI 10.1097/GIM.0b013e318164e4f5
*KAIS PERM NEW CTR, ASCR MED NEWS SERV K
Kass NE, 1996, HASTINGS CENT REP, V26, P25, DOI 10.2307/3528467
Knoppers BM, 2008, EUR J HUM GENET, V16, P664, DOI 10.1038/ejhg.2008.55
KRUEGER RA, 2000, FOCUS GROUPS PRAC TI
Mailman MD, 2007, NAT GENET, V39, P1181
MCCARTY CA, 2008, COMMUNITY GENET, V10, P2
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
Miles M. B., 1994, QUALITATIVE DATA ANA
Morgan D. L., 1998, FOCUS GROUP KIT, P1
*NIH, 2009, SACGHS REP CHAP NEED
*NIH, 2009, DES CONS POT US POP

```
   *NIH, POINTS CONS WHEN PLA
   O'Doherty KC, 2009, PUBLIC HEALTH GENOM, V12, P203, DOI 10.1159/000167801
   Ollier W, 2005, PHARMACOGENOMICS, V6, P639, DOI 10.2217/14622416.6.6.639
   Ormond KE, 2009, AM J MED GENET A, V149A, P188, DOI 10.1002/ajmg.a.32635
   Wolf WA, 2003, AM J HUM GENET, V73, P423
   2009, FED REG, V72, P49290
NR 26
TC 134
Z9 134
U1 3
U2 37
PU KARGER
PI BASEL
PA ALLSCHWILERSTRASSE 10, CH-4009 BASEL, SWITZERLAND
SN 1662-4246
J9 PUBLIC HEALTH GENOM
JI Pub. Health Genomics
PY 2010
VL 13
IS 6
BP 368
EP 377
DI 10.1159/000276767
PG 10
WC Genetics & Heredity; Public, Environmental & Occupational Health
SC Genetics & Heredity; Public, Environmental & Occupational Health
GA 646ED
UT WOS:000281518700008
PM 20805700
OA Other Gold, Green Published
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PT J
AU Walport, M
   Brest, P
AF Walport, Mark
   Brest, Paul
TI Sharing research data to improve public health
SO LANCET
LA English
DT Editorial Material
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CR Cochrane GR, 2010, NUCLEIC ACIDS RES, V38, pD1, DOI 10.1093/nar/gkp1077
   McCarthy MI, 2008, NAT REV GENET, V9, P356, DOI 10.1038/nrg2344
   Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
   Wellcome Trust, 2011, SHAR RES DAT IMPR PU
NR 4
TC 107
Z9 108
U1 0
U2 11
PU ELSEVIER SCIENCE INC
PI NEW YORK
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PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0140-6736
J9 LANCET
JI Lancet
PD FEB 12
PY 2011
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IS 9765
BP 537
EP 539
DI 10.1016/S0140-6736(10)62234-9
PG 3
WC Medicine, General & Internal
SC General & Internal Medicine
GA 724DQ
UT WOS:000287556700008
PM 21216456
DA 2019-08-06
ER

PT J
AU O'Brien, O
   Cheshire, J
   Batty, M
AF O'Brien, Oliver
   Cheshire, James
   Batty, Michael
TI Mining bicycle sharing data for generating insights into sustainable
   transport systems
SO JOURNAL OF TRANSPORT GEOGRAPHY
LA English
DT Article
DE Bike-sharing; Cycling; Cities; Commuters
ID SCHEME
AB Bicycle sharing systems (bike-shares) are becoming increasingly popular in
towns and cities around the world. They are viewed as a cheap, efficient, and
healthy means of navigating dense urban environments. This paper is the first to
take a global view of bike-sharing characteristics by analysing data from 38
systems located in Europe, the Middle East, Asia, Australasia and the Americas.
To achieve this, an extensive database depicting the geographical location and
bicycle occupancy of each docking station within a particular system has been
created over a number of years to chart the usage in the chosen systems (and
others) and provide a consistent basis on which to compare and classify them.
Analysis of the variation of occupancy rates over time, and comparison across
the system's extent, infers the likely demographics and intentions of user
groups. A classification of bike-shares, based on the geographical footprint and
diurnal, day-of-week and spatial variations in occupancy rates, is proposed. The
knowledge of such patterns and characteristics identifiable from the dataset has
a range of applications, including informing operators and policymakers about
the maintenance of a suitable balance of bicycles throughout the system area (a
nontrivial problem for many bike-shares), the location of new docking stations
and cycle lanes, and better targeting of promotional materials to encourage new
users. Within the context of transport research, the systems utilised here are
part of relatively small, closed environments that can be more easily modelled
and validated. Such work lays foundations for the analysis of larger scale
transport systems by creating a classification of the different systems and
seeks to demonstrate that bike-shares have a lot to offer both as an effective
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method of transport and a rich source of data. (C) 2013 Elsevier Ltd. All rights
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FU Engineering and Physical Sciences Research Council [EP/I018433/1]
CR Daniels R., 2011, WORLD SYMPOSIUM ON T
   DeMaio P, 2009, J PUBLIC TRANSPORT, V12, P41, DOI DOI 10.5038/2375-
0901.12.4.3
   DeMaio P., 2012, THE BIKE SHARING WOR
   Froehlich J., 2009, 21ST INTERNATIONAL J
   Haverman R., 2010, THREE GENERATIONS BI
   Jensen P, 2010, TRANSPORT RES D-TR E, V15, P522, DOI
10.1016/j.trd.2010.07.002
   Jinran Z., 2012, TOUGH TIMES IN THE B
   JZI1 and Bonnette Consulting, 2010, PHILADELPHIA BIKESHA
   Kaltenbrunner A, 2010, PERVASIVE MOB COMPUT, V6, P455, DOI
10.1016/j.pmcj.2010.07.002
   Kazis N., 2012, WITH A BOOST FROM BI
   Lathia N, 2012, TRANSPORT RES C-EMER, V22, P88, DOI 10.1016/j.trc.2011.12.004
   Mayor of London, 2010, TWENTY THIRD MAYORS
   OBIS, 2011, OBIS HANDBOOK
   Ogilvie F, 2012, PREV MED, V55, P40, DOI 10.1016/j.ypmed.2012.05.002
   Padgham M, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0037754
   Transport for London, 2009, CYCLE HIRE SCHEME DO
   Tso N., 2009, TAIWAN GOES GREEN WI
   Vogel P., 2011, PROCEDIA SOC BEHAV S, V20, P514, DOI [DOI
10.1016/J.SBSPRO.2011.08.058, DOI 10.1016/J.SBSPR0.2011.08.058]
   WARD JH, 1963, J AM STAT ASSOC, V58, P236, DOI 10.2307/2282967
NR 19
TC 97
Z9 98
U1 14
U2 185
PU ELSEVIER SCI LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, OXON, ENGLAND
SN 0966-6923
EI 1873-1236
J9 J TRANSP GEOGR
JI J. Transp. Geogr.
PD JAN
PY 2014
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BP 262
EP 273
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WC Economics; Geography; Transportation
SC Business & Economics; Geography; Transportation
GA AC4NQ
UT WOS:000332498400028
HC Y
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HP N
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PT J
AU Trinidad, SB
   Fullerton, SM
   Bares, JM
   Jarvik, GP
   Larson, EB
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AF Trinidad, Susan Brown
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   Bares, Julie M.
   Jarvik, Gail P.
   Larson, Eric B.
   Burke, Wylie
TI Genomic research and wide data sharing: Views of prospective
   participants
SO GENETICS IN MEDICINE
LA English
DT Article
DE data sharing; genetics; electronic medical records; privacy; participant
   perspectives
ID STORED BIOLOGICAL SAMPLES; INFORMED-CONSENT; GENETIC RESEARCH;
   ALZHEIMER-DISEASE; PUBLIC-ATTITUDES; MEDICAL-RECORDS; POPULATION; DNA;
   WILLINGNESS; HEALTH
AB Purpose: Sharing study data within the research community generates tension
between two important goods: promoting scientific goals and protecting the
privacy interests of study participants. This study was designed to explore the
perceptions, beliefs, and attitudes of research participants and possible future
participants regarding genome-wide association studies and repository-based
research. Methods: Focus group sessions with (1) current research participants,
(2) surrogate decision-makers, and (3) three age-defined cohorts (18-34 years,
35-50, >50). Results: Participants expressed a variety of opinions about the
acceptability of wide sharing of genetic and phenotypic information for research
purposes through large, publicly accessible data repositories. Most believed
that making de-identified study data available to the research community is a
social good that should be pursued. Privacy and confidentiality concerns were
common, although they would not necessarily preclude participation. Many
participants voiced reservations about sharing data with for-profit
organizations. Conclusions: Trust is central in participants' views regarding
data sharing. Further research is needed to develop governance models that enact
the values of stewardship. Genet Med 2010:12(8):486-495.
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FU National Institutes of Health; Washington State Life Sciences Discovery
   Fund; NHGRI; NIGMS [U01-HG-004610]; NIA [UO1-AG-06781]
FX Supported by the National Institutes of Health and the Washington State
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CR Aagaard-Tillery K, 2006, OBSTET GYNECOL, V108, P1115, DOI 10.1097/01.AOG.0000241536.19539.14
Ashburn TT, 2000, ARCH INTERN MED, V160, P3377, DOI 10.1001/archinte.160.22.3377
Bathe OF, 2009, GENET MED, V11, P712, DOI 10.1097/GIM.0b013e3181b2e168
Bhatti P, 2005, CANCER EPIDEM BIOMAR, V14, P2449, DOI 10.1158/1055-9965.EPI-05-0463
Caulfield T, 2008, PLOS BIOL, V6, P430, DOI 10.1371/journal.pbio.0060073
Chasman DI, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000730
Chen DT, 2005, ARCH INTERN MED, V165, P652, DOI 10.1001/archinte.165.6.652
Church G, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000665
Corbin J, 2008, BASICS QUALITATIVE R
Damschroder LJ, 2007, SOC SCI MED, V64, P223, DOI 10.1016/j.socscimed.2006.08.045
Eriksson S, 2005, EUR J HUM GENET, V13, P1071, DOI 10.1038/sj.ejhg.5201458
Fern E., 2001, ADV FOCUS GROUP RES
Ganesh SK, 2009, NAT GENET, V41, P1191, DOI 10.1038/ng.466
Gerring J., 2007, CASE STUDY RES PRINC
Greely HT, 2007, ANNU REV GENOM HUM G, V8, P343, DOI 10.1146/annurev.genom.7.080505.115721
Hoeyer K, 2004, SCAND J PUBLIC HEALT, V32, P224, DOI 10.1080/14034940310019506
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Hsieh HF, 2005, QUAL HEALTH RES, V15, P1277, DOI 10.1177/1049732305276687
KAHAN JP, 2001, ANAL SOCIAL ISSUES P, V1, P129, DOI DOI 10.1111/1530-2415.00007
Kaphingst KA, 2006, CLIN GENET, V69, P393, DOI 10.1111/j.1399-0004.2006.00614.x
Karp DR, 2008, PLOS MED, V5, P1333, DOI 10.1371/journal.pmed.0050190
Kass NE, 2003, J LAW MED ETHICS, V31, P429, DOI 10.1111/j.1748-720X.2003.tb00105.x
Kaufman D, 2008, GENET MED, V10, P331, DOI 10.1097/GIM.0b013e31818bb3ab
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Kettis-Lindblad A, 2006, EUR J PUBLIC HEALTH, V16, P433, DOI 10.1093/eurpub/cki198
KITZINGER J, 1995, BRIT MED J, V311, P299, DOI 10.1136/bmj.311.7000.299
KORNBLUM J, 2007, US TODAY 1027
Kukull WA, 2002, ARCH NEUROL-CHICAGO, V59, P1737, DOI 10.1001/archneur.59.11.1737
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Li G, 2005, NEUROLOGY, V65, P1045, DOI 10.1212/01.wnl.0000178989.87072.11
Lin Z, 2006, SCIENCE, V313, P441
Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
McCarty CA, 2007, COMMUNITY GENET, V10, P2, DOI 10.1159/000096274
McDonald M, 2008, J EMPIR RES HUM RES, V3, P35, DOI 10.1525/jer.2008.3.4.35
McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
McQuillan GM, 2006, GENET MED, V8, P354, DOI 10.1097/01.gim.0000223552.70393.08

Montgomery P, 2007, WESTERN J NURS RES, V29, P65, DOI 10.1177/0193945906292557
Morgan D. L., 1998, FOCUS GROUP GUIDEBOO
Morse J. M., 2002, INT J QUAL METH, V1, P1, DOI DOI 10.1177/160940690200100202
*NIH, 2003, FIN NIH STAT SHAR RE
NIH, 2007, POL SHAR DAT OBT NIH
Pentz RD, 2006, AM J MED GENET A, V140A, P733, DOI 10.1002/ajmg.a.31154
Powell RA, 1996, INT J QUAL HEALTH C, V8, P499, DOI 10.1093/intqhc/8.5.499
Pulley JM, 2008, CELL TISSUE BANK, V9, P55, DOI 10.1007/s10561-007-9051-2
Purdy S, 2000, J GEN INTERN MED, V15, P492, DOI 10.1046/j.1525-1497.2000.07025.x
Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
Sandelowski M, 2000, RES NURS HEALTH, V23, P334, DOI 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
Schwartz MD, 2001, AM J MED GENET, V98, P336, DOI 10.1002/1096-8628(20010201)98:4<336::AID-AJMG1100>3.0.CO;2-7
Sonnen JA, 2009, ARCH NEUROL-CHICAGO, V66, P315, DOI 10.1001/archneurol.2008.579
Stegmayr B, 2002, BRIT MED J, V325, P634, DOI 10.1136/bmj.325.7365.634
Sterling R, 2006, AM J PUBLIC HEALTH, V96, P1971, DOI 10.2105/AJPH.2005.069286
Stewart D. W., 2007, FOCUS GROUPS THEORY
Treloar SA, 2007, COMMUNITY GENET, V10, P61, DOI 10.1159/000099083
Treweek S, 2009, J HEALTH SERV RES PO, V14, P13, DOI 10.1258/jhsrp.2008.008016
Wang S S, 2001, Community Genet, V4, P18, DOI 10.1159/000051152
Wendler D, 2002, ARCH INTERN MED, V162, P1457, DOI 10.1001/archinte.162.13.1457
Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI 10.1016/j.ijmedinf.2005.08.009
Willison DJ, 2003, BRIT MED J, V326, P373, DOI 10.1136/bmj.326.7385.373
Yarborough M, 2009, ACAD MED, V84, P472, DOI 10.1097/ACM.0b013e31819a8aa6
NR 61
TC 94
Z9 94
U1 1
U2 20
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1098-3600
EI 1530-0366
J9 GENET MED
JI Genet. Med.
PD AUG
PY 2010
VL 12
IS 8
BP 486
EP 495
DI 10.1097/GIM.0b013e3181e38f9e
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WC Genetics & Heredity
SC Genetics & Heredity
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PT J
AU Lindwall, M
   Larsman, P
   Hagger, MS
AF Lindwall, Magnus
   Larsman, Pernilla
   Hagger, Martin S.
TI The Reciprocal Relationship Between Physical Activity and Depression in
   Older European Adults: A Prospective Cross-Lagged Panel Design Using
   SHARE Data
SO HEALTH PSYCHOLOGY
LA English
DT Article
DE depression; physical activity; cross-lagged design; prospective studies;
   gender
ID LATE-LIFE; D SCALE; CLINICAL DEPRESSION; SYMPTOMS; EXERCISE; HEALTH;
   AGE; INACTIVITY; GENDER; RISK
AB Objective: The aim of this prospective study was to investigate the
reciprocal nature of the physical activity-depressive symptoms relationship in
17,593 older adults from 11 European countries older adults (M age = 64.07, SD =
9.58) across two-year follow-up. Also, gender and age were examined as potential
moderators of this relation. Method: A two-wave cross-lagged panel design and
latent change score models with structural equation modeling was used to analyze
data. Depressive symptoms were measured at baseline (T1) and follow-up (T2)
using the EURO-D scale, capturing the two factors of affective suffering and
motivation. Physical activity was measured at T1 and T2 as frequency of moderate
physical activity and vigorous physical activity. Results: Cross-sectional
latent variable analyses revealed that higher levels of physical activity at T1
and T2 were associated with lower levels of affective suffering and motivation
at T 1 and T2. Physical activity at T1 was significantly associated with
affective suffering and motivation at T2. The relations of depressive symptoms
at T1 with physical activity at T2 were not significant. However, a cross-lagged
model showed best model fit, supporting a reciprocal prospective relationship
between physical activity and depressive symptoms in older adults. Latent change
in depressive symptoms factors was related to latent change in physical activity
indicating complex and dynamic associations across time. Conclusions: Regular
physical activity may be a valuable tool in the prevention of future depressive
symptoms in older adults, and depressive symptoms may also prevent older adults
from engaging in regular physical activity.
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RI Hagger, Martin S./G-5211-2012
OI Hagger, Martin S./0000-0002-2685-1546
FU European Commission [QLK6-CT-2001-00360, RII-CT-2006-062193,
   CIT5-CT-2005-028857]; U.S. National Institute on Aging [U01
   AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, Y1-AG-4553-01,
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FX This paper uses data from SHARE release 2.3.0, as of November 13, 2009.
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Commission through its 5th and 6th framework programmes (project numbers
QLK6-CT-2001-00360; RII-CT-2006-062193; CIT5-CT-2005-028857). Additional
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OGHA 04-064; R21 AG025169) as well as by various national sources is
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of funding institutions).

CR Biddle SJH, 2000, PHYS ACTIVITY PSYCHO, P154
Blazer DG, 2003, J GERONTOL A-BIOL, V58, P249
Blumenthal JA, 2007, PSYCHOSOM MED, V69, P587, DOI
10.1097/PSY.0b013e318148c19a
Borsch-Supan A, 2005, SURVEY HLTH AGEING R
Borsch-Supan A., 2008, HLTH AGEING RETIREME
Brosse AL, 2002, SPORTS MED, V32, P741, DOI 10.2165/00007256-200232120-00001
CAMACHO TC, 1991, AM J EPIDEMIOL, V134, P220, DOI
10.1093/oxfordjournals.aje.a116074
Cassano P, 2002, J PSYCHOSOM RES, V53, P849, DOI 10.1016/S0022-3999(02)00304-
5
Castro-Costa E, 2007, BRIT J PSYCHIAT, V191, P393, DOI
10.1192/bjp.bp.107.036772
Castro-Costa E, 2008, INT J METH PSYCH RES, V17, P12, DOI 10.1002/mpr.236
Chapman Daniel P, 2008, Prev Chronic Dis, V5, pA22
Cheung GW, 2002, STRUCT EQU MODELING, V9, P233, DOI
10.1207/S15328007SEM0902_5
Chodzko-Zajko WJ, 2009, MED SCI SPORT EXER, V41, P1510, DOI
10.1249/MSS.0b013e3181a0c95c
Craft LL, 2005, PSYCHOL SPORT EXERC, V6, P151, DOI
10.1016/j.psychsport.2003.11.003
Dishman RK, 2006, HEALTH PSYCHOL, V25, P396, DOI 10.1037/0278-6133.25.3.396
FARMER ME, 1988, AM J EPIDEMIOL, V128, P1340, DOI
10.1093/oxfordjournals.aje.a115087
Ferrer E, 2010, CURR DIR PSYCHOL SCI, V19, P149, DOI 10.1177/0963721410370300
Finkel S. E., 1995, CAUSAL ANAL PANEL DA
Fiske A, 2009, ANNU REV CLIN PSYCHO, V5, P363, DOI
10.1146/annurev.clinpsy.032408.153621
FOX KR, 2000, PHYS ACTIVITY PSYCHO, P1
Fukukawa Y, 2004, PSYCHOL AGING, V19, P346, DOI 10.1037/0882-7974.19.2.346
Hirvensalo M, 1998, J AGING PHYS ACTIV, V6, P157, DOI 10.1123/japa.6.2.157
Kaplan MS, 2001, AM J PREV MED, V21, P306, DOI 10.1016/S0749-3797(01)00364-6
Kritz-Silverstein D, 2001, AM J EPIDEMIOL, V153, P596, DOI
10.1093/aje/153.6.596
Kuh D, 2007, J GERONTOL A-BIOL, V62, P717, DOI 10.1093/gerona/62.7.717
Lampinen P, 2000, PREV MED, V30, P371, DOI 10.1006/pmed.2000.0641
Lindwall M, 2007, J AGING PHYS ACTIV, V15, P41, DOI 10.1123/japa.15.1.41
McArdle J.J., 1994, LIFE SPAN DEV PSYCHO
McAuley E, 2005, PSYCHOL AGING, V20, P295, DOI 10.1037/0882-7974.20.2.295
Mead GE, 2009, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD004366.pub4
MEREDITH W, 1993, PSYCHOMETRIKA, V58, P525, DOI 10.1007/BF02294825
Patten SB, 2009, GEN HOSP PSYCHIAT, V31, P571, DOI
10.1016/j.genhosppsych.2009.08.001
Perrino T, 2010, AGING MENT HEALTH, V14, P211, DOI 10.1080/13607860903191374
Piccinelli M, 2000, BRIT J PSYCHIAT, V177, P486, DOI 10.1192/bjp.177.6.486
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P339, DOI 10.1192/bjp.174.4.339
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
ROGOSA D, 1980, PSYCHOL BULL, V88, P245, DOI 10.1037/0033-2909.88.2.245
Roshanaei-Moghaddam B, 2009, GEN HOSP PSYCHIAT, V31, P306, DOI
10.1016/j.genhosppsych.2009.04.002

Rosqvist E, 2009, SCAND J MED SCI SPOR, V19, P398, DOI 10.1111/j.1600-0838.2008.00798.x
STEPHENS T, 1988, PREV MED, V17, P35, DOI 10.1016/0091-7435(88)90070-9
Strawbridge WJ, 2002, AM J EPIDEMIOL, V156, P328, DOI 10.1093/aje/kwf047
Taylor AH, 2004, J SPORT SCI, V22, P703, DOI 10.1080/02640410410001712421
van Gool CH, 2003, AGE AGEING, V32, P81, DOI 10.1093/ageing/32.1.81
WEYERER S, 1992, INT J SPORTS MED, V13, P492, DOI 10.1055/s-2007-1021304
WIPFLI B, SCANDINAVIA IN PRESS
NR 45
TC 80
Z9 80
U1 2
U2 54
PU AMER PSYCHOLOGICAL ASSOC
PI WASHINGTON
PA 750 FIRST ST NE, WASHINGTON, DC 20002-4242 USA
SN 0278-6133
EI 1930-7810
J9 HEALTH PSYCHOL
JI Health Psychol.
PD JUL
PY 2011
VL 30
IS 4
BP 453
EP 462
DI 10.1037/a0023268
PG 10
WC Psychology, Clinical; Psychology
SC Psychology
GA 793GT
UT WOS:000292809100010
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PT J
AU Sirven, N
Debrand, T
AF Sirven, Nicolas
Debrand, Thierry
TI Social participation and healthy ageing: An international comparison using SHARE data
SO SOCIAL SCIENCE & MEDICINE
LA English
DT Article
DE Healthy ageing; Self-reported health; Social participation; Social capital; SHARE; Counterfactual analysis; Stochastic dominance; Europe
ID SELF-RATED HEALTH; INCOME INEQUALITY; COMMUNITY; NEIGHBORHOOD; ASSOCIATION; MULTILEVEL
AB Using the Survey of Health, Ageing & retirement in Europe (SHARE) data for respondents aged 50 years and over in 2004, this study evaluates the potential contribution of increased social participation to self-reported health (SRH) in 11 European countries. The probability to report good or very good health is calculated for the whole sample (after controlling for age, education, income and household composition) using regression coefficients estimated for individuals who do and for those who do not take part in social activities (with correction for selection bias in these two cases). Counterfactual national

levels of SRH are derived from integral computation of cumulative distribution functions of the predicted probability thus obtained. The analysis reveals that social participation contributes by three percentage points to the increase in the share of individuals reporting good or very good health on average. Higher rates of social participation could improve health status within the whole sample and within most countries. Context and institutional arrangements (such as income inequality) may explain differences in social participation health efficiency. (c) 2008 Elsevier Ltd. All rights reserved.

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CR ADAM S, 2006, 200605 CREPP WP U LI
Agren G, 2006, HLTH AGEING CHALLENG, P29
Almedom AM, 2005, SOC SCI MED, V61, P943, DOI 10.1016/j.socscimed.2004.12.025
[Anonymous], 2002, ACT AG POL FRAM
BECKER G, 2000, SOCIAL EC MARKET BEH
Blakely TA, 2002, SOC SCI MED, V54, P65, DOI 10.1016/S0277-9536(01)00007-7
Bolin K, 2003, SOC SCI MED, V56, P2379, DOI 10.1016/S0277-9536(02)00242-3
Borsch-Supan A., 2005, SURVEY HLTH AGING RE
CHRISTOFOROU A, 2005, 68 FOND EN ENR MATT
Craig N, 2005, SOC SCI MED, V60, P2477, DOI 10.1016/j.socscimed.2004.11.018
d'Hombres B., 2007, DOES SOCIAL CAPITAL
Deaton AS, 1998, AM ECON REV, V88, P248
Durlauf Steven N., 2002, ECON J, V112, P459
Ellaway A, 2007, SOC SCI MED, V64, P1384, DOI 10.1016/j.socscimed.2006.11.022
Erlinghagen M, 2006, AGEING SOC, V26, P567, DOI 10.1017/S0144686X06004818
Ettner SL, 1996, J HEALTH ECON, V15, P67, DOI 10.1016/0167-6296(95)00032-1
*EUR COMM, 2006, COM2006571 EUR COMM
FEARON JD, 1991, WORLD POLIT, V43, P169, DOI 10.2307/2010470
Folland S, 2007, SOC SCI MED, V64, P2342, DOI 10.1016/j.socscimed.2007.03.003
Glaeser E. L., 2002, ECON J, V112, P437
Greene W., 2000, ECONOMETRIC ANAL
Greiner KA, 2004, SOC SCI MED, V59, P2303, DOI 10.1016/j.socscimed.2004.03.023
Hawe P, 2000, SOC SCI MED, V51, P871, DOI 10.1016/S0277-9536(00)00067-8
Helliwell JF, 2007, EAST ECON J, V33, P1, DOI 10.1057/eej.2007.1
IDLER E, 1995, J GERONTOL, V50B, pS344
Idler EL, 1997, J HEALTH SOC BEHAV, V38, P21, DOI 10.2307/2955359
JAMIESON A, 1994, SOC SCI MED, V39, P1497, DOI 10.1016/0277-9536(94)90001-9
Kaasa A, 2007, INDIVIDUAL LEVEL DET
Kawachi I, 1999, AM J PUBLIC HEALTH, V89, P1187, DOI 10.2105/AJPH.89.8.1187
Kawachi I, 2006, INT J EPIDEMIOL, V35, P989, DOI 10.1093/ije/dyl117
Kennedy BP, 1998, BRIT MED J, V317, P917
King G, 2004, AM POLIT SCI REV, V98, P191, DOI 10.1017/S000305540400108X
Kondo N, 2007, SOC SCI MED, V64, P2311, DOI 10.1016/j.socscimed.2007.02.009
Lindstrom, 2006, INT J EQUITY HEALTH, V5, P1, DOI DOI 10.1186/1475-9276-5-3
Lindstrom M, 2004, SOC SCI MED, V59, P595, DOI 10.1016/j.socscimed.2003.11.006
Morgan SL, 2007, ANAL METHOD SOC RES, P1, DOI 10.1017/CBO9780511804564
Oakes JM, 2004, SOC SCI MED, V58, P1929, DOI 10.1016/j.socscimed.2003.08.004
Pearl J, 2000, CAUSALITY MODELS REA
PETROU S, 2003, HLTH EC LET IN PRESS
Putnam R., 2000, BOWLING ALONE COLLAP
SHORROCKS AF, 1983, ECONOMICA, V50, P3, DOI 10.2307/2554117

StataCorp, 2005, STAT STAT SOFTW REL
Szreter S, 2004, INT J EPIDEMIOL, V33, P650, DOI 10.1093/ije/dyh013
United Nations, 2007, WORLD POP PROSP 2006
Veenstra G, 2005, SOC SCI MED, V60, P2799, DOI 10.1016/j.socscimed.2004.11.013
Veenstra G, 2000, SOC SCI MED, V50, P619, DOI 10.1016/S0277-9536(99)00307-X
World Health Organization (WHO), 2006, HLTH CIT URB GOV
Ziersch AM, 2004, J EPIDEMIOL COMMUN H, V58, P493, DOI 10.1136/jech.2003.009084
NR 48
TC 79
Z9 80
U1 1
U2 26
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0277-9536
J9 SOC SCI MED
JI Soc. Sci. Med.
PD DEC
PY 2008
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IS 12
BP 2017
EP 2026
DI 10.1016/j.socscimed.2008.09.056
PG 10
WC Public, Environmental & Occupational Health; Social Sciences, Biomedical
SC Public, Environmental & Occupational Health; Biomedical Social Sciences
GA 388AY
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PM 18973973
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PT J
AU Yang, JJ
Li, JQ
Niu, Y
AF Yang, Ji-Jiang
Li, Jian-Qiang
Niu, Yu
TI A hybrid solution for privacy preserving medical data sharing in the cloud environment
SO FUTURE GENERATION COMPUTER SYSTEMS-THE INTERNATIONAL JOURNAL OF ESCIENCE
LA English
DT Article
DE Privacy protection; Cloud storage; Integrity check; Medical data sharing
ID ELECTRONIC HEALTH RECORDS; ACCESS-CONTROL; SECURITY; SEARCH
AB Storing and sharing of medical data in the cloud environment, where computing resources including storage is provided by a third party service provider, raise serious concern of individual privacy for the adoption of cloud computing technologies. Existing privacy protection researches can be classified into three categories, i.e., privacy by policy, privacy by statistics, and privacy by cryptography. However, the privacy concerns and data utilization requirements on different parts of the medical data may be quite different. The solution for medical dataset sharing in the cloud should support multiple data accessing

paradigms with different privacy strengths. The statistics or cryptography technology alone cannot enforce the multiple privacy demands, which blocks their application in the real-world cloud. This paper proposes a practical solution for privacy preserving medical record sharing for cloud computing. Based on the classification of the attributes of medical records, we use vertical partition of medical dataset to achieve the consideration of different parts of medical data with different privacy concerns. It mainly includes four components, i.e., (1) vertical data partition for medical data publishing, (2) data merging for medical dataset accessing, (3) integrity checking, and (4) hybrid search across plaintext and ciphertext, where the statistical analysis and cryptography are innovatively combined together to provide multiple paradigms of balance between medical data utilization and privacy protection. A prototype system for the large scale medical data access and sharing is implemented. Extensive experiments show the effectiveness of our proposed solution. (C) 2014 Elsevier B.V. All rights reserved.

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FX This research was supported by National Fundamental Research Program of China (973 Program) (Grant no. 2011CB302505) and Beijing Chaoyang Science & Technology Commission.

CR Abdalla M, 2008, J CRYPTOL, V21, P350, DOI 10.1007/s00145-007-9006-6
Agrawal R, 2000, SIGMOD RECORD, V29, P439
Agrawal R, 2007, INT J MED INFORM, V76, P471, DOI 10.1016/j.ijmedinf.2006.09.015
Ahson SA, 2011, CLOUD COMPUTING AND SOFTWARE SERVICES: THEORY AND TECHNIQUES, P1
ANSI, 2003, 18308 ISOTS
ANSI, 2003, 18308 ANSI ISOTS
Ardagna CA, 2010, COMPUT SECUR, V29, P848, DOI 10.1016/j.cose.2010.07.001
Ateniese G, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P598
Bakker R., 1995, P HELSO WORK C, V43, P1
Ballard L., 2005, P ICICS
Barber B., 1994, SECURITY DAT PROTECT
Bellare M., 2007, P CRYPTO
Benaloh J., 2009, P 2009 ACM WORKSH CL, P103, DOI DOI 10.1145/1655008.1655024
Boneh D., 2007, P CRYPTO
Boneh D., 2004, P EUROCRYPT
Boneh D, 2007, LECT NOTES COMPUT SC, V4392, P535
Cao N, 2011, IEEE INFOCOM SER, P829, DOI 10.1109/INFCOM.2011.5935306
Chandramouli R, 2001, 17TH ANNUAL COMPUTER SECURITY APPLICATIONS CONFERENCE, PROCEEDINGS, P137, DOI 10.1109/ACSAC.2001.991530
Chang Y.-C., 2005, P ACNS
Cranor L., 2002, PLATFORM PRIVACY REF
Curtmola R., 2006, P ACM CCS
Dierks T., 1997, TSL PROTOCOL
Dinur I., 2003, P 22 ACM SIGMOD SIGA, P202, DOI DOI 10.1145/773153.773173
Dolin R.H., HL7 CLIN DOCUMENT AR
Dwork C, 2004, LECT NOTES COMPUT SC, V3152, P528

Dwork C, 2008, LECT NOTES COMPUT SC, V4978, P1, DOI 10.1007/978-3-540-79228-4_1

Elger BS, 2010, COMPUT METH PROG BIO, V99, P230, DOI 10.1016/j.cmpb.2009.12.001

EVFIMIEVSKI A., 2003, P 22 ACM SIGMOD SIGA, P211, DOI DOI 10.1145/773153.773174

Ferraiolo D. F., 2001, ACM Transactions on Information and Systems Security, V4, P224, DOI 10.1145/501978.501980

FischerHubner S., 2001, IT SECURITY PRIVACY

Fontaine C, 2007, EURASIP J INF SECUR, DOI 10.1155/2007/13801

Garets D., 2006, HIMSS ANAL WHITE PAP

Gasarch W., 2004, SURVEY PRIVATE INFOR

Ghinita G., 2007, P 33 INT C VER LARG, P758

Golle P, 2004, LECT NOTES COMPUT SC, V3089, P31

Hao Z, 2011, IEEE T KNOWL DATA EN, V23, P1432, DOI 10.1109/TKDE.2011.62

Harrington Anthony, 2003, P 8 ACM S ACC CONTR, P158

He Q., 2003, TR200309 N CAR STAT

Hu JK, 2010, COMPUT STAND INTER, V32, P274, DOI 10.1016/j.csi.2009.04.005

Hwang Y., 2007, PAIRING

Jafari M., 2010, P DIG RIGHTS MAN WOR, P55, DOI DOI 10.1145/1866870.1866883

Jin J, 2011, COMPUT SECUR, V30, P116, DOI 10.1016/j.cose.2010.09.001

Karjoth G, 2002, P IEEE CSFW, P271, DOI 10.1109/CSFW.2002.1021821

Karlton P., 1996, SSL PROTOCOL V3 0

Kaufman LM, 2009, IEEE SECUR PRIV, V7, P61, DOI 10.1109/MSP.2009.87

Kenthapadi Krishnaram, 2005, PODS, P118

Kleinberg J, 2003, J COMPUT SYST SCI, V66, P244, DOI 10.1016/S0022-0000(02)00036-3

Kuo AMH, 2011, J MED INTERNET RES, V13, DOI 10.2196/jmir.1867

Li J., 2009, ACCOUNTABLE ATTRIBUT

Li J., 2012, ENTERPRISE INF SYST

Li N, 2007, INT CONF NANO MICRO, P692

Lindell Y., 2008, SECURE MULTIPARTY CO

Liu C, 2015, IEEE T COMPUT, V64, P2609, DOI 10.1109/TC.2014.2375190

Fernandez-Aleman JL, 2013, J BIOMED INFORM, V46, P541, DOI 10.1016/j.jbi.2012.12.003

Narayan S, 2010, PROCEEDINGS OF THE 2010 ACM WORKSHOP CLOUD COMPUTING SECURITY WORKSHOP (CCSW'10:), P47, DOI 10.1145/1866835.1866845

Ni Q, 2010, ACM T INFORM SYST SE, V13, DOI 10.1145/1805974.1805980

OASIS, 2005, EXT ACC CONTR MARK L

Ostrovsky R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P195

Park J., 2004, ACM Transactions on Information and Systems Security, V7, P128, DOI 10.1145/984334.984339

Quantin C, 2011, INT J MED INFORM, V80, pE6, DOI 10.1016/j.ijmedinf.2010.10.003

Robert H.D., 2006, J AM MED INFORM ASSN, V13, P30

Robertson S.E., 1992, TEXT RETR C

Sandhu RS, 1996, COMPUTER, V29, P38, DOI 10.1109/2.485845

Song D., 2000, P S P

Spiekermann S., 2009, IEEE T SOFTW ENG, V35

Stansfield S, 2005, B WORLD HEALTH ORGAN, V83, P562

Tian Y., 2009, IEEE INT COMM

Wang C., 2010, P ICDCS10

Wang LZ, 2013, COMPUT ELECTR ENG, V39, P3, DOI 10.1016/j.compeleceng.2012.05.001

Wang LZ, 2010, NEW GENERAT COMPUT, V28, P137, DOI 10.1007/s00354-008-0081-5

Win KT, 2006, J MED SYST, V30, P309, DOI 10.1007/s10916-006-9019-y

Xu J., 2006, P 12 ACM SIGKDD INT, P785, DOI DOI 10.1145/1150402.1150504

```
   Zhao JQ, 2014, J COMPUT SYST SCI, V80, P994, DOI 10.1016/j.jcss.2014.02.006
   Zissis D, 2012, FUTURE GENER COMP SY, V28, P583, DOI
10.1016/j.future.2010.12.006
NR 74
TC 78
Z9 80
U1 5
U2 70
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0167-739X
EI 1872-7115
J9 FUTURE GENER COMP SY
JI Futur. Gener. Comp. Syst.
PD FEB
PY 2015
VL 43-44
BP 74
EP 86
DI 10.1016/j.future.2014.06.004
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WC Computer Science, Theory & Methods
SC Computer Science
GA AW3UY
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AU Piwowar, HA
AF Piwowar, Heather A.
TI Who Shares? Who Doesn't? Factors Associated with Openly Archiving Raw
   Research Data
SO PLOS ONE
LA English
DT Article
ID MICROARRAY DATA; NATIONAL-SURVEY; PUBLIC REPOSITORIES; LIFE SCIENCES;
   INFORMATION; MOTIVATION; SUBMISSION; PROFILES; GENETICS
AB Many initiatives encourage investigators to share their raw datasets in hopes
of increasing research efficiency and quality. Despite these investments of time
and money, we do not have a firm grasp of who openly shares raw research data,
who doesn't, and which initiatives are correlated with high rates of data
sharing. In this analysis I use bibliometric methods to identify patterns in the
frequency with which investigators openly archive their raw gene expression
microarray datasets after study publication. Automated methods identified 11,603
articles published between 2000 and 2009 that describe the creation of gene
expression microarray data. Associated datasets in best-practice repositories
were found for 25% of these articles, increasing from less than 5% in 2001 to
30%-35% in 2007-2009. Accounting for sensitivity of the automated methods,
approximately 45% of recent gene expression studies made their data publicly
available. First-order factor analysis on 124 diverse bibliometric attributes of
the data creation articles revealed 15 factors describing authorship, funding,
institution, publication, and domain environments. In multivariate regression,
authors were most likely to share data if they had prior experience sharing or
reusing data, if their study was published in an open access journal or a
journal with a relatively strong data sharing policy, or if the study was funded
by a large number of NIH grants. Authors of studies on cancer and human subjects
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were least likely to make their datasets available. These results suggest
research data sharing levels are still low and increasing only slowly, and data
is least available in areas where it could make the biggest impact. Let's learn
from those with high rates of sharing to embrace the full potential of our
research output.
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CR [Anonymous], 2002, Nature, V419, P323
Ball CA, 2004, PLOS BIOL, V2, P1276, DOI 10.1371/journal.pbio.0020317
Barrett T, 2007, NUCL ACIDS RES, V35, pD760
Bird S, 2006, NATURAL LANGUAGE TOO
Bitzer J, 2007, J COMP ECON, V35, P160, DOI 10.1016/j.jce.2006.10.001
Blumenthal D, 2006, ACAD MED, V81, P137, DOI 10.1097/00001888-200602000-00008
Blumenthal D, 1997, JAMA-J AM MED ASSOC, V277, P1224, DOI
10.1001/jama.277.15.1224
Bornmann L, 2009, J AM SOC INF SCI TEC, V60, P1286, DOI 10.1002/asi.21016
Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
Brown C, 2003, J AM SOC INF SCI TEC, V54, P926, DOI 10.1002/asi.10289
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI
10.1001/jama.287.4.473
Cech TR, 2003, PLANT PHYSIOL, V132, P19, DOI 10.1104/pp.900068
CONSTANT D, 1994, INFORM SYST RES, V5, P400, DOI 10.1287/isre.5.4.400
Fienberg S. E., 1985, SHARING RES DATA
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
GIORDANO R, 2007, E SOCIAL SCI
Gorsuch R. L., 1983, FACTOR ANAL
Harrell F. E., 2001, REGRESSION MODELING
HEDSTROM M, 2006, IASSIST C 2006 PRES
HEDSTROM M, 2008, DAT IMPL ARCH REC MA
Hosek S, 2005, GENDER DIFFERENCES M
Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
Kakazu Kerry K, 2004, Hawaii Med J, V63, P273
KIM J, 2007, J DIGITAL INFORM, V8, P2
Kuo FY, 2008, J AM SOC INF SCI TEC, V59, P1224, DOI 10.1002/asi.20816
Kyzas PA, 2005, JNCI-J NATL CANCER I, V97, P1043, DOI 10.1093/jnci/dji184
Lee C. P., 2006, P 2006 20 ANN C COMP
Lowrance W. W., 2006, ACCESS COLLECTIONS D
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
Manolio TA, 2007, NAT GENET, V39, P1045, DOI 10.1038/ng2127
Matzler K, 2008, J ECON PSYCHOL, V29, P301, DOI 10.1016/j.joep.2007.06.004
MCCAIN KW, 1995, SCI COMMUN, V16, P403, DOI 10.1177/1075547095016004003
McCullough BD, 2008, CAN J ECON, V41, P1406, DOI 10.1111/j.1540-
5982.2008.00509.x
National Institutes of Health, 2003, NOTOD03032 NIH
Navarro Robert, 2008, Inform Prim Care, V16, P257
NIH, 2007, NOTOD08013 NIH
NIU J, 2006, INCENTIVE STUDY RES
Noor MAF, 2006, PLOS BIOL, V4, P1113, DOI 10.1371/journal.pbio.0040228

```
   NSF, 2011, GRANT PROP GUID
   Ochsner SA, 2008, NAT METHODS, V5, P991, DOI 10.1038/nmeth1208-991
   Parkinson H, 2007, NUCLEIC ACIDS RES, V35, pD747, DOI 10.1093/nar/gkl995
   Piwowar H. A., 2008, REV J POLICIES SHARI
   PIWOWAR HA, 2010, THESIS U PITTSBURGH
   PIWOWAR HA, 2011, DATA WHO SHARES WHO, DOI DOI 10.5061/DRYAD.MFLSD
   Piwowar HA, 2010, J BIOMED DISCOV COLL, V5, P7
   Piwowar HA, 2010, J INFORMETR, V4, P148, DOI 10.1016/j.joi.2009.11.010
   R Development Core Team, 2008, R LANG ENV STAT COMP
   Reidpath DD, 2001, BIOETHICS, V15, P125, DOI 10.1111/1467-8519.00220
   Rhodes DR, 2004, P NATL ACAD SCI USA, V101, P9309, DOI
10.1073/pnas.0401994101
   Ryu S, 2003, EXPERT SYST APPL, V25, P113, DOI 10.1016/S0957-4174(03)00011-3
   Seonghee K., 2008, LIB INFORM SCI RES, V30, P282, DOI DOI
10.1016/J.LISR.2008.04.003
   Siemsen E, 2008, J OPER MANAG, V26, P426, DOI 10.1016/j.jom.2007.09.001
   Theus M., 2008, INTERACTIVE GRAPHICS
   TORVIK V, 2009, T KNOWLEDGE DISCOVER, P1
   Tucker J, 2009, THESIS VIRGINIA POLY
   *U NOTT JULIET, RES FUND OP ACC POL
   Ventura B, 2005, PHYSIOL GENOMICS, V20, P153, DOI
10.1152/physiolgenomics.00264.2004
   VICKERS AJ, 2008, CANC DATA SORRY CANT
   Vogeli C, 2006, ACAD MED, V81, P128, DOI 10.1097/00001888-200602000-00007
   Warlick Stefanie E, 2007, Biomed Digit Libr, V4, P1, DOI 10.1186/1742-5581-4-
1
   Wellcome Trust, 2010, SHAR RES DAT IMPR PU
   Yu W, 2007, BMC MED INFORM DECIS, V7, DOI 10.1186/1472-6947-7-17
   2007, NAT NEUROSCI, V10, P931
   2007, NAT BIOTECH, V25, P821
NR 64
TC 70
Z9 71
U1 1
U2 67
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 185 BERRY ST, STE 1300, SAN FRANCISCO, CA 94107 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD JUL 13
PY 2011
VL 6
IS 7
AR e18657
DI 10.1371/journal.pone.0018657
PG 13
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA 792WQ
UT WOS:000292781500001
PM 21765886
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ER

PT J
```

AU Knoppers, BM
Harris, JR
Tasse, AM
Budin-Ljosne, I
Kaye, J
Deschenes, M
Zawati, MH
AF Knoppers, Bartha Maria
Harris, Jennifer R.
Tasse, Anne Marie
Budin-Ljosne, Isabelle
Kaye, Jane
Deschenes, Mylene
Zawati, Ma'n H.
TI Towards a data sharing Code of Conduct for international genomic research
SO GENOME MEDICINE
LA English
DT Article
AB Data sharing is increasingly regarded as an ethical and scientific imperative that advances knowledge and thereby respects the contributions of the participants. Because of this and the ever-increasing amount of data access requests currently filed around the world, three groups have decided to develop data sharing principles specific to the context of collaborative international genomics research. These groups are: the international Public Population Project in Genomics (P3G), an international consortium of projects partaking in large-scale genetic epidemiological studies and biobanks; the European Network for Genetic and Genomic Epidemiology (ENGAGE), a research project aiming to translate data from large-scale epidemiological research initiatives into relevant clinical information; and the Centre for Health, Law and Emerging Technologies (HeLEX). We propose seven different principles and a preliminary international data sharing Code of Conduct for ongoing discussion.
C1 [Knoppers, Bartha Maria; Tasse, Anne Marie; Zawati, Ma'n H.] McGill Univ, Dept Human Genet, Montreal, PQ H3A 1A4, Canada.
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FU Wellcome Trust [096599]
CR Cambon-Thomsen A, 2003, NAT GENET, V34, P25, DOI 10.1038/ng0503-25b
European Society of Human Genetics, 2003, Eur J Hum Genet, V11 Suppl 2, pS8
Hum. Genome Organ. (HUGO), 2003, J INT BIOETHIQUE, V14, P207
Human Genome Organization (HUGO), 1996, PRINC AGR 1 INT STRA
Kauffmann F, 2008, JAMA-J AM MED ASSOC, V299, P2316, DOI 10.1001/jama.299.19.2316
Laurie G, 2010, MED LAW INT, P315, DOI DOI 10.1177/096853321001000404
O'Brien SJ, 2009, ANNU REV GENOM HUM G, V10, P193, DOI 10.1146/annurev-genom-082908-150133
Rodriguez H, 2009, J PROTEOME RES, V8, P3689, DOI 10.1021/pr900023z
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
NR 9
TC 70

```
Z9 73
U1 0
U2 10
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1756-994X
J9 GENOME MED
JI Genome Med.
PY 2011
VL 3
AR 46
DI 10.1186/gm262
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WC Genetics & Heredity
SC Genetics & Heredity
GA V27QJ
UT WOS:000208627400046
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PT J
AU Piwowar, HA
   Becich, MJ
   Bilofsky, H
   Crowley, RS
AF Piwowar, Heather A.
   Becich, Michael J.
   Bilofsky, Howard
   Crowley, Rebecca S.
CA caBIG Data Sharing Intellectual
TI Towards a Data Sharing Culture: Recommendations for Leadership from
   Academic Health Centers
SO PLOS MEDICINE
LA English
DT Editorial Material
ID NEUROSCIENCE; SCIENCES
C1 [Piwowar, Heather A.; Becich, Michael J.; Crowley, Rebecca S.] Univ
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OI Piwowar, Heather/0000-0003-1613-5981
FU PHS HHS [79207CBS10, 79580CBS10]; NCATS NIH HHS [UL1 TR000005]; NLM NIH
   HHS [T15 LM007059, 5T15-LM007059-19]
CR Altman M., 2007, D LIB MAGAZINE, V13
   Altman RB, 2007, PHARMACOGENOMICS, V8, P519, DOI 10.2217/14622416.8.5.519
   *AM MED INF ASS, 2007, AMIA 10 10 PROGR
   Ball CA, 2004, NAT BIOTECHNOL, V22, P1179, DOI 10.1038/nbt0904-1179
   Blumenthal D, 2006, ACAD MED, V81, P137, DOI 10.1097/00001888-200602000-00008
   Butler D, 2007, NATURE, V446, P10, DOI 10.1038/446010b
   *CABIG, 2008, DAT SHAR PLAN CONT G
   *CABIG STRAT PLANN, 2007, STUD HLTH TECHNOL IN, V12, P330
   Campbell Eric G, 2003, J Health Care Law Policy, V6, P241
```

```
   *COMM RESP AUTH BI, 2003, SHAR PUBL REL DAT MA
   Davies H D, 1996, CMAJ, V155, P877
   Detmer Don E, 2003, BMC Med Inform Decis Mak, V3, P1, DOI 10.1186/1472-6947-
3-1
   FIENBERG SE, 1994, ANNU REV PUBL HEALTH, V15, P1
   Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
   Gardner D, 2003, NEUROINFORMATICS, V1, P289, DOI 10.1385/NI:1:3:289
   Grethe JS, 2005, ST HEAL T, V112, P100
   HAGA S, 2007, EXPLORING ATTITUDES
   *HARV FAC ARTS SCI, 2008, HARV COLL DISS SCHOL
   Liu Y, 2007, NEUROINFORMATICS, V5, P143, DOI 10.1007/s12021-007-0009-0
   Lowrance W, 2006, ACCESS COLLECTIONS D
   *NAT COMM VIT HLTH, 2007, ENH PROT US HLTH DAT
   National Institutes of Health, 2003, NOTOD03032 NIH
   *NIH, 2008, NOTOD08033 NIH
   *NIH, 2007, NOTOD07088 NIH
   *NIH, 2007, GUID DEV DAT SHAR PL
   *NIH, 2007, POINTS CONS IRBS I T
   PIWOWAR HA, 2008, P 12 INT C EL PUBL 2
   PIWOWAR HA, 2008, AMIA 2008 ANN S
   Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
   RASHID A, 2006, P ACM CHI 2006 C HUM
   Ruttenberg A, 2007, BMC BIOINFORMATICS, V8, DOI 10.1186/1471-2105-8-S3-S2
   Safran C, 2007, J AM MED INFORM ASSN, V14, P1, DOI 10.1197/jamia.M2273
   SINNOTT RO, 2005, LARGE SCALE DATA SHA
   *SPARC, 2008, BERK STEPS FORW BOLD
   Teeters JL, 2008, NEUROINFORMATICS, V6, P47, DOI 10.1007/s12021-008-9009-y
   Theologis A, 2004, PLANT PHYSIOL, V135, P4, DOI 10.1104/pp.104.043083
   *U N CAR CHAP HILL, 2005, OP ACC AUTH FUND
   *U WISC MAD, 2005, SEED MON OP ACC PUBL
   Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
   2007, NAT BIOTECHNOL, V25, P821
   2001, J CELL SCI, V114, P1037
   2007, NAT GENET, V39, P931
   2007, NAT NEUROSCI, V10, P931
   2005, NATURE, V438, P531
NR 44
TC 70
Z9 72
U1 0
U2 14
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1549-1676
J9 PLOS MED
JI PLos Med.
PD SEP
PY 2008
VL 5
IS 9
BP 1315
EP 1319
AR e183
DI 10.1371/journal.pmed.0050183
PG 5
WC Medicine, General & Internal
SC General & Internal Medicine
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PT J
AU Bjorling, E
   Uhlen, M
AF Bjorling, Erik
   Uhlen, Mathias
TI Antibodypedia, a Portal for Sharing Antibody and Antigen Validation Data
SO MOLECULAR & CELLULAR PROTEOMICS
LA English
DT Article
ID B-CELL EPITOPES; HUMAN PROTEOME; CANCER TISSUES; RESOURCE; ATLAS;
   GENERATION; PREDICTION; PEPTIDES; PROTEINS; ENSEMBL
AB Antibodies are useful tools to characterize the components of the human
proteome and to validate potential protein biomarkers discovered through various
clinical proteomics efforts. The lack of validation results across various
applications for most antibodies often makes it necessary to perform cumbersome
investigations to ensure specificity of a particular antibody in a certain
application. A need therefore exists for a standardized system for sharing
validation data about publicly available antibodies and to allow antibody
providers as well as users to contribute and edit experimental evidence data,
including data also on the antigen. Here we describe a new publicly available
portal called Antibodypedia, which has been developed to allow sharing of
information regarding validation of antibodies in which providers can submit
their own validation results and reliability scores. We report standardized
validation criteria and submission rules for applications such as Western blots,
protein arrays, immunohistochemistry, and immunofluorescence. The contributor is
expected to provide experimental evidence and a validation score for each
antibody, and the users can subsequently provide feedback and comments on the
use of the antibody. The database thus provides a virtual resource of publicly
available antibodies toward human proteins with accompanying experimental
evidence supporting an individual validation score for each antibody in an
application-specific manner. Molecular & Cellular Proteomics 7: 2028-2037, 2008.
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OI Uhlen, Mathias/0000-0002-4858-8056
FU Knut and Alice Wallenberg Foundation; European Union
FX This work was supported by grants from the Knut and Alice Wallenberg
   Foundation and the European Union 6th framework network program
   ProteomeBinders. The costs of publication of this article were defrayed
   in part by the payment of page charges. This article must therefore be
   hereby marked "advertisement" in accordance with 18 U.S.C. Section 1734
   solely to indicate this fact.
CR Andersen PH, 2006, PROTEIN SCI, V15, P2558, DOI 10.1110/ps.062405906
   Anderson NL, 2002, MOL CELL PROTEOMICS, V1, P845, DOI 10.1074/mcp.R200007-
MCP200
   Bairoch A, 2008, NUCLEIC ACIDS RES, V36, pD190, DOI 10.1093/nar/gkm895
   Barbe L, 2008, MOL CELL PROTEOMICS, V7, P499, DOI 10.1074/mcp.M700325-MCP200
   Berglund L, 2008, PROTEIN SCI, V17, P606, DOI 10.1110/ps.073347208
```

```
   Birney E, 2004, GENOME RES, V14, P925, DOI 10.1101/gr.1860604
   Birney E, 2007, NATURE, V447, P799, DOI 10.1038/nature05874
   Bjorling E, 2008, MOL CELL PROTEOMICS, V7, P825, DOI 10.1074/mcp.M700411-
MCP200
   BLAKE MS, 1984, ANAL BIOCHEM, V136, P175, DOI 10.1016/0003-2697(84)90320-8
   Blow N, 2007, NATURE, V447, P741, DOI 10.1038/447741a
   Celis JE, 2005, FEBS J, V272, P2, DOI 10.1111/j.1432-1033.2004.04418.x
   ENGVALL E, 1971, IMMUNOCHEMISTRY, V8, P874
   Flicek P, 2008, NUCLEIC ACIDS RES, V36, pD707, DOI 10.1093/nar/gkm988
   Gardy JL, 2005, BIOINFORMATICS, V21, P617, DOI 10.1093/bioinformatics/bti057
   Haab BB, 2006, MOL CELL PROTEOMICS, V5, P1996, DOI 10.1074/mcp.T600020-MCP200
   Kallioniemi OP, 2001, HUM MOL GENET, V10, P657, DOI 10.1093/hmg/10.7.657
   Kampf C., 2004, CLIN PROTEOM, V1, P285, DOI DOI 10.1385/CP:1:3-4:285
   Kerrien S, 2007, BMC BIOL, V5, DOI 10.1186/1741-7007-5-44
   KOHLER G, 1975, NATURE, V256, P497
   Mathivanan S, 2008, NAT BIOTECHNOL, V26, P164, DOI 10.1038/nbt0208-164
   Meloen RH, 2003, CURR PROTEIN PEPT SC, V4, P253, DOI 10.2174/1389203033487144
   Nilsson P, 2005, PROTEOMICS, V5, P4327, DOI 10.1002/pmic.200500072
   Nygren PA, 2004, J IMMUNOL METHODS, V290, P3, DOI 10.1016/j.jim.2004.04.006
   Orchard S, 2007, NAT BIOTECHNOL, V25, P894, DOI 10.1038/nbt1324
   Schwenk JM, 2007, MOL CELL PROTEOMICS, V6, P125, DOI 10.1074/mcp.T60035-
MCP200
   TANG DC, 1992, NATURE, V356, P152, DOI 10.1038/356152a0
   Taussig MJ, 2007, NAT METHODS, V4, P13, DOI 10.1038/nmeth0107-13
   Tyers M, 2003, NATURE, V422, P193, DOI 10.1038/nature01510
   Uhlen M, 2005, MOL CELL PROTEOMICS, V4, P1920, DOI 10.1074/mcp.M500279-MCP200
   Uhlen M, 2005, MOL CELL PROTEOMICS, V4, P384, DOI 10.1074/mcp.R500009-MCP200
   Uhlen M, 2008, BIOTECHNIQUES, V44, P649, DOI 10.2144/000112803
   Uhlen M, 2007, MOL CELL PROTEOMICS, V6, P1455
   Van Regenmortel MHV, 2006, J MOL RECOGNIT, V19, P183, DOI 10.1002/jmr.768
NR 33
TC 69
Z9 72
U1 0
U2 2
PU AMER SOC BIOCHEMISTRY MOLECULAR BIOLOGY INC
PI BETHESDA
PA 9650 ROCKVILLE PIKE, BETHESDA, MD 20814-3996 USA
SN 1535-9476
J9 MOL CELL PROTEOMICS
JI Mol. Cell. Proteomics
PD OCT
PY 2008
VL 7
IS 10
BP 2028
EP 2037
DI 10.1074/mcp.M800264-MCP200
PG 10
WC Biochemical Research Methods
SC Biochemistry & Molecular Biology
GA 365RE
UT WOS:000260424700019
PM 18667413
OA Bronze
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PT J
AU Fabian, B
Ermakova, T
Junghanns, P
AF Fabian, Benjamin
Ermakova, Tatiana
Junghanns, Philipp
TI Collaborative and secure sharing of healthcare data in multi-clouds
SO INFORMATION SYSTEMS
LA English
DT Article
DE Cloud computing; Healthcare; Security; Privacy
ID INFORMATION

AB In healthcare, inter-organizational sharing and collaborative use of big data become increasingly important The cloud-computing paradigm is expected to provide an environment perfectly matching the needs of collaborating healthcare workers. However, there are still many security and privacy challenges impeding the wide adoption of cloud computing in this domain. In this paper, we present a novel architecture and its implementation for interorganizational data sharing, which provides a high level of security and privacy for patient data in semi-trusted cloud computing environments. This architecture features attribute-based encryption for selective access authorization and cryptographic secret sharing in order to disperse data across multiple clouds, reducing the adversarial capabilities of curious cloud providers. An implementation and evaluation by several experiments demonstrate the practical feasibility and good performance of our approach. (C) 2014 Elsevier Ltd. All rights reserved.

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OI Fabian, Benjamin/0000-0002-9585-1814

CR Abbadi I.M., 2011, P 3 INT WORKSH CLOUD
Akinyele J.A, 2010, 2010565 CRYPT EPRINT
[Anonymous], 2013, GOOGLE CLOUD STORAGE
Basu S., IEEE COMP SPEC ISS M
Berndt R. D., 2012, P 9 INT MULT SYST SI
Bessani A, 2011, EUROSYS 11: PROCEEDINGS OF THE EUROSYS 2011 CONFERENCE, P31
Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
Chen L., 2011, P IEEE INT C HIGH PE
Chen T.-S., J MED SYST, V6
Chen Y.-Y., J MED SYST, V5
Chong R.F., 2012, CHANGING WORLD BIG D
De Cam A., 2012, JAVA PAIRING BASED C
Deng M., 2012, P IEEE 4 INT C CLOUD
Dierks T., 2006, TRANSPORT LAYER SECU
Eastlake D., 2001, US SECURE HASH ALGOR
ENISA, 2009, CLOUD COMP BEN RISKS
Ermakova T., 2013, P IEEE C BUS INF
Ermakova T., 2013, SUBM AM C INF SYST
Fabian B, 2013, DECIS SUPPORT SYST, V55, P385, DOI 10.1016/j.dss.2012.05.049
Fabian B, 2010, REQUIR ENG, V15, P7, DOI 10.1007/s00766-009-0092-x
Ferraiolo D. F., 2001, ACM Transactions on Information and Systems Security, V4, P224, DOI 10.1145/501978.501980
Ferraiolo David F, 2007, ROLE BASED ACCESS CO

Fielding R. T, THESIS
Guo L, 2010, P INT C E HLTH NETW
Hardesty L., 2013, BIG MED DAT
He C., 2010, P IEEE INT C INT COM
Hevner A., 2010, DESIGN RES INF SYSTE
Hintze JL, 1998, AM STAT, V52, P181, DOI 10.2307/2685478
Hoang D. B., 2010, P IEEE AS PAC SERV C
Huang Q., 2011, P INT C NETW COMP IN
Ibraimi L., 2009, TECHNICAL REPORT
Juels A, 2013, COMMUN ACM, V56, P64, DOI 10.1145/2408776.2408793
Kanagaraj G., 2011, P 3 INT C TRENDS INF
Karthikeyan N., J MED SYST, V6
Koufi V., 2010, P 10 IEEE INT C INF
Krawczyk H., 1994, Advances in Cryptology - CRYPTO '93. 13th Annual International Cryptology Conference Proceedings, P136
Krawczyk H., 1993, Proceedings of the Twelfth Annual ACM Symposium on Principles of Distributed Computing, P207, DOI 10.1145/164051.164075
Krawczyk M., 1997, HMAC KEYED HASHING M
Li M., 2011, P 31 INT C DISTR COM
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Li M, 2010, L N INST COMP SCI SO, V50, P89
Li Z.-R., 2011, P IEEE 15 INT S CONS
Loehr H., 2010, P ACM INT HLTH INF S
Mell P., 2012, TECHNICAL REPORT
Narayan S., 2010, P ACM WORKSH CLOUD C
NIST, 2011, NIST SPECIAL PUBLICA
NIST, 2001, NIST SPECIAL PUBLICA, V800-22
NIST Digital Signature Standard (DSS), 2009, NIST FED INF PROC ST
NIST The Keyed-Hash Message Authentication Code (HMAC), 2008, NIST FED INF PROC ST
OASIS, 2012, WEB SERV SEC V1 1 1
OsiriX DICOM Viewer, 2013, DICOM SAMPL IM SETS
Peffers K, 2007, J MANAGE INFORM SYST, V24, P45, DOI 10.2753/MIS0742-1222240302
Poulymenopoulou M., 2011, P PERVASIVE TECHNOLO
RABIN MO, 1989, J ACM, V36, P335, DOI 10.1145/62044.62050
Ratnam KA, 2012, P INT C COMP INF SCI
Rolim C.O., 2010, P 2 TEL SOC MED
Schultz D.A., ACM T INF SYST SECUR, V13, P34
SHAMIR A, 1979, COMMUN ACM, V22, P612, DOI 10.1145/359168.359176
Sharieh S., 2012, P 15 COMM NETW SIM S
Shim SSY, 2005, COMPUTER, V38, P120, DOI 10.1109/MC.2005.408
Shini S, 2012, P INT C MOD OPT COMP
Stallings W., 2010, CRYPTOGRAPHY NETWORK
U. S. Department of Health and Human Services, 2013, HLTH INF PRIV
Vazhenin D., 2012, P JOINT INT C HUM CT
Wang J, 2013, JAVA REALIZATION CIP
Yu S., 2010, P 29 C INF COMM
NR 66
TC 68
Z9 70
U1 3
U2 90
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0306-4379
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```
J9 INFORM SYST
JI Inf. Syst.
PD MAR
PY 2015
VL 48
BP 132
EP 150
DI 10.1016/j.is.2014.05.004
PG 19
WC Computer Science, Information Systems
SC Computer Science
GA AW4CZ
UT WOS:000346230200008
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ER

PT J
AU van Panhuis, WG
   Paul, P
   Emerson, C
   Grefenstette, J
   Wilder, R
   Herbst, AJ
   Heymann, D
   Burke, DS
AF van Panhuis, Willem G.
   Paul, Proma
   Emerson, Claudia
   Grefenstette, John
   Wilder, Richard
   Herbst, Abraham J.
   Heymann, David
   Burke, Donald S.
TI A systematic review of barriers to data sharing in public health
SO BMC PUBLIC HEALTH
LA English
DT Review
DE Data sharing; Public health; Surveillance
ID DISEASE SURVEILLANCE SYSTEMS; INFORMATION; STATISTICS; PRIVACY;
   CONFIDENTIALITY; FRAMEWORK; LESSONS; COUNTS; ACCESS; IMPACT
AB Background: In the current information age, the use of data has become
essential for decision making in public health at the local, national, and
global level. Despite a global commitment to the use and sharing of public
health data, this can be challenging in reality. No systematic framework or
global operational guidelines have been created for data sharing in public
health. Barriers at different levels have limited data sharing but have only
been anecdotally discussed or in the context of specific case studies.
Incomplete systematic evidence on the scope and variety of these barriers has
limited opportunities to maximize the value and use of public health data for
science and policy.
   Methods: We conducted a systematic literature review of potential barriers to
public health data sharing. Documents that described barriers to sharing of
routinely collected public health data were eligible for inclusion and reviewed
independently by a team of experts. We grouped identified barriers in a taxonomy
for a focused international dialogue on solutions.
   Results: Twenty potential barriers were identified and classified in six
categories: technical, motivational, economic, political, legal and ethical. The
first three categories are deeply rooted in well-known challenges of health
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information systems for which structural solutions have yet to be found; the last three have solutions that lie in an international dialogue aimed at generating consensus on policies and instruments for data sharing.

Conclusions: The simultaneous effect of multiple interacting barriers ranging from technical to intangible issues has greatly complicated advances in public health data sharing. A systematic framework of barriers to data sharing in public health will be essential to accelerate the use of valuable information for the global good.

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CR AbouZahr C, 2007, LANCET, V369, P1039, DOI 10.1016/S0140-6736(07)60463-2
AbouZahr C, 2007, LANCET, V370, P1791, DOI 10.1016/S0140-6736(07)61310-5
Anderson M, 2009, J PRIVACY CONFIDENTI, V1, P7
[Anonymous], 2010, LANCET, V375, P1940, DOI 10.1016/S0140-6736(10)60906-3
[Anonymous], 2013, NATURE, V494, P281
Arofan G, 2007, DDI SDMX COMPLEMENTA
Baldwin W, 2009, DEMOGRAPHIC DATA DEV
Boerma JT, 2007, LANCET, V369, P779, DOI 10.1016/S0140-6736(07)60364-X
Boussard E, 1996, BRIT MED J, V313, P1381, DOI 10.1136/bmj.313.7069.1381
Brest P, 2007, COMMUNICATION
Butler D, 2013, NATURE, V497, P14, DOI 10.1038/497014a
Byass P, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000155
Cash RA, 2000, B WORLD HEALTH ORGAN, V78, P1358
CDC/ATSDR: CDC-CSTE Intergovernmental Data Release Guidelines Working Group (DRGWG) Report, 2005, COMM MOB GUID WE CAN, P1
Center MP, 2014, INT PUBL US MICR SER
Centers for Disease Control and Prevention, 2011, DAT SEC CONF GUID HI
Centers for Disease Control and Prevention (CDC), 2003, MMWR Suppl, V52, P1
Chan M, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000223
Chandramohan D, 2008, PLOS MED, V5, P169, DOI 10.1371/journal.pmed.0050057
Chen L, 2004, LANCET, V364, P1984, DOI 10.1016/S0140-6736(04)17482-5
Chretien JP, 2008, PLOS MED, V5, P367, DOI 10.1371/journal.pmed.0050072
Croner CM, 2003, ANNU REV PUBL HEALTH, V24, P57, DOI 10.1146/annurev.publhealth.24.012902.140835
Dupriez O, 2010, DISSEMINATION MICROD
El Emam K, 2011, BMC PUBLIC HEALTH, V11, DOI 10.1186/1471-2458-11-454

Fan XU, 2007, STUD HEALTH TECHNOL, V129, P316

Fidler DP, 2008, EMERG INFECT DIS, V14, P88, DOI 10.3201/eid1401.070700

Fidler DP, 2011, JAMA-J AM MED ASSOC, V306, P200, DOI 10.1001/jama.2011.960

FLAHERTY DH, 1992, CAN PUBLIC ADMIN, V35, P75, DOI 10.1111/j.1754-7121.1992.tb00680.x

Fountain Jane E, 2004, Prev Chronic Dis, V1, pA2

Friedman DJ, 2001, PUBLIC HEALTH REP, V116, P132, DOI 10.1016/S0033-3549(04)50005-5

Gao S, 2008, INT J HEALTH GEOGR, V7, DOI 10.1186/1476-072X-7-8

Georgia Department of Human Resources (DHR) Division of Public Health, HIPAA FACT SHET PUBL

GOSTIN LO, 1995, CORNELL LAW REV, V80, P451

Heeks R., 2000, GOVT DATA UNDERSTAND

Heymann D L, 2001, Lancet Infect Dis, V1, P345, DOI 10.1016/S1473-3099(01)00148-7

Irwin R, 2010, GLOBAL HLTH GOVERNAN, V3

Keller M, 2009, EMERG INFECT DIS, V15, P689, DOI 10.3201/eid1505.081114

Kephart G, 2002, BARRIERS ACCESSING A

Kupferschmidt K, 2014, SCIENCE, V345, P1108, DOI 10.1126/science.345.6201.1108

Laine C, 2007, ANN INTERN MED, V146, P450, DOI 10.7326/0003-4819-146-6-200703200-00154

Lane J, 2010, HEALTH SERV RES, V45, P1456, DOI 10.1111/j.1475-6773.2010.01141.x

Lang TD, 2011, SCIENCE, V331, P714, DOI 10.1126/science.1199349

Lee LM, 2009, JAMA-J AM MED ASSOC, V302

Lewis SH, 2008, J HOPKINS APL TECH D, V27, P366

Lim SS, 2008, LANCET, V372, P2031, DOI 10.1016/S0140-6736(08)61869-3

Lopez AD, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.078956

Lungo JH, 2004, INT ICT WORKSH 2004

Mahapatra P, 2007, LANCET, V370, P1653, DOI 10.1016/S0140-6736(07)61308-7

Marsh Inc, 2008, EC SOC IMP EM INF DI

McGraw D, 2013, J AM MED INFORM ASSN, V20, P29, DOI 10.1136/amiajnl-2012-000936

McNabb SJN, 2010, BMC PUBLIC HEALTH, V10, DOI 10.1186/1471-2458-10-S1-S3

Moher D, 2010, INT J SURG, V8, P336, DOI 10.1016/j.ijsu.2010.02.007

Morse SS, 2007, HEALTH AFFAIR, V26, P1069, DOI 10.1377/hlthaff.26.4.1069

Murray CJL, 2007, LANCET, V369, P862, DOI 10.1016/S0140-6736(07)60415-2

National Center for Vital Statistics, 1980, ICDA819681978 NAT CT

Office of E-government and IT Office of Management and Budget, 2009, DAT GOV CON IN PRESS

Pisani E, 2012, OPENEPI NEW CULTURE

Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393

Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0

Rudolph R, 2005, NAHDO WORKING TECHNI, P51

Safran C, 2007, J AM MED INFORM ASSN, V14, P1, DOI 10.1197/jamia.M2273

Sankoh O, 2013, LANCET GLOB HEALTH, V1, pE69, DOI 10.1016/S2214-109X(13)70034-2

Setel PW, 2007, LANCET, V370, P1569, DOI 10.1016/S0140-6736(07)61307-5

Stansfield S, 2008, B WORLD HEALTH ORGAN, V86, P170

States U, 2001, GLOBAL HLTH CHALLENG

Strobl J, 2000, BRIT MED J, V321, P890, DOI 10.1136/bmj.321.7265.890

Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129

Thacker Stephen B, 2012, MMWR Suppl, V61, P3

Turner Kathryn, 2011, Morbidity and Mortality Weekly Report, V60, P1421

US Department of Health and Human Services, 2003, SUMM HIPAA PRIV RUL

Vogel G, 2012, SCIENCE, V336, P1372, DOI 10.1126/science.336.6087.1372

```
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wartenberg D, 2010, AM J PUBLIC HEALTH, V100, P407, DOI
10.2105/AJPH.2009.166249
   Whitworth J, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.079202
   Wilkins K, 2008, PUBLIC HEALTH, V122, P914, DOI 10.1016/j.puhe.2007.11.002
   Willison D., 2012, FRAMEWORK ETHICAL CO
   World Health Organization, 2008, HLTH METR NETW FRAM
   Wright G., 2010, OPEN GOVT DATA STUDY
   Wu Min, 2005, J Med Syst, V29, P303, DOI 10.1007/s10916-005-5890-1
NR 79
TC 64
Z9 64
U1 2
U2 18
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
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JI BMC Public Health
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AR 1144
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PT J
AU Mascalzoni, D
   Dove, ES
   Rubinstein, Y
   Dawkins, HJS
   Kole, A
   McCormack, P
   Woods, S
   Riess, O
   Schaefer, F
   Lochmuller, H
   Knoppers, BM
   Hansson, M
AF Mascalzoni, Deborah
   Dove, Edward S.
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```

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TI International Charter of principles for sharing bio-specimens and data

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DT Article

ID BROAD CONSENT; BIOBANKS; PRIVACY; ETHICS

AB There is a growing international agreement on the need to provide greater access to research data and bio-specimen collections to optimize their long-term value and exploit their potential for health discovery and validation. This is especially evident for rare disease research. Currently, the rising value of data and bio-specimen collections does not correspond with an equal increase in data/sample-sharing and data/sample access. Contradictory legal and ethical frameworks across national borders are obstacles to effective sharing: more specifically, the absence of an integrated model proves to be a major logistical obstruction. The Charter intends to amend the obstacle by providing both the ethical foundations on which data sharing should be based, as well as a general Material and Data Transfer Agreement (MTA/DTA). This Charter is the result of a careful negotiation of different stakeholders' interest and is built on earlier consensus documents and position statements, which provided the general international legal framework. Further to this, the Charter provides tools that may help accelerate sharing. The Charter has been formulated to serve as an enabling tool for effective and transparent data and bio-specimen sharing and the general MTA/DTA constitutes a mechanism to ensure uniformity of access across projects and countries, and may be regarded as a consistent basic agreement for addressing data and material sharing globally. The Charter is forward looking in terms of emerging issues from the perspective of a multi-stakeholder group, and where possible, provides strategies that may address these issues.

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CR Arnason V, 2004, BIOETHICS, V18, P27, DOI 10.1111/j.1467-8519.2004.00377.x
Birney, NATURE, V461, P168
Budin-Ljosne I, 2011, BMC MED GENOMICS, V4, DOI 10.1186/1755-8794-4-69
Caulfield T., 2007, KINGS LAW J, V18, P209
European Council, 2009, 2009C15102 EC
Fortier I, 2010, INT J EPIDEMIOL, P1
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hansson MG, 2009, BRIT J CANCER, V100, P8, DOI 10.1038/sj.bjc.6604795
Hansson MG, 2012, CANCER EPIDEMIOL, V36, P575, DOI 10.1016/j.canep.2012.06.009
Hansson MG, 2012, ARCH DIS CHILD, V97, P561, DOI 10.1136/archdischild-2011-301175
Hansson MG, 2006, LANCET ONCOL, V7, P266, DOI 10.1016/S1470-2045(06)70618-0
Helgesson G, 2007, NAT BIOTECHNOL, V25, P973, DOI 10.1038/nbt0907-973b
Hoeyer K, 2010, PUBLIC HEALTH GENOM, V13, P345, DOI 10.1159/000262329
Kaijser M, 2003, BIOBANKS RESOURCES H, P33
Kaye J, 2011, BMJ-BRIT MED J, P343
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Kaye J, 2012, NAT REV GENET, V13, P371, DOI 10.1038/nrg3218
Knoppers BM, 2013, NAT BIOTECHNOL, V31, P384, DOI 10.1038/nbt.2567
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Lunshof JE, 2008, NAT REV GENET, V9, P406, DOI 10.1038/nrg2360
Mascalzoni D, 2014, APPL TRANSL GENOM, V3, P23, DOI 10.1016/j.atg.2014.04.003
Mascalzoni D, 2008, PLOS MED, V5, P1302, DOI 10.1371/journal.pmed.0050192
McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339

```
   Ness RB, 2007, CANCER EPIDEM BIOMAR, V16, P188, DOI 10.1158/1055-9965.EPI-06-
1011
   O'Brien SJ, 2009, ANNU REV GENOM HUM G, V10, P193, DOI 10.1146/annurev-genom-
082908-150133
   Shamoo A. E., 2009, RESPONSIBLE CONDUCT
   Sheehan M, 2011, PUBLIC HEALTH ETH-UK, V4, P226, DOI 10.1093/phe/phr020
   Steinsbekk KS, 2011, PUBLIC HEALTH ETH-UK, V4, P236, DOI 10.1093/phe/phr031
   van Veen EB, 2006, EUR J CANCER, V42, P2914, DOI 10.1016/j.ejca.2006.04.028
NR 29
TC 63
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U1 1
U2 13
PU NATURE PUBLISHING GROUP
PI LONDON
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   Chapman, Brian E.
   Chapman, Wendy W.
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TI iDASH: integrating data for analysis, anonymization, and sharing
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ID PRESERVING SVM CLASSIFICATION; PATIENT PRIVACY; SURVEILLANCE; DATABASES;
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AB iDASH (integrating data for analysis, anonymization, and sharing) is the
newest National Center for Biomedical Computing funded by the NIH. It focuses on
algorithms and tools for sharing data in a privacy-preserving manner.
Foundational privacy technology research performed within iDASH is coupled with
innovative engineering for collaborative tool development and data-sharing
capabilities in a private Health Insurance Portability and Accountability Act
(HIPAA)-certified cloud. Driving Biological Projects, which span different
biological levels (from molecules to individuals to populations) and focus on
various health conditions, help guide research and development within this
Center. Furthermore, training and dissemination efforts connect the Center with
its stakeholders and educate data owners and data consumers on how to share and
use clinical and biological data. Through these various mechanisms, iDASH
implements its goal of providing biomedical and behavioral researchers with
access to data, software, and a high-performance computing environment, thus
enabling them to generate and test new hypotheses.
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```

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CR [Anonymous], 2011, OBSERVATIONAL MED OU
[Anonymous], NCBO ANN
Arrott M, 2007, 2007 IEEE INTERNATIONAL CONFERENCE ON WEB SERVICES, PROCEEDINGS, P176
Barak B, 2007, P PRINC DAT SYST ASS
Bathe OF, 2009, GENET MED, V11, P712, DOI 10.1097/GIM.0b013e3181b2e168
Blum A, 2008, ACM S THEORY COMPUT, P609
Chapman BE, 2011, J BIOMED INFORM, V44, P728, DOI 10.1016/j.jbi.2011.03.011
Chapman WW, 2011, J AM MED INFORM ASSN, V18, P540, DOI 10.1136/amiajnl-2011-000465
Chaudhuri K, 2011, P 24 ANN C LEARN THE
Chaudhuri K, 2011, J MACH LEARN RES, V12, P1069
Chawla S, 2005, LECT NOTES COMPUT SC, V3378, P363
Dasgupta S, 2011, THEOR COMPUT SCI, V412, P1767, DOI 10.1016/j.tcs.2010.12.054
Dinur I., 2003, P 22 ACM SIGMOD SIGA, P202, DOI DOI 10.1145/773153.773173
Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1
Eiseman E, 2003, CASE STUDIES EXISTIN
Jiang X, 2011, AMIA SUMMITS TRANSLA
Jiang X, 2011, 17 ACM C KNOWL DISC
Jonquet Clement, 2010, J Biomed Semantics, V1 Suppl 1, pS1, DOI 10.1186/2041-1480-1-S1-S1
Kanehisa M, 2003, NAT GENET, V33, P305, DOI 10.1038/ng1109
Karp DR, 2008, PLOS MED, V5, P1333, DOI 10.1371/journal.pmed.0050190
Kim J, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-75
Kozanitis C, 2011, J COMPUT BIOL, V18, P401, DOI 10.1089/cmb.2010.0253
Lander ES, 2001, NATURE, V409, P860, DOI 10.1038/35057062
Lasko TA, 2010, IEEE T KNOWL DATA EN, V22, P437, DOI 10.1109/TKDE.2009.88
Loukides G, 2010, J AM MED INFORM ASSN, V17, P322, DOI 10.1136/jamia.2009.002725
Malin B, 2001, J AM MED INFORM ASSN, P423
Malin B, 2000, J AM MED INFORM ASSN, P537
Malin B, 2011, J AM MED INFORM ASSN, V18, P3, DOI 10.1136/jamia.2010.004622
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
Matheny ME, 2008, AM HEART J, V155, P114, DOI 10.1016/j.ahj.2007.08.022
Matheny Michael E, 2007, AMIA Annu Symp Proc, P518
Matheny ME, 2009, MED DECIS MAKING, V29, P247, DOI 10.1177/0272989X08327110
Ohno-Machado L, 2004, INT J MED INFORM, V73, P599, DOI 10.1016/j.ijmedinf.2004.05.002
Ohrn A, 1999, ARTIF INTELL MED, V15, P235, DOI 10.1016/S0933-3657(98)00056-6
Resnic FS, 2010, JAMA-J AM MED ASSOC, V304, P2019, DOI 10.1001/jama.2010.1633
Roeder C, 2010, BIOINFORMATICS, V26, P1800, DOI 10.1093/bioinformatics/btq250
Sarkar IN, 2011, J AM MED INFORM ASSN, V18, P354, DOI 10.1136/amiajnl-2011-000245
Shimizu C, 2011, CIRC-CARDIOVASC GENE, V4, P16, DOI 10.1161/CIRCGENETICS.110.940858
SMITH MK, 2004, OWL WEB ONTOLOGY LAN
Sweeney L, 1997, J AM MED INFORM ASSN, P51
Sweeney L, 2005, IEEE INTELL SYST, V20, P83
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Vaidya J, 2008, KNOWL INF SYST, V14, P161, DOI 10.1007/s10115-007-0073-7
Venter JC, 2001, SCIENCE, V291, P1304, DOI 10.1126/science.1058040
Vidi VD, 2011, CONTEMP CLIN TRIALS, V32, P309, DOI 10.1016/j.cct.2011.02.001
Vinterbo SA, 2004, IEEE T KNOWL DATA EN, V16, P939, DOI 10.1109/TKDE.2004.31

```
   Yu H, 2006, LECT NOTES ARTIF INT, V3918, P647
NR 47
TC 60
Z9 60
U1 1
U2 46
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AU Pisani, E
   AbouZahr, C
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   AbouZahr, Carla
TI Sharing health data: good intentions are not enough
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Article
ID TRIALS
AB Epidemiologists and public health researchers are moving very slowly in the
data sharing revolution, and agencies that maintain global health databases are
reluctant to share data too. Once investments in infrastructure have, been made,
recycling and combining data provide access to maximum knowledge for minimal
additional cost. By refusing to share data, researchers are slowing progress
towards reducing illness and death and are denying a public good to taxpayers
who support most of the research.
   Funders of public health research are beginning to call for change and
developing data sharing policies. However they are not yet adequately addressing
the obstacles that underpin the failure to share data. These include
professional structures that reward publication of analysis but not of data, and
funding streams and career paths that continue to undervalue critical data
management work. Practical issues need to be sorted out too: how and where
should data be stored for the long term, who will control access, and who will
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pay for those services? Existing metadata standards need to be extended to cope with health data.

These obstacles have been known for some time; most can be overcome in the field of public health just as they have been overcome in other fields. However no institution has taken the lead in defining a work plan and carving up the tasks and the bill. In this round table paper, we suggest goals for data sharing and a work plan for reaching them, and challenge respondents to move beyond well intentioned but largely aspirational data sharing plans.

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CR Altman M., 2007, D LIB, P13
[Anonymous], 2008, PLOS MED, V5, P1007, DOI 10.1371/journal.pmed.0050160
[Anonymous], 2009, NATURE, V461, P145, DOI 10.1038/461145a
Chandramohan D, 2008, PLOS MED, V5, P169, DOI 10.1371/journal.pmed.0050057
Corti L, 2002, MRC POPULATION DATA
Elobeid MA, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0006624
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
*GERM NAT LIB SCI, 2009, DATACITE INT IN FAC
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
*IPUMS INT, APPL US RESTR MICR
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
LAINE C, 2009, 6 INT C PEER REV BIO
Lord P., 2006, LARGE SCALE DATA SHA
Lowrance W, 2006, ACCESS COLLECTIONS D
Mascalzoni D, 2008, PLOS MED, V5, P1302, DOI 10.1371/journal.pmed.0050192
*MED RES COUNC, 2008, MRC POL DAT SHAR PRE
*NAT OC ATM ADM, 2009, INT COMPR OC ATM DAT
National Academy of Sciences, 2009, ENS INT ACC STEW RES
*NIH, 2003, NIH GUID FIN NIH STA
Nuesch E, 2009, BMJ-BRIT MED J, V339, DOI 10.1136/bmj.b3244
Organisation for Economic Co-operation and Development, 2007, OECD PRINC GUID ACC
Paskin Norman, 2008, ENCY LIB INFORM SCI
PISANI E, 2008, OPENEPI NEW CULTURE
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
SMITH D, 1996, HUMAN GENOME NEWS, V7
SUPARI SF, 2008, SAATNYA DUNIA BERUBA
*UK DAT ARCH, 2008, END US LIC
Wellcome Trust, 2008, SHAR PUBL HLTH DAT C
Wellcome Trust, 2007, POL DAT MAN SHAR
World Health Organization, 2009, INT CLIN TRIALS REG
World Health Organization (WHO), 2008, GLOB STRAT PLAN ACT
2002, NATURE, V416, P1, DOI DOI 10.1038/416001B

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   O'Leary, D
   Ho, BC
   Brauns, S
   Manoach, DS
   Seidman, L
   Bustillo, JR
   Lauriello, J
   Bockholt, J
   Lim, KO
   Rosen, BR
   Schulz, SC
   Calhoun, VD
   Andreasen, NC
AF Gollub, Randy L.
   Shoemaker, Jody M.
   King, Margaret D.
   White, Tonya
   Ehrlich, Stefan
   Sponheim, Scott R.
   Clark, Vincent P.
   Turner, Jessica A.
   Mueller, Bryon A.
   Magnotta, Vince
   O'Leary, Daniel
   Ho, Beng C.
   Brauns, Stefan
   Manoach, Dara S.
   Seidman, Larry
   Bustillo, Juan R.
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   Lauriello, John
   Bockholt, Jeremy
   Lim, Kelvin O.
   Rosen, Bruce R.
   Schulz, S. Charles
   Calhoun, Vince D.
   Andreasen, Nancy C.
TI The MCIC Collection: A Shared Repository of Multi-Modal, Multi-Site
   Brain Image Data from a Clinical Investigation of Schizophrenia
SO NEUROINFORMATICS
LA English
DT Article
DE Medical Image Data repository; Schizophrenia; fMRI; DWI; mMRI; Healthy
   controls
ID INDEPENDENT COMPONENT ANALYSIS; DORSOLATERAL PREFRONTAL CORTEX;
   HIPPOCAMPAL VOLUME REDUCTION; SURFACE-BASED ANALYSIS; HUMAN
   CEREBRAL-CORTEX; CORTICAL THICKNESS; WORKING-MEMORY; 1ST EPISODE; NEURAL
   MODULATION; TEMPORAL-LOBE
AB Expertly collected, well-curated data sets consisting of comprehensive
clinical characterization and raw structural, functional and diffusion-weighted
DICOM images in schizophrenia patients and sex and age-matched controls are now
accessible to the scientific community through an on-line data repository
(coins.mrn.org). The Mental Illness and Neuroscience Discovery Institute, now
the Mind Research Network (MRN, http://www.mrn.org/), comprised of investigators
at the University of New Mexico, the University of Minnesota, Massachusetts
General Hospital, and the University of Iowa, conducted a cross-sectional study
to identify quantitative neuroimaging biomarkers of schizophrenia. Data
acquisition across multiple sites permitted the integration and cross-validation
of clinical, cognitive, morphometric, and functional neuroimaging results
gathered from unique samples of schizophrenia patients and controls using a
common protocol across sites. Particular effort was made to recruit patients
early in the course of their illness, at the onset of their symptoms. There is a
relatively even sampling of illness duration in chronic patients. This data
repository will be useful to 1) scientists who can study schizophrenia by
further analysis of this cohort and/or by pooling with other data; 2) computer
scientists and software algorithm developers for testing and validating novel
registration, segmentation, and other analysis software; and 3) educators in the
fields of neuroimaging, medical image analysis and medical imaging informatics
who need exemplar data sets for courses and workshops. Sharing provides the
opportunity for independent replication of already published results from this
data set and novel exploration. This manuscript describes the
inclusion/exclusion criteria, imaging parameters and other information that will
assist those wishing to use this data repository.
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OI Ho, Beng-Choon/0000-0003-3976-1555; Turner, Jessica/0000-0003-0076-8434; Clark, Vincent/0000-0002-9151-2102; Sponheim, Scott/0000-0002-2782-0856; O'Leary, Daniel/0000-0003-1959-6521; Andreasen, Nancy/0000-0001-5730-9744; Magnotta, Vincent/0000-0001-8639-5354; Ehrlich, Stefan/0000-0003-2132-4445; Gollub, Randy L./0000-0002-9434-4044

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CR Abbott C, 2011, PROG NEURO-PSYCHOPH, V35, P473, DOI 10.1016/j.pnpbp.2010.12.001
Abbott CC, 2010, AM J GERIAT PSYCHIAT, V18, P897, DOI 10.1097/JGP.0b013e3181e9b9d9
ADDINGTON D, 1992, SCHIZOPHR RES, V6, P201, DOI 10.1016/0920-9964(92)90003-N
Adriano F, 2012, NEUROSCIENTIST, V18, P180, DOI 10.1177/1073858410395147
Andreasen N., 1984, SCALE ASSESSMENT POS
Andreasen N., 1983, SCALE ASSESSMENT NEG
Andreasen N. C., 1987, PSYCHIAT SYMPTOMS YO
Andreasen NC, 2010, BIOL PSYCHIAT, V67, P255, DOI 10.1016/j.biopsych.2009.08.040
ANDREASEN NC, 1992, ARCH GEN PSYCHIAT, V49, P615
ANNETT M, 1970, BRIT J PSYCHOL, V61, P303, DOI 10.1111/j.2044-8295.1970.tb01248.x

BARNES TRE, 1989, BRIT J PSYCHIAT, V154, P672, DOI 10.1192/bjp.154.5.672
Bockholt Henry J, 2010, Front Neuroinform, V3, P36, DOI 10.3389/neuro.11.036.2009
Brandt J, 1991, CLIN NEUROPSYCHOL, V5, P125, DOI DOI 10.1080/13854049108403297
Brauns S, 2011, NEUROIMAGE, V57, P1591, DOI 10.1016/j.neuroimage.2011.05.058
Braus DF, 1999, SCHIZOPHR RES, V39, P19, DOI 10.1016/S0920-9964(99)00032-8
Brown GG, 2009, SCHIZOPHRENIA BULL, V35, P32, DOI 10.1093/schbul/sbn149
Buckner RL, 2004, NEUROIMAGE, V23, P724, DOI 10.1016/j.neuroimage.2004.06.018
Calhoun V., 2009, IEEE T INF TECHNOL B, V13, P1, DOI DOI 10.1109/TITB.2008.923773
Calhoun VD, 2006, HUM BRAIN MAPP, V27, P47, DOI 10.1002/hbm.20166
Calhoun VD, 2008, HUM BRAIN MAPP, V29, P1265, DOI 10.1002/hbm.20463
Calhoun Vince D, 2012, IEEE Rev Biomed Eng, V5, P60, DOI 10.1109/RBME.2012.2211076
Chen JY, 2012, NEUROIMAGE, V61, P866, DOI 10.1016/j.neuroimage.2012.03.022
Christodoulou AG, 2013, MAGN RESON IMAGING, V31, P707, DOI 10.1016/j.mri.2012.11.007
Clark VP, 2012, NEUROIMAGE, V62, P1190, DOI 10.1016/j.neuroimage.2012.01.010
Clark VP, 2000, J NEUROPHYSIOL, V83, P3133
Cullen KR, 2012, PSYCHIAT RES-NEUROIM, V201, P152, DOI 10.1016/j.pscychresns.2011.08.010
Dale AM, 1999, NEUROIMAGE, V9, P179, DOI 10.1006/nimg.1998.0395
Delis D.C., 2001, DELIS KAPLAN EXECUTI
Demirci O, 2008, NEUROIMAGE, V39, P1774, DOI 10.1016/j.neuroimage.2007.10.012
Demirci O, 2008, BRAIN IMAGING BEHAV, V2, P207, DOI 10.1007/s11682-008-9028-1
Demirci O, 2009, NEUROIMAGE, V46, P419, DOI 10.1016/j.neuroimage.2009.02.014
Desikan RS, 2006, NEUROIMAGE, V31, P968, DOI 10.1016/j.neuroimage.2006.01.021
Desikan RS, 2010, NEUROBIOL AGING, V31, P1364, DOI 10.1016/j.neurobiolaging.2010.04.023
Ehrlich S, 2012, PSYCHOL MED, V42, P267, DOI 10.1017/S003329171100119X
Ehrlich S, 2012, SCHIZOPHRENIA BULL, V38, P1050, DOI 10.1093/schbul/sbr018
Ehrlich S, 2010, NEUROIMAGE, V53, P992, DOI 10.1016/j.neuroimage.2009.12.046
Fennema-Notestine C, 2007, NEUROINFORMATICS, V5, P235, DOI 10.1007/s12021-007-9003-9
Fischl B, 1999, HUM BRAIN MAPP, V8, P272, DOI 10.1002/(SICI)1097-0193(1999)8:4<272::AID-HBM10>3.0.CO;2-4
Fischl B, 1999, NEUROIMAGE, V9, P195, DOI 10.1006/nimg.1998.0396
Fischl B, 2002, NEURON, V33, P341, DOI 10.1016/S0896-6273(02)00569-X
Fischl B, 2000, P NATL ACAD SCI USA, V97, P11050, DOI 10.1073/pnas.200033797
Friedman JI, 2008, AM J PSYCHIAT, V165, P1024, DOI 10.1176/appi.ajp.2008.07101640
Friedman L, 2008, HUM BRAIN MAPP, V29, P958, DOI 10.1002/hbm.20440
Friedman L, 2006, NEUROIMAGE, V33, P471, DOI 10.1016/j.neuroimage.2006.07.012
Glover GH, 2012, J MAGN RESON IMAGING, V36, P39, DOI 10.1002/jmri.23572
Goldman AL, 2009, ARCH GEN PSYCHIAT, V66, P467, DOI 10.1001/archgenpsychiatry.2009.24
Han X, 2006, NEUROIMAGE, V32, P180, DOI 10.1016/j.neuroimage.2006.02.051
He H, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0038195
Head D, 2005, CEREB CORTEX, V15, P732, DOI 10.1093/cercor/bhh174
Health N. I. O.M, 1976, DHEW PUBL, P534
Honea R, 2005, AM J PSYCHIAT, V162, P2233, DOI 10.1176/appi.ajp.162.12.2233
Huettel S.A., 2009, FUNCTIONAL MAGNETIC
Jovicich J, 2006, NEUROIMAGE, V30, P436, DOI 10.1016/j.neuroimage.2005.09.046
Jovicich J, 2009, NEUROIMAGE, V46, P177, DOI 10.1016/j.neuroimage.2009.02.010
Karageorgiou E, 2011, NEUROINFORMATICS, V9, P321, DOI 10.1007/s12021-010-9094-6
Kiehl KA, 2005, NEUROIMAGE, V25, P899, DOI 10.1016/j.neuroimage.2004.12.035

Kiehl KA, 2005, BIOL PSYCHIAT, V57, P1029, DOI 10.1016/j.biopsych.2005.01.035
Kiehl KA, 2001, SCHIZOPHR RES, V48, P159, DOI 10.1016/S0920-9964(00)00117-1
Kim DI, 2010, NEUROINFORMATICS, V8, P213, DOI 10.1007/s12021-010-9077-7
Kim DI, 2009, HUM BRAIN MAPP, V30, P3795, DOI 10.1002/hbm.20807
Kim DI, 2009, SCHIZOPHRENIA BULL, V35, P67, DOI 10.1093/schbul/sbn133
Kuperberg GR, 2003, ARCH GEN PSYCHIAT, V60, P878, DOI 10.1001/archpsyc.60.9.878
Le Bihan D, 2006, J MAGN RESON IMAGING, V24, P478, DOI 10.1002/jmri.20683
Liu JY, 2009, HUM BRAIN MAPP, V30, P241, DOI 10.1002/hbm.20508
Manoach DS, 1999, BIOL PSYCHIAT, V45, P1128, DOI 10.1016/S0006-3223(98)00318-7
Manoach DS, 2000, BIOL PSYCHIAT, V48, P99, DOI 10.1016/S0006-3223(00)00227-4
Michael AM, 2010, NEUROIMAGE, V49, P2626, DOI 10.1016/j.neuroimage.2009.08.056
Michael AM, 2009, HUM BRAIN MAPP, V30, P2512, DOI 10.1002/hbm.20691
Miller EN, 1990, CALIFORNIA COMPUTERI
Mueller SG, 2005, NEUROIMAG CLIN N AM, V15, P869, DOI 10.1016/j.nic.2005.09.008
Mueller Susanne G, 2005, Alzheimers Dement, V1, P55, DOI 10.1016/j.jalz.2005.06.003
Muller JL, 2002, PSYCHIAT CLIN NEUROS, V56, P77, DOI 10.1046/j.1440-1819.2002.00932.x
Narr KL, 2005, CEREB CORTEX, V15, P708, DOI 10.1093/cercor/bhh172
Navari S, 2009, PSYCHOL MED, V39, P1763, DOI 10.1017/S0033291709005315
Nelson MD, 1998, ARCH GEN PSYCHIAT, V55, P433, DOI 10.1001/archpsyc.55.5.433
Nesvag R, 2008, SCHIZOPHR RES, V98, P16, DOI 10.1016/j.schres.2007.09.015
O'Brien LM, 2006, HARVARD REV PSYCHIAT, V14, P141, DOI 10.1080/10673220600784119
Potkin SG, 2009, SCHIZOPHRENIA BULL, V35, P19, DOI 10.1093/schbul/sbn162
Potkin SG, 2009, SCHIZOPHRENIA BULL, V35, P15, DOI 10.1093/schbul/sbn159
Ragland JD, 2007, INT REV PSYCHIATR, V19, P419, DOI 10.1080/09540260701486365
REITAN R. M., 1958, PERCEPT MOT SKILLS, V8, P271
Reuter M, 2010, NEUROIMAGE, V53, P1181, DOI 10.1016/j.neuroimage.2010.07.020
Rimol LM, 2012, BIOL PSYCHIAT, V71, P552, DOI 10.1016/j.biopsych.2011.11.026
Rimol LM, 2010, BIOL PSYCHIAT, V68, P41, DOI 10.1016/j.biopsych.2010.03.036
Risacher SL, 2009, CURR ALZHEIMER RES, V6, P347, DOI 10.2174/156720509788929273
Roffman JL, 2008, P NATL ACAD SCI USA, V105, P17573, DOI 10.1073/pnas.0803727105
RUFF RM, 1993, PERCEPT MOTOR SKILL, V76, P1219, DOI 10.2466/pms.1993.76.3c.1219
Schultz CC, 2010, SCHIZOPHR RES, V116, P204, DOI 10.1016/j.schres.2009.11.001
Scott Adam, 2011, Front Neuroinform, V5, P33, DOI 10.3389/fninf.2011.00033
Segall JM, 2009, SCHIZOPHRENIA BULL, V35, P82, DOI 10.1093/schbul/sbn150
Segonne F, 2005, LECT NOTES COMPUT SC, V3565, P393
SHALLICE T, 1982, PHILOS T ROY SOC B, V298, P199, DOI 10.1098/rstb.1982.0082
Shen L, 2010, LECT NOTES COMPUT SC, V6363, P611
SIMPSON GM, 1970, ACTA PSYCHIAT SCAND, P11
Sivan A.B, 1992, BENTON VISUAL RETENT
Smieskova R, 2009, CURR PHARM DESIGN, V15, P2535, DOI 10.2174/138161209788957456
Sponheim SR, 2010, J PSYCHIATR RES, V44, P421, DOI 10.1016/j.jpsychires.2009.09.010
STERNBERG S, 1966, SCIENCE, V153, P652, DOI 10.1126/science.153.3736.652
Stonnington CM, 2008, NEUROIMAGE, V39, P1180, DOI 10.1016/j.neuroimage.2007.09.066
Sui J, 2013, NEUROIMAGE, V66, P119, DOI 10.1016/j.neuroimage.2012.10.051
Sui J, 2012, J NEUROSCI METH, V204, P68, DOI 10.1016/j.jneumeth.2011.10.031

Sui J, 2011, NEUROIMAGE, V57, P839, DOI 10.1016/j.neuroimage.2011.05.055
Sui J, 2010, NEUROIMAGE, V51, P123, DOI 10.1016/j.neuroimage.2010.01.069
Sui J, 2009, HUM BRAIN MAPP, V30, P2953, DOI 10.1002/hbm.20721
Sui J, 2009, NEUROIMAGE, V46, P73, DOI 10.1016/j.neuroimage.2009.01.026
Tabangin Meredith E, 2009, BMC Proc, V3 Suppl 7, pS41, DOI 10.1186/1753-6561-3-S7-S41
Tost H, 2006, BIOL PSYCHIAT, V60, P1196, DOI 10.1016/j.biopsych.2006.04.014
van der Kouwe AJW, 2006, MAGN RESON MED, V56, P1019, DOI 10.1002/mrm.21038
Walton E, 2013, SCHIZOPHRENIA BULL, V39, P703, DOI 10.1093/schbul/sbr190
Watson DR, 2012, BRAIN IMAGING BEHAV, V6, P49, DOI 10.1007/s11682-011-9141-4
Wechsler D., 1997, WECHSLER MEMORY SCAL
Wechsler D., 1997, WECHSLER ADULT INTEL
White T, 2013, SCHIZOPHRENIA BULL, V39, P1077, DOI 10.1093/schbul/sbs106
White T, 2011, SCHIZOPHRENIA BULL, V37, P222, DOI 10.1093/schbul/sbp088
White Tonya, 2008, Top Magn Reson Imaging, V19, P97, DOI 10.1097/RMR.0b013e3181809f1e
White T, 2009, PSYCHIAT RES-NEUROIM, V174, P110, DOI 10.1016/j.pscychresns.2009.04.014
Whitfield-Gabrieli S, 2009, P NATL ACAD SCI USA, V106, P1279, DOI 10.1073/pnas.0809141106
Wilkinson G. S., 1993, WIDE RANGE ACHIEVEME
Wright IC, 2000, AM J PSYCHIAT, V157, P16, DOI 10.1176/ajp.157.1.16
Xu L, 2009, NEUROIMAGE, V44, P777, DOI 10.1016/j.neuroimage.2008.09.051
Yang HH, 2010, FRONT HUM NEUROSCI, V4, DOI 10.3389/fnhum.2010.00192
Yendiki Anastasia, 2011, Front Neuroinform, V5, P23, DOI 10.3389/fninf.2011.00023
Yendiki A, 2010, NEUROIMAGE, V53, P119, DOI 10.1016/j.neuroimage.2010.02.084
Yu QB, 2012, FRONT SYST NEUROSCI, V5, DOI [10.3389/fnsys.2011.00103, 10.3389/fnsys.2011.00007]
NR 124
TC 59
Z9 60
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PT J
AU Malin, B
   Karp, D
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AF Malin, Bradley
   Karp, David
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TI Technical and Policy Approaches to Balancing Patient Privacy and Data Sharing in Clinical and Translational Research
SO JOURNAL OF INVESTIGATIVE MEDICINE
LA English
DT Article
DE clinical research; translational research; databases; privacy
ID GENOME-WIDE ASSOCIATION; CONFIDENTIALITY; TECHNOLOGY; ANONYMITY; BIOBANKS; NETWORK; SOCIETY; SCIENCE; US

AB Introduction: Clinical researchers need to share data to support scientific validation and information reuse and to comply with a host of regulations and directives from funders. Various organizations are constructing informatics resources in the form of centralized databases to ensure reuse of data derived from sponsored research. The widespread use of such open databases is contingent on the protection of patient privacy.

Methods: We review privacy-related problems associated with data sharing for clinical research from technical and policy perspectives. We investigate existing policies for secondary data sharing and privacy requirements in the context of data derived from research and clinical settings. In particular, we focus on policies specified by the US National Institutes of Health and the Health Insurance Portability and Accountability Act and touch oil how these policies are related to current and future use of data stored in public database archives. We address aspects of data privacy and identifiability from a technical, although approachable, perspective and summarize how biomedical databanks can be exploited and seemingly anonymous records can be reidentified using various resources without hacking into secure computer systems.

Results: We highlight which clinical and translational data features, specified in emerging research models, are potentially vulnerable or exploitable. In the process, we recount a recent privacy-related concern associated with the publication of aggregate statistics from pooled genome-wide association studies that have had a significant impact on the data sharing policies of National Institutes of Health-sponsored databanks.

Conclusion: Based on our analysis and observations we provide a list of recommendations that cover various technical, legal, and policy mechanisms that open clinical databases can adopt to strengthen data privacy protection as they move toward wider deployment and adoption.

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CR Aldhous Peter, 2008, NEW SCI

Altman RB, 2002, ANNU REV PHARMACOL, V42, P113, DOI 10.1146/annurev.pharmtox.42.082401.140850
Brawley SH, 1999, J PHYCOL, V35, P433, DOI 10.1046/j.1529-8817.1999.3520433.x
Caulfield T, 2003, BMC MED ETHICS, V4, P1, DOI DOI 10.1186/1472-6939-4-1
Clabby C, 2009, AM SCI, V97, P113, DOI 10.1511/2009.77.113
De Moor GJE, 2003, METHOD INFORM MED, V42, P148
Dugas Martin, 2002, In Silico Biology, V2, P383
FERRIS N, 2009, GOVT HLTH IT MAGAZIN
Golle P, 2006, P 5 ACM WORKSH PRIV, DOI [10.1145/1179601.1179615, DOI 10.1145/1179601.1179615]
Gostin LO, 2009, JAMA-J AM MED ASSOC, V301, P1373, DOI 10.1001/jama.2009.424
Greely HT, 2007, ANNU REV GENOM HUM G, V8, P343, DOI 10.1146/annurev.genom.7.080505.115721
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Jacobs KB, 2009, NAT GENET, V41, P1253, DOI 10.1038/ng.455
Kaiser J, 2002, SCIENCE, V298, P1158, DOI 10.1126/science.298.5596.1158
Kargupta H, 2005, KNOWL INF SYST, V7, P387, DOI 10.1007/s10115-004-0173-6
Karp DR, 2008, PLOS MED, V5, P1333, DOI 10.1371/journal.pmed.0050190
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Lin Z, 2002, AMIA 2002 SYMPOSIUM, PROCEEDINGS, P454
Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
LOUKIDES G, 2009, P AMIA S IN PRESS
Mailman MD, 2007, NAT GENET, V39, P1181
Malin B, 2004, J BIOMED INFORM, V37, P179, DOI 10.1016/j.jbi.2004.04.005
Malin B, 2005, J PRIVACY TECHNOLOGY
MALIN B, 2006, P AMIA S, P524
Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
Manolio TA, 2009, PHARMACOGENOMICS, V10, P235, DOI 10.2217/14622416.10.2.235
Manolio TA, 2007, NAT GENET, V39, P1045, DOI 10.1038/ng2127
McGuire AL, 2008, NAT REV GENET, V9, P152, DOI 10.1038/nrg2302
*NAT ASS HLTH DAT, 2008, NAHDO INV STAT WID H
National Institutes of Health, 2003, NOTOD03032 NIH
*NIH, 2007, NOTOD07088 NIH
Patoine B, 2008, ANN NEUROL, V64, pA18
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Sankararaman S, 2009, NAT GENET, V41, P965, DOI 10.1038/ng.436
SCHOENMAN J, 2009, VALUE HOSP DISCHARGE
Sweeney L, 1997, J LAW MED ETHICS, V25, P98, DOI 10.1111/j.1748-720X.1997.tb01885.x
Sweeney L, 1997, J AM MED INFORM ASSN, P51
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Sweeney Latanya, 2000, UNIQUENESS SIMPLE DE
U.S. Department of Health and Human Services, 2002, FED REGISTER, V67, P53182
Zerhouni EA, 2008, SCIENCE, V322, P44, DOI 10.1126/science.1165490
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AF Lutomski, Jennifer E.
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CA TOPICS-MDS Consortium
TI The Development of the Older Persons and Informal Caregivers Survey
   Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative
SO PLOS ONE
LA English
DT Article
ID QUALITY-OF-LIFE; FUNCTIONAL STATUS; DATA SET; FRAILTY; INSTRUMENT; CARE;
   RAND-36; EUROQOL
AB Introduction: In 2008, the Ministry of Health, Welfare and Sport commissioned
the National Care for the Elderly Programme. While numerous research projects in
older persons' health care were to be conducted under this national agenda, the
Programme further advocated the development of The Older Persons and Informal
Caregivers Survey Minimum DataSet (TOPICS-MDS) which would be integrated into
all funded research protocols. In this context, we describe TOPICS data sharing
initiative (www.topics-mds.eu).
   Materials and Methods: A working group drafted TOPICS-MDS prototype, which
was subsequently approved by a multidisciplinary panel. Using instruments
validated for older populations, information was collected on demographics,
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morbidity, quality of life, functional limitations, mental health, social functioning and health service utilisation. For informal caregivers, information was collected on demographics, hours of informal care and quality of life (including subjective care-related burden).

Results: Between 2010 and 2013, a total of 41 research projects contributed data to TOPICS-MDS, resulting in preliminary data available for 32,310 older persons and 3,940 informal caregivers. The majority of studies sampled were from primary care settings and inclusion criteria differed across studies.

Discussion: TOPICS-MDS is a public data repository which contains essential data to better understand health challenges experienced by older persons and informal caregivers. Such findings are relevant for countries where increasing health-related expenditure has necessitated the evaluation of contemporary health care delivery. Although open sharing of data can be difficult to achieve in practice, proactively addressing issues of data protection, conflicting data analysis requests and funding limitations during TOPICS-MDS developmental phase has fostered a data sharing culture. To date, TOPICS-MDS has been successfully incorporated into 41 research projects, thus supporting the feasibility of constructing a large (>30,000 observations), standardised dataset pooled from various study protocols with different sampling frameworks. This unique implementation strategy improves efficiency and facilitates individual-level data meta-analysis.

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CR Borchelt M, 1999, Z GERONTOL GERIATR, V32, P11, DOI 10.1007/PL00007912
Boulton G, 2011, LANCET, V377, P1633, DOI 10.1016/S0140-6736(11)60647-8
Brooks R, 1996, HEALTH POLICY, V37, P53, DOI 10.1016/0168-8510(96)00822-6
Brouwer WBF, 2006, QUAL LIFE RES, V15, P1005, DOI 10.1007/s11136-005-5994-6
Buurman BM, 2011, J CLIN EPIDEMIOL, V64, P619, DOI 10.1016/j.jclinepi.2010.07.005
Cantril H, 1965, PATTERN HUMAN CONCER
Christensen K, 2009, LANCET, V374, P1196, DOI 10.1016/S0140-6736(09)61460-4
Clegg A, 2013, LANCET, V381, P752, DOI 10.1016/S0140-6736(12)62167-9
Deeken JF, 2003, J PAIN SYMPTOM MANAG, V26, P922, DOI 10.1016/S0885-3924(03)00327-0
Ellul J, 1998, AGE AGEING, V27, P115, DOI 10.1093/ageing/27.2.115
Eysenbach G, 2001, BRIT MED J, V323, P166, DOI 10.1136/bmj.323.7305.166
Hays RD, 2001, ANN MED, V33, P350, DOI 10.3109/07853890109002089
Haywood KL, 2005, QUAL LIFE RES, V14, P1651, DOI 10.1007/s11136-005-1743-0
Krabbe PFM, 1999, J CLIN EPIDEMIOL, V52, P293, DOI 10.1016/S0895-4356(98)00163-2
Lamers LM, 2005, NED TIJDSCHR GENEES, V149, P1574
Larsen Kenneth D, 2012, Perm J, V16, P4
Melis RJF, 2011, LANCET, V378, P1995, DOI 10.1016/S0140-6736(11)61870-9
Mitnitski AB, 2002, MECH AGEING DEV, V123, P1457, DOI 10.1016/S0047-6374(02)00082-9
Moorer P, 2001, QUAL LIFE RES, V10, P637, DOI 10.1023/A:1013131617125
MORRIS JN, 1990, GERONTOLOGIST, V30, P293, DOI 10.1093/geront/30.3.293
Palmer M, 2012, HEALTH POLICY PLANN, V27, P357, DOI 10.1093/heapol/czr047
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Riley RD, 2010, BMJ-BRIT MED J, V340, DOI 10.1136/bmj.c221
Rockwood K, 2005, CAN MED ASSOC J, V173, P489, DOI 10.1503/cmaj.050051
Romero-Ortuno R, 2012, AGE AGEING, V41, P684, DOI 10.1093/ageing/afs051
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Schuurmans H, 2004, J GERONTOL A-BIOL, V59, P962
Sgadari A, 1997, AGE AGEING, V26, P27, DOI 10.1093/ageing/26.suppl_2.27
Stroup DF, 2000, JAMA-J AM MED ASSOC, V283, P2008, DOI 10.1001/jama.283.15.2008
Stukel TA, 2001, STAT MED, V20, P2115, DOI 10.1002/sim.852
van den Berg B, 2006, HEALTH ECON, V15, P447, DOI 10.1002/hec.1075
van der Bie R, 2012, BABY BOOMERS NETHERL
van der Zee KI, METEN ALGEMENE GEZON
Van Kan GA, 2008, J NUTR HEALTH AGING, V12, P197, DOI 10.1007/BF02982620
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
WEINBERGER M, 1992, J AM GERIATR SOC, V40, P585, DOI 10.1111/j.1532-5415.1992.tb02107.x

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TI Assessing the Privacy Risks of Data Sharing in Genomics
SO PUBLIC HEALTH GENOMICS
LA English
DT Article
DE Access to information; Confidentiality; Genetic privacy; Genetic
   research/ethics; Genome/human; Genomics; Humans; Information
   dissemination; Informed consent; Internet
ID GENETIC PRIVACY; ETHICS; ANONYMITY; CONSENT; SOCIETY; SCIENCE; RACE
AB The protection of identity of participants in medical research has
traditionally been guaranteed by the maintenance of the confidentiality of
health information through mechanisms such as only releasing data in an
aggregated form or after identifying variables have been removed. This
protection of privacy is regarded as a fundamental principle of research ethics,
through which the support of research participants and the public is maintained.
Whilst this traditional model was adopted for genetics and genomics research,
and was generally considered broadly fit for purpose, we argue that this
approach is increasingly untenable in genomics. Privacy risk assessments need to
have regard to the whole data environment, not merely the quality of the dataset
to be released in isolation. As sources of data proliferate, issues of privacy
protection are increasingly problematic in relation to the release of genomic
data. However, we conclude that, by paying careful attention to potential
pitfalls, scientific funders and researchers can take an important part in
attempts to safeguard the public and ensure the continuation of potentially
important scientific research. Copyright (C) 2010 S. Karger AG, Basel
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CR [Anonymous], 2008, NATURE, V455, P13
   *BAST NAT, SEARCH RES ROOTS REC
   Beskow LM, 2008, SCIENCE, V322, P1054, DOI 10.1126/science.1164100
   Bonham VL, 2005, AM PSYCHOL, V60, P9, DOI 10.1037/0003-066X.60.1.9
   Campbell AV, 2007, KINGS LAW J, V18, P227, DOI DOI
10.1080/09615768.2007.11427675
   Cassa CA, 2008, BMC MED GENOMICS, V1, DOI 10.1186/1755-8794-1-32
   COHEN N, 2009, OBSERVER        1109
   Couzin J, 2008, SCIENCE, V321, P1278, DOI 10.1126/science.321.5894.1278
   Elliot M, 1999, NETHERLANDS OFFICIAL, V14, P6
   Elliot MJ, 1998, RES OFF STAT, V1, P53
   Foster MW, 2006, HUM MOL GENET, V15, pR45, DOI 10.1093/hmg/ddl049
   GERBER ER, 2001, CONFIDENTIALITY DISC
   Gitschier J, 2009, AM J HUM GENET, V84, P251, DOI 10.1016/j.ajhg.2009.01.018
   Greenbaum D, 2008, AM J BIOETHICS, V8, P71, DOI 10.1080/15265160802478560
   Hansson SO, 2004, CAMB Q HEALTHC ETHIC, V13, P319
   He WJ, 2008, CELL HOST MICROBE, V4, P52, DOI 10.1016/j.chom.2008.06.002
   HEENEY C, 2009, HDB RES SOCIOTECHNIC, P110
   Holm S, 2007, BRIT MED J, V334, P1196, DOI 10.1136/bmj.39216.468495.AD
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Kaye J., 2006, GENOMICS SOC POLICY, V2, P16
   Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
   Kaye J, 2008, HUM MOL GENET, V17, pR180, DOI 10.1093/hmg/ddn253
   Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
   Lowrance WW, 2007, SCIENCE, V317, P600, DOI 10.1126/science.1147699
   Lunshof JE, 2008, NAT REV GENET, V9, P406, DOI 10.1038/nrg2360
   Malin B, 2004, J BIOMED INFORM, V37, P179, DOI 10.1016/j.jbi.2004.04.005
   *MOND DIPL, NOBL PRIZ DISC GEN H
   Nissenbaum H, 2004, WASH LAW REV, V79, P119
   Nyholt DR, 2009, EUR J HUM GENET, V17, P147, DOI 10.1038/ejhg.2008.198
   Organisation for Economic Cooperation and Development, 2008, OECD GLOSS STAT
TERM
   Staley K, 2005, POLICE NATL DNA DATA
   Sweeney L, 2001, CONFIDENTIALITY DISC
   Tavani Herman T, 2004, Ethics Inf Technol, V6, P15, DOI
10.1023/B:ETIN.0000036156.77169.31
   Taylor P, 2008, NATURE, V456, P32, DOI 10.1038/456032a
   TORRA V, 2003, 3 JOINT UNECE EUR WO
   VEDDER A, 2001, READINGS CYBERETHICS, P404
   VEDDER A, 2000, LAW MED CURRENT LEGA, P441
   Wailoo K, 2006, LANCET, V367, P531, DOI 10.1016/S0140-6736(06)68186-5
   Walport M., 2008, DATA SHARING REV REP
   2001, DIVIDED INFORM DIGIT
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PU KARGER
PI BASEL
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AF Wicks, Paul
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TI Perceived benefits of sharing health data between people with epilepsy
   on an online platform
SO EPILEPSY & BEHAVIOR
LA English
DT Article
DE Online communities; Seizure control; Internet; Patient education;
   E-patients; Health 2.0; Patient empowerment; Seizure diary
ID QUALITY-OF-LIFE; SOCIAL SUPPORT; INFORMATION; INTERNET; STIGMA;
   PATIENTSLIKEME; COMMUNITIES; NETWORKS; ILLNESS; TRIALS
AB An epilepsy community was developed on PatientsLikeMe.com to share data
between patients to improve their outcomes by finding other patients like them.
In a 14-day response period, 221 patients with epilepsy (mean age: 40 years, SD:
12, range: 17-72, 66% female) completed a survey about benefits they perceived.
Prior to using the site, a third of respondents (30%) did not know anyone else
with epilepsy with whom they could talk; of these, 63% now had at least one
other patient with whom they could connect. Perceived benefits included: finding
another patient experiencing the same symptoms (59%), gaining a better
understanding of seizures (58%), and learning more about symptoms or treatments
(55%). Number of benefits was associated with number of relationships with other
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patients, F(4,216)=8.173, P<0.001). Patients with epilepsy reported an array of perceived benefits similar to those reported by populations with other diseases. Controlled sharing of health data may have the potential to improve disease self-management of people with epilepsy. (C) 2011 Elsevier Inc. All rights reserved.

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FU UCB; Abbott; Acorda; Avanir; Biogen; Novartis; Sanofi
FX UCB funded the design and coding of the epilepsy community on PatientsLikeMe. UCB was involved in the design of the epilepsy community through clinician advice (J.I.), selection of patient-reported outcomes (D.K., C.D.), and beta-testing with epilepsy advocates (D.K., C.D., J.I.); PatientsLikeMe retained final decisions on community design, however. UCB assisted in the design of the current study (D.K., C.D., J.I.) including drafting questions, proposing analyses, and commenting on revisions of the article.; P.W., C.B., M.M., and J.H. are paid employees of PatientsLikeMe and own stock/stock options in the company. PatientsLikeMe has received research support from Abbott, Acorda, Avanir, Biogen, Novartis, Sanofi, and UCB.

CR Ahmad F, 2006, J MED INTERNET RES, V8, DOI 10.2196/jmir.8.3.e22
[Anonymous], 2010, AM EP SOC 64 ANN GEN
Barak A, 2008, COMPUT HUM BEHAV, V24, P1867, DOI 10.1016/j.chb.2008.02.004
Berger M, 2005, SOC SCI MED, V61, P1821, DOI 10.1016/j.socscimed.2005.03.025
Bergin P, 2007, EPILEPSIA, V48, P147
Bergin P, 2007, EPILEPSIA, V48, P1415, DOI 10.1111/j.1528-1167.2007.01060_1.x
Bergin PS, 2010, EPILEPSIA, V51, P868, DOI 10.1111/j.1528-1167.2009.02393.x
Christakis NA, 2004, BRIT MED J, V329, P184, DOI 10.1136/bmj.329.7459.184
Coker MF, 2011, SEIZURE-EUR J EPILEP, V20, P55, DOI 10.1016/j.seizure.2010.10.007
Cramer JA, 1998, EPILEPSIA, V39, P81, DOI 10.1111/j.1528-1157.1998.tb01278.x
Crocco AG, 2002, JAMA-J AM MED ASSOC, V287, P2869, DOI 10.1001/jama.287.21.2869
de Boer HM, 2008, EPILEPSY BEHAV, V12, P540, DOI 10.1016/j.yebeh.2007.12.019
de la Loge C, 2011, VALUE HEALTH, V14, pA209, DOI 10.1016/j.jval.2011.02.1153
De la Loge C, 2011, NEUROLOGY S4, V76, pA49
Dilorio C, 2009, HLTH ED RES, V24, P185
Dilorio CK, 2010, EPILEPSY BEHAV, V19, P218, DOI 10.1016/j.yebeh.2010.07.027
Escoffery C, 2008, EPILEPSY BEHAV, V12, P109, DOI 10.1016/j.yebeh.2007.07.013
Eysenbach G, 2004, BMJ-BRIT MED J, V328, P1166, DOI 10.1136/bmj.328.7449.1166
Ferguson T, 2004, BMJ-BRIT MED J, V328, P1148, DOI 10.1136/bmj.328.7449.1148
Fernandes PT, 2011, EPILEPSY BEHAV, V22, P55, DOI 10.1016/j.yebeh.2011.02.014
Fox S, CHRONIC DIS INTERNET
Francis LP, 2010, J LAW MED ETHICS, V38, P36, DOI 10.1111/j.1748-720X.2010.00464.x
Frost J, 2011, J MED INTERNET RES, V13, P129, DOI 10.2196/jmir.1643
Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
Gallant MP, 2003, HEALTH EDUC BEHAV, V30, P170, DOI 10.1177/1090198102251030
Hoch DB, 1999, SEIZURE-EUR J EPILEP, V8, P30, DOI 10.1053/seiz.1998.0217
Idriss SZ, 2009, ARCH DERMATOL, V145, P46, DOI 10.1001/archdermatol.2008.529

```
   MacLeod JS, 2003, EPILEPSY BEHAV, V4, P112, DOI 10.1016/S1525-5050(03)00007-6
   Mo PKH, 2010, J HEALTH PSYCHOL, V15, P339, DOI 10.1177/1359105309348808
   OREILLY T, 2007, COMMUNICATIONS STRAT, V1, P17
   Pramuka M, 2010, EPILEPSY BEHAV, V17, P366, DOI 10.1016/j.yebeh.2009.11.016
   Rabin R, 2001, ANN MED, V33, P337, DOI 10.3109/07853890109002087
   Shafer P, 2003, LIVING WELL EPILEPSY
   Shirky C., 2008, HERE COMES EVERYBODY
   Stone AA, 2003, CONTROL CLIN TRIALS, V24, P182, DOI 10.1016/S0197-
2456(02)00320-3
   Whatley AD, 2010, HEALTH EDUC RES, V25, P575, DOI 10.1093/her/cyq001
   White M, 2001, HEALTH EDUC RES, V16, P693, DOI 10.1093/her/16.6.693
   Wicks P, 2011, NAT BIOTECHNOL, V29, P411, DOI 10.1038/nbt.1837
   Wicks P, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1549
   ZIGMOND AS, 1983, ACTA PSYCHIAT SCAND, V67, P361, DOI 10.1111/j.1600-
0447.1983.tb09716.x
NR 40
TC 55
Z9 55
U1 1
U2 14
PU ACADEMIC PRESS INC ELSEVIER SCIENCE
PI SAN DIEGO
PA 525 B ST, STE 1900, SAN DIEGO, CA 92101-4495 USA
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WC Behavioral Sciences; Clinical Neurology; Psychiatry
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OA Other Gold
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PT J
AU Thilakanathan, D
   Chen, SP
   Nepal, S
   Calvo, R
   Alem, L
AF Thilakanathan, Danan
   Chen, Shiping
   Nepal, Surya
   Calvo, Rafael
   Alem, Leila
TI A platform for secure monitoring and sharing of generic health data in
   the Cloud
SO FUTURE GENERATION COMPUTER SYSTEMS-THE INTERNATIONAL JOURNAL OF ESCIENCE
LA English
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DT Article

DE Secure data sharing; Cloud computing; Proxy re-encryption; Health monitoring system; Cryptography

AB The growing need for the remote caring of patients at home combined with the ever-increasing popularity of mobile devices due to their ubiquitous nature has resulted in many apps being developed to enable mobile telecare. The Cloud, in combination with mobile technologies has enabled doctors to conveniently monitor and assess a patient's health while the patient is at the comfort of their own home. This demands sharing of health information between healthcare teams such as doctors and nurses in order to provide better and safer care of patients. However, the sharing of health information introduces privacy and security issues which may conflict with HIPAA standards. In this paper, we attempt to address the issues of privacy and security in the domain of mobile telecare and Cloud computing. We first demonstrate a telecare application that will allow doctors to remotely monitor patients via the Cloud. We then use this system as a basis to showcase our model that will allow patients to share their health information with other doctors, nurses or medical professional in a secure and confidential manner. The key features of our model include the ability to handle large data sizes and efficient user revocation. Crown Copyright (C) 2013 Published by Elsevier B.V. All rights reserved.

C1 [Thilakanathan, Danan; Calvo, Rafael] Univ Sydney, Sydney, NSW 2006, Australia.
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OI Chen, Shiping/0000-0002-4603-0024; Nepal, Surya/0000-0002-3289-6599; Chen, Shiping/0000-0002-4603-0024

CR [Anonymous], 2012, M2 PRESSWIRE 0308
[Anonymous], 2012, M2 PRESSWIRE 1115
[Anonymous], 2012, NETWORK WEEKLY NEWS, P625
[Anonymous], 2013, BUSINESS WIRE 0308
[Anonymous], SPECIAL PUBLICATION, V800-144
Aramudhan M., 2010, INT J COMPUTER APPL, V8, P10
Bellifemine F, 2011, SOFTWARE PRACT EXPER, V41, P237, DOI 10.1002/spe.998
Butler D, 2007, NATURE, V449, P644, DOI 10.1038/449644a
CardioComm solutions inc, 2011, BUSINESS WIRE 1122
Deyan Chen, 2012, Proceedings of the 2012 International Conference on Computer Science and Electronics Engineering (ICCSEE 2012), P647, DOI 10.1109/ICCSEE.2012.193
Duncan A. J., 2012, 2012 IEEE 11th International Conference on Trust, Security and Privacy in Computing and Communications (TrustCom), P857, DOI 10.1109/TrustCom.2012.188
ElGamal T., 1985, P CRYPT 84 ADV CRYPT
Feldman L, 2012, LANCET, V379, P1877, DOI 10.1016/S0140-6736(12)60809-5
Fortino G., 2012, P IEEE 4 INT C CLOUD
Fortino G, 2013, IEEE T HUM-MACH SYST, V43, P115, DOI 10.1109/TSMCC.2012.2215852
Gellin A., 2012, BUFFALO NEWS
Giniat Edward J, 2011, Healthc Financ Manage, V65, P130
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Gradl S, 2012, IEEE ENG MED BIO, P2452, DOI 10.1109/EMBC.2012.6346460
Healey Michael, 2010, INFORM WEEK
Hung Nguyen Thanh, 2012, IEEE INT C INT SEC I, P1
Iran D.H, 2011, P 8 INT C INF COMM S, P1

```
   Li J, 2010, INT CONF COMP SCI, P608, DOI 10.1109/ICCSIT.2010.5564633
   Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
   Marti R, 2004, 2004 IEEE INTERNATIONAL CONFERNECE ON E-TECHNOLOGY, E-COMMERE
AND E-SERVICE, PROCEEDINGS, P241
   Minqi Zhou, 2010, Proceedings 2010 Sixth International Conference on
Semantics Knowledge and Grid (SKG 2010), P105, DOI 10.1109/SKG.2010.19
   Nguyen Thanh Hung, 2012, Proceedings of the 2012 IEEE International
Conference on Intelligence and Security Informatics. Cyberspace, Border, and
Immigration Securities (ISI 2012), P1, DOI 10.1109/ISI.2012.6281922
   Nick Galvin, 2012, AGE            0123
   Pandey S, 2012, FUTURE GENER COMP SY, V28, P147, DOI
10.1016/j.future.2011.04.022
   Riley-Huff Debra A, 2010, Library Hi Tech News, V27, P12, DOI
10.1108/07419051011083181
   Rocha F, 2011, COMPUTER, V44, P44, DOI 10.1109/MC.2011.223
   RuWei Huang, 2011, Proceedings of the 2011 International Conference on
Network Computing and Information Security (NCIS), P93, DOI 10.1109/NCIS.2011.27
   Saarinen Juha, 2012, ITNEWS TECHNOLOGY NE
   Sarathy R, 2006, DECIS SUPPORT SYST, V42, P204, DOI 10.1016/j.dss.2004.10.013
   Shin SeongHan, 2011, INT C SEC PUBL CLOUD, P103
   Tu SS, 2012, IEEE SYM PARA DISTR, P2146, DOI 10.1109/IPDPSW.2012.265
   Wang X., 2010, INT C BIOM ENG COMP, P1
   Wayne Swan MP, 2010, AUSTR 2050 FUTURE CH
   Wu R., 2012, THESIS ARIZ STATE, P77
   Xia HN, 2013, COMPUT METH PROG BIO, V110, P253, DOI
10.1016/j.cmpb.2012.11.008
   Yanjiang Yang, 2011, Proceedings of the 2011 International Conference on
Parallel Processing Workshops (ICPPW 2011), P145, DOI 10.1109/ICPPW.2011.51
NR 41
TC 54
Z9 54
U1 1
U2 83
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0167-739X
EI 1872-7115
J9 FUTURE GENER COMP SY
JI Futur. Gener. Comp. Syst.
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GA AE3CS
UT WOS:000333855200010
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ER

PT J
AU Rodriguez, H
   Snyder, M
   Uhlen, M
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   Andrews, P
   Beavis, R
   Borchers, C
   Chalkley, RJ
   Cho, SY
   Cottingham, K
   Dunn, M
   Dylag, T
   Edgar, R
   Hare, P
   Heck, AJR
   Hirsch, RF
   Kennedy, K
   Kolar, P
   Kraus, HJ
   Mallick, P
   Nesvizhskii, A
   Ping, PP
   Ponten, F
   Yang, LM
   Yates, JR
   Stein, SE
   Hermjakob, H
   Kinsinger, CR
   Apweiler, R
AF Rodriguez, Henry
   Snyder, Mike
   Uhlen, Mathias
   Andrews, Phil
   Beavis, Ronald
   Borchers, Christoph
   Chalkley, Robert J.
   Cho, Sang Yun
   Cottingham, Katie
   Dunn, Michael
   Dylag, Tomasz
   Edgar, Ron
   Hare, Peter
   Heck, Albert J. R.
   Hirsch, Roland F.
   Kennedy, Karen
   Kolar, Patrik
   Kraus, Hans-Joachim
   Mallick, Parag
   Nesvizhskii, Alexey
   Ping, Peipei
   Ponten, Fredrik
   Yang, Liming
   Yates, John R.
   Stein, Stephen E.
   Hermjakob, Henning
   Kinsinger, Christopher R.
   Apweiler, Rolf
TI Recommendations from the 2008 International Summit on Proteomics Data
   Release and Sharing Policy: The Amsterdam Principles
SO JOURNAL OF PROTEOME RESEARCH
LA English
DT Article
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DE proteomic; data; policy; release; resource; sharing; Bermuda principles; Amsterdam principles; open; standards

AB Policies supporting the rapid and open sharing of genomic data have directly fueled the accelerated pace of discovery in large-scale genomics research. The proteomics community is starting to implement analogous policies and infrastructure for making large-scale proteomics data widely available on a precompetitive basis. On August 14, 2008, the National Cancer Institute (NCI) convened the "International Summit on Proteomics Data Release and Sharing Policy" in Amsterdam, The Netherlands, to identify and address potential roadblocks to rapid and open access to data. The six principles agreed upon by key stakeholders at the summit addressed issues surrounding (1) timing, (2) comprehensiveness, (3) format, (4) deposition to repositories, (5) quality metrics, and (6) responsibility for proteomics data release. This summit report explores various approaches to develop a framework of data release and sharing principles that will most effectively fulfill the needs of the funding agencies and the research community.

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RI Uhlen, Mathias/B-3262-2016; Heck, Albert/D-7098-2011; BORCHERS,

```
   Christoph/U-5964-2019; Nesvizhskii, Alexey/A-5410-2012
OI Uhlen, Mathias/0000-0002-4858-8056; Heck, Albert/0000-0002-2405-4404;
   Nesvizhskii, Alexey/0000-0002-2806-7819; Ping,
   Peipei/0000-0003-3583-3881; Apweiler, Rolf/0000-0001-7078-200X;
   Hermjakob, Henning/0000-0001-8479-0262; Andrews,
   Philip/0000-0001-6843-5420; Chalkley, Robert/0000-0002-9757-7302
FU Intramural NIH HHS [Z99 CA999999]
CR Deutsch E, 2008, PROTEOMICS, V8, P2776, DOI 10.1002/pmic.200890049
   Hermjakob H, 2006, EXPERT REV PROTEOMIC, V3, P1, DOI 10.1586/14789450.3.1.1
   *HUM PROT ORG, PROT STAND IN
   *MOL CELL PROT, PUBL GUID AN DOC PEP
   Rodriguez H, 2008, J PROTEOME RES, V7, P4609, DOI 10.1021/pr800779q
   The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
   *US DOE HUM GEN PR, POL REL HUM GEN SEQ
   Wilkins MR, 2006, PROTEOMICS, V6, P4, DOI 10.1002/pmic.200500856
NR 8
TC 54
Z9 55
U1 0
U2 10
PU AMER CHEMICAL SOC
PI WASHINGTON
PA 1155 16TH ST, NW, WASHINGTON, DC 20036 USA
SN 1535-3893
J9 J PROTEOME RES
JI J. Proteome Res.
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WC Biochemical Research Methods
SC Biochemistry & Molecular Biology
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ER

PT J
AU Harding, A
   Harper, B
   Stone, D
   O'Neill, C
   Berger, P
   Harris, S
   Donatuto, J
AF Harding, Anna
   Harper, Barbara
   Stone, Dave
   O'Neill, Catherine
   Berger, Patricia
   Harris, Stuart
   Donatuto, Jamie
```

TI Conducting Research with Tribal Communities: Sovereignty, Ethics, and
   Data-Sharing Issues
SO ENVIRONMENTAL HEALTH PERSPECTIVES
LA English
DT Article
DE American Indian; data sharing; informed consent; intellectual property;
   IRB; research ethics; sovereignty; tribal
ID ET-AL 2010; PARTICIPATORY RESEARCH; TRANSLATION; LESSONS
AB BACKGROUND: When conducting research with American Indian tribes, informed consent beyond conventional institutional review board (IRB) review is needed because of the potential for adverse consequences at a community or governmental level that are unrecognized by academic researchers.

OBJECTIVES: In this article, we review sovereignty, research ethics, and data-sharing considerations when doing community-based participatory health related or natural-resource related research with American Indian nations and present a model material and data-sharing agreement that meets tribal and university requirements.

DISCUSSION: Only tribal nations themselves can identify potential adverse outcomes, and they can do this only if they understand the assumptions and methods of the proposed research. Tribes must be truly equal partners in study design, data collection, interpretation, and publication. Advances in protection of intellectual property rights (IPR) are also applicable to IRB reviews, as are principles of sovereignty and indigenous rights, all of which affect data ownership and control.

CONCLUSIONS: Academic researchers engaged in tribal projects should become familiar with all three areas: sovereignty, ethics and informed consent, and IPR. We recommend developing an agreement with tribal partners that reflects both health-related IRB and natural-resource related IPR considerations.
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   [P42ES016465]
FX Support for this research was provided by the National Institute of
   Environmental Health Sciences (NIEHS; award P42ES016465).
CR American Anthropological Association, 1998, COD ETH AM ANTHR ASS
   American Indian Law Center Inc., 1999, MOD TRIB RES COD
   [Anonymous], 2000, GUID RESP CULT KNOWL
   Australian Institute of Aboriginal and Torres Strait Islander Studies, 1999, GUID ETH RES IND STU
   Beauchamp T. L., 1994, PRINCIPLES BIOMEDICA
   Canadian Institutes of Health Research, 2007, CIHR GUID HLTH RES I
   Clinton Robert N., 2007, AM INDIAN LAW NATIVE
   Cornell Stephen, 1988, RETURN NATIVE AM IND
   Cruickshank J, 1990, LIFE LIVED STORY LIF
   Delistraty D, 2010, ENVIRON RES, V110, P810, DOI 10.1016/j.envres.2010.08.008
   Delistraty D, 2010, ENVIRON RES, V110, P169, DOI 10.1016/j.envres.2009.10.013
   Deloria Jr V, 1979, SPIRIT REASON VINE D

Desert Knowledge Cooperative Research Centre, 2009, DKCRC AB KNOWL INT P
Donatuto J, 2008, RISK ANAL, V26, P1497
Fleming ES, 2008, ETHNICITY DIS S2, V18, P1515
Freeman W, 2004, IRB APPENDIX PROTECT
Glasgow RE, 2007, ANNU REV PUBL HEALTH, V28, P413, DOI 10.1146/annurev.publhealth.28.021406.144145
HANSEN STEPHEN A, 2003, TRADITIONAL KNOWLEDG
Harper Barbara, 2009, WABANAKI TRADITIONAL
Harris S, 2010, ENVIRON RES, V110, P808, DOI 10.1016/j.envres.2010.08.006
Ho-Chunk Nation, 2005, HO CHUNK NAT TRIB RE
Indian Health Service, 2006, HUM RES PART PROT IN
Indigenous Peoples Council on Biocolonialism, 2000, IND RES PROT ACT
International Society of Ethnobiology, 2006, ISE COD ETH 2008 ADD
Israel B., 2005, METHODS COMMUNITY BA
JONSEN AR, 1998, CLIN ETHICS
Louis R.P., 2009, DISCUSSION PAPER RES
Macaulay A, 1994, CAN FAM PHYSICIAN, V40, P1894
Macaulay AC, 1998, CAN J PUBLIC HEALTH, V89, P105
MACAULAY AC, 1994, CAN FAM PHYSICIAN, V40, P1888
MADDOCKS I, 1992, MED J AUSTRALIA, V157, P553
Mello MM, 2010, NEW ENGL J MED, V363, P204, DOI 10.1056/NEJMp1005203
Minkler M, 2008, COMMUNITY BASED PART
Minogue B, 1996, BIOETHICS COMMITTEE
National Science Foundation, 2004, GUID IMPR COOP ARCT
National Science Foundation, 2004, PRINC COND RES ARCT
Navajo Nation, 1996, NAV NAT HUM RES COD
NCAI Policy Research Center, 2010, RES BEN NAT PEOPL GU
NCAL, 2006, NAT C AM IND 2006 AN
[NIEHS National Institute of Environmental Health Science], 2010, ENV JUST COMM BAS PA
*NIH, 2003, FIN NIH STAT SHAR RE
Quigley D, 2001, COMPILATION ENV HLTH
Quinault Indian Nation, 1975, CONST QUIN IND NAT
Resnik David B, 2006, IRB, V28, P1
Resnik DB, 2010, ACCOUNT RES, V17, P198, DOI 10.1080/08989621.2010.493095
Sahota PC, 2007, RES REGULATION AM IN
Sharp RR, 2002, ENVIRON HEALTH PERSP, V110, P145, DOI 10.1289/ehp.02110s2145
Tsosie R, 2002, ARIZ ST LJ, V34, P299
Tsosie R, 2007, J LAW MED ETHICS, V35, P396, DOI 10.1111/j.1748-720X.2007.00163.x
U. S. DHHS (U. S. Department of Health and Human Services), 2005, COD FED REG TITL 46
U. S. DHHS (U. S. Department of Health and Human Services), 2010, COMM BAS PART RES
United Nations, 2007, UN DECL RIGHTS IND P
Williams Robert, 1994, W VA L REV, V96, P1133
Wong JPH, 2010, J TRANSCULT NURS, V21, P151, DOI 10.1177/1043659609357637
World Health Organization, 2010, IND PEOPL PART HLTH

NR 55
TC 53
Z9 54
U1 1
U2 123

PU US DEPT HEALTH HUMAN SCIENCES PUBLIC HEALTH SCIENCE
PI RES TRIANGLE PK
PA NATL INST HEALTH, NATL INST ENVIRONMENTAL HEALTH SCIENCES, PO BOX 12233, RES TRIANGLE PK, NC 27709-2233 USA
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WC Environmental Sciences; Public, Environmental & Occupational Health;
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SC Environmental Sciences & Ecology; Public, Environmental & Occupational
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PM 21890450
OA DOAJ Gold, Green Published
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ER

PT J
AU Joly, Y
   Dove, ES
   Knoppers, BM
   Bobrow, M
   Chalmers, D
AF Joly, Yann
   Dove, Edward S.
   Knoppers, Bartha M.
   Bobrow, Martin
   Chalmers, Don
TI Data Sharing in the Post-Genomic World: The Experience of the
   International Cancer Genome Consortium (ICGC) Data Access Compliance
   Office (DACO)
SO PLOS COMPUTATIONAL BIOLOGY
LA English
DT Article
ID BENEFITS; PRIVACY
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FX The authors acknowledge the ongoing financial support of the Ontario
   Institute for Cancer Research, Genome Canada, and Genome Quebec. The
   funders had no role in the preparation of the manuscript.
CR [Anonymous], 2008, NATURE, V455, P13, DOI [10.1038/455013a, DOI
10.1038/455013A]
```

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   [Anonymous], 2003, M ORG WELLC TRUST HE
   BIRNEY E, 2009, NATURE, V461, P168, DOI DOI 10.1038/461168A
   Caulfield T, 2008, PLOS BIOL, V6, P430, DOI 10.1371/journal.pbio.0060073
   Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
   Fortin S, 2011, PUBLIC HEALTH GENOM, V14, P104, DOI 10.1159/000309852
   Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
   Gitter DM, 2011, J MARSHALL REV INT L, V10, P476
   Gitter DM, 2010, BIOTECHNOL LAW REP, V29, P623, DOI 10.1089/blr.2010.9909
   Greenbaum D, 2011, PLOS COMPUT BIOL, V7, DOI 10.1371/journal.pcbi.1002278
   Hallowell N., 2008, CLIN ETHICS, V3, P85, DOI DOI 10.1258/CE.2008.008014
   Holden C, 2009, SCIENCE, V325, P1486, DOI 10.1126/science.325_1486a
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Im HK, 2012, AM J HUM GENET, V90, P591, DOI 10.1016/j.ajhg.2012.02.008
   International Cancer Genome Consortium, 2008, GOALS STRUCT POL GUI
   Jamrozik K, 2004, BRIT MED J, V329, P286, DOI 10.1136/bmj.329.7460.286
   Joly Y, 2011, HUM GENET, V130, P441, DOI 10.1007/s00439-011-1044-3
   Knoppers BM, 2007, KINGS LAW J, V18, P291
   Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
   McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
   Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
   Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
   Schadt EE, 2012, NAT GENET, V44, P603, DOI 10.1038/ng.2248
   Silberman G, 2011, MILBANK Q, V89, P599, DOI 10.1111/j.1468-0009.2011.00644.x
   Stewart PM, 2008, BMJ-BRIT MED J, V337, DOI 10.1136/bmj.a1732
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
NR 27
TC 51
Z9 51
U1 0
U2 13
PU PUBLIC LIBRARY SCIENCE
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PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1553-7358
J9 PLOS COMPUT BIOL
JI PLoS Comput. Biol.
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WC Biochemical Research Methods; Mathematical & Computational Biology
SC Biochemistry & Molecular Biology; Mathematical & Computational Biology
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PT J
AU Liang, KT
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AF Liang, Kaitai
   Susilo, Willy
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TI Searchable Attribute-Based Mechanism With Efficient Data Sharing for Secure Cloud Storage
SO IEEE TRANSACTIONS ON INFORMATION FORENSICS AND SECURITY
LA English
DT Article
DE Searchable attribute-based encryption; keyword update; encrypted data sharing
ID CONJUNCTIVE KEYWORD SEARCH; PUBLIC-KEY ENCRYPTION; PROXY RE-ENCRYPTION; DELEGATION

AB To date, the growth of electronic personal data leads to a trend that data owners prefer to remotely outsource their data to clouds for the enjoyment of the high-quality retrieval and storage service without worrying the burden of local data management and maintenance. However, secure share and search for the outsourced data is a formidable task, which may easily incur the leakage of sensitive personal information. Efficient data sharing and searching with security is of critical importance. This paper, for the first time, proposes a searchable attribute-based proxy reencryption system. When compared with the existing systems only supporting either searchable attribute-based functionality or attribute-based proxy reencryption, our new primitive supports both abilities and provides flexible keyword update service. In particular, the system enables a data owner to efficiently share his data to a specified group of users matching a sharing policy and meanwhile, the data will maintain its searchable property but also the corresponding search keyword(s) can be updated after the data sharing. The new mechanism is applicable to many real-world applications, such as electronic health record systems. It is also proved chosen ciphertext secure in the random oracle model.

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OI Liang, Kaitai/0000-0003-0262-7678;

FU Privacy-Aware Retrieval and Modeling of Genomic Data [13283250]; Academy of Finland, Finland; Australian Research Council [ARC DP130101383]
FX The work of K. Liang was supported by Privacy-Aware Retrieval and Modeling of Genomic Data under Grant 13283250 and in part by the Academy of Finland, Finland. The work of W. Susilo was supported by the Australian Research Council Discovery Project under Grant ARC DP130101383. The associate editor coordinating the review of this manuscript and approving it for publication was L. Chen. (Corresponding author: Willy Susilo.)

CR [Anonymous], 2013, JAVA PAIRING BASED C
Ateniese G., 2006, ACM Transactions on Information and Systems Security, V9, P1, DOI 10.1145/1127345.1127346
Bellare M, 2007, LECT NOTES COMPUT SC, V4622, P535
Benabbas S, 2011, LECT NOTES COMPUT SC, V6841, P111, DOI 10.1007/978-3-642-22792-9_7
Blaze M, 1998, LECT NOTES COMPUT SC, V1403, P127
Boneh D, 2005, LECT NOTES COMPUT SC, V3494, P440
Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P506
Boneh D, 2007, LECT NOTES COMPUT SC, V4392, P535
Canetti R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P185
Chandran N, 2012, LECT NOTES COMPUT SC, V7194, P404, DOI 10.1007/978-3-642-28914-9_23
Chase M, 2010, LECT NOTES COMPUT SC, V6477, P577, DOI 10.1007/978-3-642-17373-8_33

Cheung L, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P456
Cramer R, 2003, SIAM J COMPUT, V33, P167, DOI 10.1137/S0097539702403773
Ducas L, 2010, LECT NOTES COMPUT SC, V5985, P148, DOI 10.1007/978-3-642-11925-5_11
Golle P, 2004, LECT NOTES COMPUT SC, V3089, P31
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Hohenberger S, 2013, LECT NOTES COMPUT SC, V7778, P162, DOI 10.1007/978-3-642-36362-7_11
Hwang YH, 2007, LECT NOTES COMPUT SC, V4575, P2
Kaitai Liang, 2014, Information Security Practice and Experience. 10th International Conference, ISPEC 2014. Proceedings: LNCS 8434, P448, DOI 10.1007/978-3-319-06320-1_33
Kaitai Liang, 2013, 2013 5th International Conference on Intelligent Networking and Collaborative Systems, P552, DOI 10.1109/INCoS.2013.103
Kaitai Liang, 2013, Information Security Practice and Experience. 9th International Conference, ISPEC 2013. Proceedings, P132, DOI 10.1007/978-3-642-38033-4_10
Lewko A, 2012, LECT NOTES COMPUT SC, V7417, P180
Liang K., 2012, LNCS, P231
Liang K, 2014, LECT NOTES COMPUT SC, V8712, P257, DOI 10.1007/978-3-319-11203-9_15
Liang KT, 2014, IEEE T INF FOREN SEC, V9, P1667, DOI 10.1109/TIFS.2014.2346023
Liang KT, 2014, THEOR COMPUT SCI, V539, P87, DOI 10.1016/j.tcs.2014.04.027
Liang X., 2009, P 4 INT S INF COMP C, P276, DOI DOI 10.1145/1533057.1533094
Libert B, 2008, LECT NOTES COMPUT SC, V4939, P360, DOI 10.1007/978-3-540-78440-1_21
Lu RX, 2014, LECT NOTES COMPUT SC, V8782, P194, DOI 10.1007/978-3-319-12475-9_14
Luo S, 2010, LECT NOTES COMPUT SC, V6476, P401, DOI 10.1007/978-3-642-17650-0_28
Mambo M, 1997, IEICE T FUND ELECTR, VE80A, P54
Mizuno T, 2010, LECT NOTES COMPUT SC, V6151, P288, DOI 10.1007/978-3-642-16342-5_21
Sahai A, 2005, LECT NOTES COMPUT SC, V3494, P457
Song DXD, 2000, P IEEE S SECUR PRIV, P44, DOI 10.1109/SECPRI.2000.848445
Wang C, 2012, IEEE T PARALL DISTR, V23, P1467, DOI 10.1109/TPDS.2011.282
Waters B, 2011, LECT NOTES COMPUT SC, V6571, P53, DOI 10.1007/978-3-642-19379-8_4
Zhang Y, 2013, P 8 ACM SIGSAC S INF, P511, DOI DOI 10.1145/2484313.2484381
Zheng QJ, 2014, IEEE INFOCOM SER, P522, DOI 10.1109/INFOCOM.2014.6847976
NR 38
TC 49
Z9 55
U1 2
U2 50
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
PI PISCATAWAY
PA 445 HOES LANE, PISCATAWAY, NJ 08855-4141 USA
SN 1556-6013
EI 1556-6021
J9 IEEE T INF FOREN SEC
JI IEEE Trans. Inf. Forensic Secur.
PD SEP
PY 2015
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BP 1981
EP 1992
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PG 12
WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic
SC Computer Science; Engineering
GA CO0ZO
UT WOS:000358882800002
DA 2019-08-06
ER

PT J
AU Knoppers, BM
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   Dove, ES
AF Knoppers, Bartha M.
   Harris, Jennifer R.
   Budin-Ljosne, Isabelle
   Dove, Edward S.
TI A human rights approach to an international code of conduct for genomic
   and clinical data sharing
SO HUMAN GENETICS
LA English
DT Article
ID WIDE ASSOCIATION; GLOBAL SCIENCE; BIOTECHNOLOGY; EXPERIENCE; BIOBANKING;
   KNOWLEDGE; MEDICINE; HEALTH; ETHICS
AB Fostering data sharing is a scientific and ethical imperative. Health gains
can be achieved more comprehensively and quickly by combining large,
information-rich datasets from across conventionally siloed disciplines and
geographic areas. While collaboration for data sharing is increasingly embraced
by policymakers and the international biomedical community, we lack a common
ethical and legal framework to connect regulators, funders, consortia, and
research projects so as to facilitate genomic and clinical data linkage, global
science collaboration, and responsible research conduct. Governance tools can be
used to responsibly steer the sharing of data for proper stewardship of research
discovery, genomics research resources, and their clinical applications. In this
article, we propose that an international code of conduct be designed to enable
global genomic and clinical data sharing for biomedical research. To give this
proposed code universal application and accountability, however, we propose to
position it within a human rights framework. This proposition is not without
precedent: international treaties have long recognized that everyone has a right
to the benefits of scientific progress and its applications, and a right to the
protection of the moral and material interests resulting from scientific
productions. It is time to apply these twin rights to internationally
collaborative genomic and clinical data sharing.
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FU BioSHaRE-EU (Biobank Standardisation and Harmonisation for Research
   Excellence in the European Union) (FP7-Health); Biobanking and
   Biomolecular Resources Research Infrastructure (BBMRI); Personalised
   Risk Stratification for Prevention and Early Detection of Breast Cancer
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project (Genome Canada); Public Population Project in Genomics and Society-International Policy interoperability and data Access Clearinghouse (P3G-IPAC) (Genome Canada/Genome Quebec); Reseau de medecine genetique appliquee (RMGA) (Fonds de recherche du Quebec-Sante); Biobank Norway - Research Council of Norway [RCN 197443/F50]

FX The authors are grateful for the funding support of BioSHaRE-EU (Biobank Standardisation and Harmonisation for Research Excellence in the European Union) (FP7-Health); the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI); the Personalised Risk Stratification for Prevention and Early Detection of Breast Cancer project (Genome Canada); the Public Population Project in Genomics and Society-International Policy interoperability and data Access Clearinghouse (P3G-IPAC) (Genome Canada/Genome Quebec); the Reseau de medecine genetique appliquee (RMGA) (Fonds de recherche du Quebec-Sante); and Biobank Norway funded by the Research Council of Norway (RCN 197443/F50). The authors are grateful as well as for the fruitful discussions with the members of the Global Alliance for Genomics and Health.

CR [Anonymous], 2013, NAT GENET, V45, P579, DOI 10.1038/ng.2665
[Anonymous], 2011, PREC MED BUILD KNOWL
Ashcroft RE, 2007, PHARMACOGENOMICS, V8, P391, DOI 10.2217/14622416.8.4.391
Austin MA, 2012, AM J EPIDEMIOL, V175, P962, DOI 10.1093/aje/kwr441
Benatar David, 2005, Dev World Bioeth, V5, P220, DOI 10.1111/j.1471-8847.2005.00119.x
Budin-Ljosne I, 2014, EUR J HUM GENET, V22, P317, DOI 10.1038/ejhg.2013.131
Chapman A, 2013, SCIENCE, V340, P1291, DOI 10.1126/science.1233319
Chapman AR, 2009, J HUM RIGHTS, V8, P1, DOI 10.1080/14754830802701200
Contopoulos-Ioannidis DG, 2008, SCIENCE, V321, P1298, DOI 10.1126/science.1160622
Dandara Collet, 2012, Current Pharmacogenomics & Personalized Medicine, V10, P7
Donders Y, 2011, MED HEALTH CARE PHIL, V14, P371, DOI 10.1007/s11019-011-9327-y
Dove ES, 2013, GENOME MED, V5, DOI 10.1186/gm503
Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
European Commission, 2012, PROP REG EUR PARL CO
Fortin S, 2011, PUBLIC HEALTH GENOM, V14, P104, DOI 10.1159/000309852
Global Alliance, 2013, 7 TOR RES ORG JOIN N
Global Alliance, 2013, CREAT GLOB ALL EN RE
H3Africa, 2013, HIGH LEV PRINC ETH G
Hansson MG, 2013, LANCET ONCOL, V14, P451, DOI 10.1016/S1470-2045(13)70129-3
Harris JR, 2012, EUR J HUM GENET, V20, P1105, DOI 10.1038/ejhg.2012.96
Hum. Genome Organ. (HUGO) Ethics Comm, 2002, STAT HUM GEN DAT
Human Genome Organization (HUGO), 1996, PRINC AGR 1 INT STRA
International Cancer Genome Consortium (ICGC), 2012, CONS POL GUID
IRDIRC, 2013, POL GUID
Joly Y, 2011, HUM GENET, V130, P441, DOI 10.1007/s00439-011-1044-3
Kaye J, 2012, NAT REV GENET, V13, P371, DOI 10.1038/nrg3218
Knoppers BM, 2007, TRENDS BIOTECHNOL, V25, P284, DOI 10.1016/j.tibtech.2007.04.006
Knoppers BM, 2012, AM J HUM GENET, V91, P577, DOI 10.1016/j.ajhg.2012.05.027
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Knoppers BM, 2011, J MED ETHICS, V37, P515, DOI 10.1136/jme.2011.043042
Knoppers BM, 2004, COMMUNITY GENET, V7, P176, DOI 10.1159/000082257
Knoppers BM, 1991, HUMAN DIGINITY GENET
Kuner C, 2013, TRANSBORDER DATA FLO
Kuppuswamy C, 2009, GENET SOC, P1

Lemmens T, 2013, J LAW MED ETHICS, V41, P163, DOI 10.1111/jlme.12012
Leshner AI, 2009, SCIENCE, V326, P1459, DOI 10.1126/science.1184624
McGuire AL, 2011, GENOME RES, V21, P1001, DOI 10.1101/gr.120329.111
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Meslin EM, 2011, HUM GENET, V130, P451, DOI 10.1007/s00439-011-1061-2
MOEREL L., 2012, BINDING CORPORATE RU
Ohno-Machado L, 2012, SCI TRANSL MED, V4, DOI 10.1126/scitranslmed.3004454
Otlowski M, 2012, ANNU REV GENOM HUM G, V13, P433, DOI 10.1146/annurev-genom-090711-163800
Pan HQ, 2012, HUM MUTAT, V33, P849, DOI 10.1002/humu.22074
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Peppercorn J, 2012, CANCER-AM CANCER SOC, V118, P5060, DOI 10.1002/cncr.27515
Rhodes R, 2011, AM J BIOETHICS, V11, P1, DOI 10.1080/15265161.2011.615588
Sethi Nayha, 2013, Med Law Int, V13, P168
Shaheed F, 2012, REPORT SPECIAL RAPPO
Terry SF, 2013, GENET TEST MOL BIOMA, V17, P175, DOI 10.1089/gtmb.2012.1542
Terry SF, 2011, SCI TRANSL MED, V3, DOI 10.1126/scitranslmed.3001857
UNESCO, 2009, VEN STAT RIGHT ENJ B
UNESCO, 2005, UN DECL BIOETH HUM R
United Nations, 1966, INT COV EC SOC CULT
United Nations, 2008, OPT PROT INT COV EC
United Nations, 1948, UN DECL HUM RIGHTS
United Nations Committee on Economic, 1990, GEN COMM NO 3 NAT ST
United Nations Committee on Economic Social and Cultural Rights, 2001, HUM RIGHTS INT PROP
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
Vries J, 2011, BMC MED ETHICS, V12, P5, DOI [10.1186/1472-6939-12, DOI 10.1186/1472-6939-12-]
Wuchty S, 2007, SCIENCE, V316, P1036, DOI 10.1126/science.1136099
Zink A, 2008, ANN RHEUM DIS, V67, P1041, DOI 10.1136/ard.2007.080598
NR 61
TC 49
Z9 49
U1 0
U2 21
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
EI 1432-1203
J9 HUM GENET
JI Hum. Genet.
PD JUL
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WC Genetics & Heredity
SC Genetics & Heredity
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PT J
AU Curtis, LH
   Brown, J
   Platt, R
AF Curtis, Lesley H.
   Brown, Jeffrey
   Platt, Richard
TI Four Health Data Networks Illustrate The Potential For A Shared National
   Multipurpose Big-Data Network
SO HEALTH AFFAIRS
LA English
DT Article
ID DATA QUALITY ASSESSMENT; PRACTICE GUIDELINES; MEDICARE; CARE; SYSTEM;
   RISK
AB Information in electronic health data that are drawn from large populations of patients is transforming health care, public health practice, and clinical research. This article describes our experience in developing data networks that repurpose electronic health records and administrative data. The four programs we feature are the Food and Drug Administration's Mini-Sentinel program (which focuses on medical product safety), the National Patient-Centered Clinical Research Network (PCORnet, comparative effectiveness research), the National Institutes of Health's Health Care Systems Research Collaboratory Distributed Research Network (biomedical research), and ESPnet (public health surveillance). Challenges to these uses of electronic health data include understanding the factors driving the collection, coding, and preservation of the data; the extensive customization of different systems that collect similar data; the fragmentation of the US health care delivery system and its records; and privacy and proprietary considerations. We view these four programs as examples of the first stage in the development of a shared national big-data resource that leverages the investments of many agencies and organizations for the benefit of multiple networks and users.
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RI PAN, ZEQIANG/X-6341-2018; Ucar, Abdullah/P-8329-2017
OI Brown, Jeffrey/0000-0002-9340-7189
CR Bayley KB, 2013, MED CARE, V51, pS80, DOI 10.1097/MLR.0b013e31829b1d48
   Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
   Botsis Taxiarchis, 2010, Summit Transl Bioinform, V2010, P1
   Bourgeois FC, 2010, ARCH INTERN MED, V170, P1989, DOI 10.1001/archinternmed.2010.439
   Brown JS, 2013, MED CARE, V51, pS22, DOI 10.1097/MLR.0b013e31829b1e2c
   Chen J, 2011, JAMA-J AM MED ASSOC, V306, P1669, DOI 10.1001/jama.2011.1474
   Curtis LH, 2012, PHARMACOEPIDEM DR S, V21, P23, DOI 10.1002/pds.2336
   Curtis LH, 2014, MIN SENT COORD CTR D
   Fleurence RL, 2014, HEALTH AFFAIR, V33, P1212, DOI 10.1377/hlthaff.2014.0113
   Food and Drug Administration, 2010, SENT IN INT
   Hammill BG, 2009, AM HEART J, V157, P995, DOI 10.1016/j.ahj.2009.04.002
   Institute of Medicine, 2010, CLIN DAT BAS STAPL H
   Jencks SF, 2009, NEW ENGL J MED, V360, P1418, DOI 10.1056/NEJMsa0803563
   Kahn MG, 2012, MED CARE, V50, pS21, DOI 10.1097/MLR.0b013e318257dd67
   Klompas Michael, 2012, Am J Public Health, V102 Suppl 3, pS325, DOI 10.2105/AJPH.2012.300811
   Klompas M, 2009, CRIT CARE, V13, DOI 10.1186/cc8036

```
   Lee DH, 2011, ARCH INTERN MED, V171, P18, DOI 10.1001/archinternmed.2010.482
   Mini-Sentinel, 2010, MOD PROGR INT
   Patient-Centered Outcomes Research Institute, 2014, PCORN NAT PAT CTR CL
   Pham HH, 2007, NEW ENGL J MED, V356, P1130, DOI 10.1056/NEJMsa063979
   Toh S, 2012, ARCH INTERN MED, V172, P1582, DOI 10.1001/2013.jamainternmed.34
   Tricoci P, 2009, JAMA-J AM MED ASSOC, V301, P831, DOI 10.1001/jama.2009.205
   WARREN JL, 2002, MED CARE, V40, P18
   Yih WK, 2014, NEW ENGL J MED, V370, P503, DOI 10.1056/NEJMoa1303164
NR 24
TC 48
Z9 51
U1 0
U2 64
PU PROJECT HOPE
PI BETHESDA
PA 7500 OLD GEORGETOWN RD, STE 600, BETHESDA, MD 20814-6133 USA
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J9 HEALTH AFFAIR
JI Health Aff.
PD JUL
PY 2014
VL 33
IS 7
BP 1178
EP 1186
DI 10.1377/hlthaff.2014.0121
PG 9
WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA AN3FC
UT WOS:000340469700011
PM 25006144
DA 2019-08-06
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PT J
AU Diamond, CC
   Mostashari, F
   Shirky, C
AF Diamond, Carol C.
   Mostashari, Farzad
   Shirky, Clay
TI Collecting And Sharing Data For Population Health: A New Paradigm
SO HEALTH AFFAIRS
LA English
DT Article
ID PUBLIC-HEALTH; INFORMATION-TECHNOLOGY; SURVEILLANCE; ARCHITECTURE;
   SYSTEMS
AB Health information technology (IT) has great potential to transform health
care and inform population health goals in clinical research, quality
measurement, and public safety. To fully realize the benefits of health IT for
population health, we must focus on new models that maximize efficiency,
encourage rapid learning, and protect patients' privacy. In this paper we
explore the advantages of a networked model for analyzing population health
information, providing several examples. Although broadening the use of
networked models is challenging, the societal benefits of a networked model
merit continued exploration and the development of workable solutions. [Health
Affairs 28, no. 2 (2009): 454-466; 10.1377/hlthaff.28.2.454]
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FU National Center for Public Health Informatics; Centers for Disease Control and Prevention (CDC); Markle Foundation; CDC Contract [8P01-CD000275]; Agency for Healthcare Research and Quality [1R18HS017059-01]
FX The themes in this paper were presented by Carol Diamond at two Institute of Medicine (IOM) Roundtable on Evidence-Based Medicine meetings, 29 February 2008 and 30 July 2008, in Washington, D. C. The DiSTRIBuTE project was conducted by the International Society for Disease Surveillance under a contract with the National Association of County and City Health Officials with funding from the National Center for Public Health Informatics, Centers for Disease Control and Prevention (CDC). Additional funding was provided by the Markle Foundation. The Primary Care Information Project was completed under CDC Contract no. 8P01-CD000275, "Center of Excellence in Public Health Informatics," and Agency for Healthcare Research and Quality Contract no. 1R18HS017059-01, " Bringing Measurement to the Point of Care." The authors thank the Markle staff for their help preparing this manuscript.
CR *AG HEALTHC RES QU, 2007, FR04JN0743 AHRQ
Balas EA, 2000, YB MED INFORM
Barthell EN, 2004, ACAD EMERG MED, V11, P1142, DOI 10.1197/j.aem.2004.08.008
Bravata DM, 2004, ANN INTERN MED, V140, P910, DOI 10.7326/0003-4819-140-11-200406010-00013
Bridges to Excellence, BRIDG EXC OV
*CANC BIOM INF GRI, AB CABIG
*CONN HLTH, 2006, CONN PROF PRIV SEC I
*CONN HLTH, 2004, CONN HLTH COMM FRAM
*CONN HLTH, CONN HLTH COMM FRAM
*CONN HLTH, 2007, DEC MAK POP HLTH 1 P
*COUNC STAT TERR E, 2004, COLL PLANN DEV IMPL
de Brantes Francois, 2007, J Healthc Inf Manag, V21, P69
DIAMOND, ARCHITECTURE PRIVACY
Diamond C, 2008, CAMB Q HEALTHC ETHIC, V17, P429, DOI 10.1017/S0963180108080559
Diamond CC, 2008, HEALTH AFFAIR, V27, pW383, DOI 10.1377/hlthaff.27.5.w383
EBAN K, 2007, SCIENTIST, V21
Effler P, 1999, JAMA-J AM MED ASSOC, V282, P1845, DOI 10.1001/jama.282.19.1845
*FASTERCURES, 2006, ENS INCL CLIN RES NA
GARSON GD, 2006, PUBLIC INFORM TECHNO, P387
HJELM HF, 1965, J EDUC MEAS, V2, P144, DOI 10.1111/j.1745-3984.1965.tb00407.x
*IOM, 2008, PROT IND PRIV STRUGG
Karp DR, 2008, PLOS MED, V5, P1333, DOI 10.1371/journal.pmed.0050190
KERNER JF, 2006, AM ASS CANC ED SAN D
Krohn Rick, 2004, J Healthc Inf Manag, V18, P14
Lazarus R, 2006, BMC PUBLIC HEALTH, V6, DOI 10.1186/1471-2458-6-235
LIANG L, 2007, HLTH AFF, V26, P119
LOMBARDO JS, 2006, ADV DIS SURVEILLANCE, V1
Lorenzi N. M., 2003, STRATEGIES CREATING
LUSIGNAN S, 2002, J AM MED INFORM ASSN, V9, P395
Mandl KD, 2004, J AM MED INFORM ASSN, V11, P141, DOI 10.1197/jamia.M1356
*MARKL FDN TASK FO, 2006, MOB INF PREV TERR AC
*MARKL FDN TASK FO, 2004, RESP SEN COMM REQ TE
Markle Foundation Task Force, 2002, PROT AM FREED INF AG

```
   Markle Foundation Task Force on National Security in the Information Age,
2003, CREAT TRUST NETW HOM
   MCDONALD D, 2004, DATA QUALITY MANAGEM
   McMurry AJ, 2007, J AM MED INFORM ASSN, V14, P527, DOI 10.1197/jamia.M2371
   Mostashari F, 2009, HEALTH AFFAIR, V28, P345, DOI 10.1377/hlthaff.28.2.345
   OLSEN J, 2003, DATA QUALITY ACCURAC, V13
   Olsen LA, 2007, LEARNING HEALTHCARE
   Overhage JM, 2008, AM J PUBLIC HEALTH, V98, P344, DOI
10.2105/AJPH.2006.092700
   PHAM, IMPACT QUALITY REPOR
   Pham HH, 2006, HEALTH AFFAIR, V25, P1412, DOI 10.1377/hlthaff.25.5.1412
   SAVEL T, 2008, PUBLIC HLTH INFORM R
   Slobogin C, 2008, U CHICAGO LAW REV, V75, P317
   *SPIN, CONC RES
   *US DEP HHS, BETT QUAL INF PIL
   Wagner MM, 2003, J AM MED INFORM ASSN, V10, P409, DOI 10.1197/jamia.M1357
   2008, FED REG         0730, V73
NR 48
TC 48
Z9 49
U1 1
U2 10
PU PROJECT HOPE
PI BETHESDA
PA 7500 OLD GEORGETOWN RD, STE 600, BETHESDA, MD 20814-6133 USA
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J9 HEALTH AFFAIR
JI Health Aff.
PD MAR-APR
PY 2009
VL 28
IS 2
BP 454
EP 466
DI 10.1377/hlthaff.28.2.454
PG 13
WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA 422RJ
UT WOS:000264445100021
PM 19276005
OA Bronze
DA 2019-08-06
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PT J
AU Argimon, S
   Abudahab, K
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   Glasner, C
   Feil, EJ
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   Yeats, CA
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   Aanensen, DM
```

AF Argimon, Silvia
   Abudahab, Khalil
   Goater, Richard J. E.
   Fedosejev, Artemij
   Bhai, Jyothish
   Glasner, Corinna
   Feil, Edward J.
   Holden, Matthew T. G.
   Yeats, Corin A.
   Grundmann, Hajo
   Spratt, Brian G.
   Aanensen, David M.
TI Microreact: visualizing and sharing data for genomic epidemiology and phylogeography
SO MICROBIAL GENOMICS
LA English
DT Article
DE Open data; phylogenomics; phylogeography; population genomics; trees
ID REAL-TIME; HISTORY
AB Visualization is frequently used to aid our interpretation of complex datasets. Within microbial genomics, visualizing the relationships between multiple genomes as a tree provides a framework onto which associated data (geographical, temporal, phenotypic and epidemiological) are added to generate hypotheses and to explore the dynamics of the system under investigation. Selected static images are then used within publications to highlight the key findings to a wider audience. However, these images are a very inadequate way of exploring and interpreting the richness of the data. There is, therefore, a need for flexible, interactive software that presents the population genomic outputs and associated data in a user-friendly manner for a wide range of end users, from trained bioinformaticians to front-line epidemiologists and health workers. Here, we present Microreact, a web application for the easy visualization of datasets consisting of any combination of trees, geographical, temporal and associated metadata. Data files can be uploaded to Microreact directly via the web browser or by linking to their location (e.g. from Google Drive/Dropbox or via API), and an integrated visualization via trees, maps, timelines and tables provides interactive querying of the data. The visualization can be shared as a permanent web link among collaborators, or embedded within publications to enable readers to explore and download the data. Microreact can act as an end point for any tool or bioinformatic pipeline that ultimately generates a tree, and provides a simple, yet powerful, visualization method that will aid research and discovery and the open sharing of datasets.
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OI Bhai, Jyothish/0000-0002-2815-7478
CR Aanensen DM, 2016, MBIO, V7, DOI 10.1128/mBio.00444-16
   Cochrane G, 2016, NUCLEIC ACIDS RES, V44, pD48, DOI 10.1093/nar/gkv1323

```
   Crellen T, 2016, SCI REP-UK, V6, DOI 10.1038/srep20954
   Croucher NJ, 2015, SCI DATA, V2, DOI 10.1038/sdata.2015.58
   Currie TE, 2013, P ROY SOC B-BIOL SCI, V280, DOI 10.1098/rspb.2013.0695
   Faria NR, 2016, SCIENCE, V352, P345, DOI 10.1126/science.aaf5036
   Gardy J, 2015, GENOME BIOL, V16, DOI 10.1186/s13059-015-0726-x
   Gibson R, 2016, NUCLEIC ACIDS RES, V44, pD58, DOI 10.1093/nar/gkv1311
   Goodwin S, 2016, NAT REV GENET, V17, P333, DOI 10.1038/nrg.2016.49
   Hallast P, 2015, MOL BIOL EVOL, V32, P661, DOI 10.1093/molbev/msu327
   Imamura H, 2016, ELIFE, V5, DOI 10.7554/eLife.12613
   Knetsch CW, 2014, EUROSURVEILLANCE, V19, P30, DOI 10.2807/1560-
7917.ES2014.19.45.20954
   Njamkepo E, 2016, NAT MICROBIOL, V1, DOI [10.1038/NMICROBIOL.2016.27,
10.1038/nmicrobiol.2016.27]
   Page AJ, 2015, BIOINFORMATICS, V31, P3691, DOI 10.1093/bioinformatics/btv421
   Quick J, 2016, NATURE, V530, P228, DOI 10.1038/nature16996
   Reuter S, 2015, MICROB GENOMICS, V1, DOI 10.1099/mgen.0.000030
   Vernikos G, 2015, CURR OPIN MICROBIOL, V23, P148, DOI
10.1016/j.mib.2014.11.016
   Wong VK, 2015, NAT GENET, V47, P632, DOI 10.1038/ng.3281
   Xiao JF, 2015, GENOM PROTEOM BIOINF, V13, P73, DOI 10.1016/j.gpb.2015.01.007
NR 19
TC 47
Z9 47
U1 1
U2 1
PU MICROBIOLOGY SOC
PI LONDON
PA CHARLES DARWIN HOUSE, 12 ROGER ST, LONDON WC1N 2JU, ERKS, ENGLAND
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J9 MICROB GENOMICS
JI Microb. Genomics
PD NOV
PY 2016
VL 2
IS 11
AR 000093
DI 10.1099/mgen.0.000093
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WC Genetics & Heredity; Microbiology
SC Genetics & Heredity; Microbiology
GA VC1QS
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OA DOAJ Gold, Green Published
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PT J
AU McGuire, AL
   Basford, M
   Dressler, LG
   Fullerton, SM
   Koenig, BA
   Li, RL
   McCarty, CA
   Ramos, E
   Smith, ME
   Somkin, CP
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   Waudby, C
   Wolf, WA
   Clayton, EW
AF McGuire, Amy L.
   Basford, Melissa
   Dressler, Lynn G.
   Fullerton, Stephanie M.
   Koenig, Barbara A.
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   McCarty, Cathy A.
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   Wolf, Wendy A.
   Clayton, Ellen Wright
TI Ethical and practical challenges of sharing data from genome-wide
   association studies: The eMERGE Consortium experience
SO GENOME RESEARCH
LA English
DT Article
ID ELECTRONIC MEDICAL-RECORDS; HIPAA PRIVACY RULE; PARTICIPANTS; DISEASE
AB In 2007, the National Human Genome Research Institute (NHGRI) established the
Electronic MEdical Records and GEnomics (eMERGE) Consortium (www.gwas.net) to
develop, disseminate, and apply approaches to research that combine DNA
biorepositories with electronic medical record (EMR) systems for large-scale,
high-throughput genetic research. One of the major ethical and administrative
challenges for the eMERGE Consortium has been complying with existing data-
sharing policies. This paper discusses the challenges of sharing genomic data
linked to health information in the electronic medical record (EMR) and explores
the issues as they relate to sharing both within a large consortium and in
compliance with the National Institutes of Health (NIH) data-sharing policy. We
use the eMERGE Consortium experience to explore data-sharing challenges from the
perspective of multiple stakeholders (i.e., research participants, investigators,
and research institutions), provide recommendations for researchers and
institutions, and call for clearer guidance from the NIH regarding ethical
implementation of its data-sharing policy.
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OI Fullerton, Stephanie Malia/0000-0002-0938-6048; McCarty,
   Catherine/0000-0003-1089-0142
FU NHGRI [R01HG004333]; National Institute of General Medical Sciences
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CR Benitez K, 2010, J AM MED INFORM ASSN, V17, P169, DOI 10.1136/jamia.2009.000026
Clayton EW, 2010, GENET MED, V12, P616, DOI 10.1097/GIM.0b013e3181efdbd0
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
Kukull WA, 2002, ARCH NEUROL-CHICAGO, V59, P1737, DOI 10.1001/archneur.59.11.1737
Kullo IJ, 2010, J AM MED INFORM ASSN, V17, P568, DOI 10.1136/jamia.2010.004366
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
Ludman EJ, 2010, J EMPIR RES HUM RES, V5, P9, DOI 10.1525/jer.2010.5.3.9
Mailman MD, 2007, NAT GENET, V39, P1181
Malin B, 2011, J AM MED INFORM ASSN, V18, P3, DOI 10.1136/jamia.2010.004622
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
MCCARTY CA, 2011, AM J MED GE IN PRESS
McCarty Catherine A, 2005, Per Med, V2, P49, DOI 10.1517/17410541.2.1.49
McCarty CA, 2011, BMC MED GENOMICS, V4, DOI 10.1186/1755-8794-4-13
McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
Menikoff J, 2010, NEW ENGL J MED, V363, P1591, DOI 10.1056/NEJMp1005101
*NAT I HLTH, 2007, IMPL GUID INSTR APPL
Office for Human Research Protections, 2008, GUID RES INV COD PRI
Roden DM, 2008, CLIN PHARMACOL THER, V84, P362, DOI 10.1038/clpt.2008.89
Trinidad SB, 2011, SCIENCE, V331, P287, DOI 10.1126/science.1199000

```
   Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
   Wolf WA, 2003, AM J HUM GENET, V73, P423
NR 23
TC 46
Z9 46
U1 0
U2 19
PU COLD SPRING HARBOR LAB PRESS, PUBLICATIONS DEPT
PI COLD SPRING HARBOR
PA 1 BUNGTOWN RD, COLD SPRING HARBOR, NY 11724 USA
SN 1088-9051
EI 1549-5469
J9 GENOME RES
JI Genome Res.
PD JUL
PY 2011
VL 21
IS 7
BP 1001
EP 1007
DI 10.1101/gr.120329.111
PG 7
WC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology;
   Genetics & Heredity
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology;
   Genetics & Heredity
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PT J
AU Sundareswaran, S
   Squicciarini, AC
   Lin, D
AF Sundareswaran, Smitha
   Squicciarini, Anna C.
   Lin, Dan
TI Ensuring Distributed Accountability for Data Sharing in the Cloud
SO IEEE TRANSACTIONS ON DEPENDABLE AND SECURE COMPUTING
LA English
DT Article
DE Cloud computing; accountability; data sharing
AB Cloud computing enables highly scalable services to be easily consumed over
the Internet on an as-needed basis. A major feature of the cloud services is
that users' data are usually processed remotely in unknown machines that users
do not own or operate. While enjoying the convenience brought by this new
emerging technology, users' fears of losing control of their own data
(particularly, financial and health data) can become a significant barrier to
the wide adoption of cloud services. To address this problem, in this paper, we
propose a novel highly decentralized information accountability framework to
keep track of the actual usage of the users' data in the cloud. In particular,
we propose an object-centered approach that enables enclosing our logging
mechanism together with users' data and policies. We leverage the JAR
programmable capabilities to both create a dynamic and traveling object, and to
ensure that any access to users' data will trigger authentication and automated
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logging local to the JARs. To strengthen user's control, we also provide distributed auditing mechanisms. We provide extensive experimental studies that demonstrate the efficiency and effectiveness of the proposed approaches.

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CR AMMANN P, 1993, ACM T COMPUT SYST, V11, P205, DOI 10.1145/152864.152865
[Anonymous], 2012, EM NETW EM TESTB
[Anonymous], 2012, TRUST JAV VIRT MACH
Ateniese G, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P598
Barka E, 2008, Journal of Computer Systems, Networks, and Communications, V2008, DOI 10.1155/2008/380468
Boneh D., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P213
Bose R, 2005, ACM COMPUT SURV, V37, P1, DOI 10.1145/1057977.1057978
Buneman P., 2006, P 2006 ACM SIGMOD IN, P539, DOI DOI 10.1145/1142473.1142534
Chen YQ, 2003, LECT NOTES COMPUT SC, V2578, P400
Chun B., 2004, P ANN HAW INT C SYST
Corin R, 2005, INT FED INFO PROC, V173, P187
Crispo B., 2001, P 3 INT C INF COMM S, P251
Etalle S, 2007, SACMAT'07: PROCEEDINGS OF THE 12TH ACM SYMPOSIUM ON ACCESS CONTROL MODELS AND TECHNOLOGIES, P11
Feng XY, 2007, PROCEEDINGS OF THE TLDI 2007: 2007 ACM SIGPLAN INTERNATIONAL WORKSHOP ON TYPES IN LANGUAGES DESIGN AND IMPLEMENTATION, P67, DOI 10.1145/1190315.1190325
Hasan R., 2009, FAST, P1
Hightower J, 2001, COMPUTER, V34, P57, DOI 10.1109/2.940014
Holford J. W., 2004, P 27 AUSTR C COMP SC, V26, P341
Jaeger P. T., 2009, J INF TECHNOL, V5, P269
Jagadeesan R, 2009, LECT NOTES COMPUT SC, V5789, P152
Kailar R, 1996, IEEE T SOFTWARE ENG, V22, P313, DOI 10.1109/32.502224
Lee WJ, 2009, INT CON DISTR COMP S, P145, DOI 10.1109/ICDCS.2009.54
Lin J. H., 2004, US Patent, Patent No. [6,766,353, 6766353]
Martinelli F, 2010, FUTURE GENER COMP SY, V26, P1032, DOI 10.1016/j.future.2009.12.005
Mather T., 2009, THEORY PRACTICE
Mont MC, 2003, 14TH INTERNATIONAL WORKSHOP ON DATABASE AND EXPERT SYSTEMS APPLICATIONS, PROCEEDINGS, P377, DOI 10.1109/DEXA.2003.1232051
Oaks S., 2001, JAVA SECURITY
OASIS Security Services Technical Committee, 2012, SEC ASS MARK LANG SA
Park J., 2004, ACM Transactions on Information and Systems Security, V7, P128, DOI 10.1145/984334.984339
Park J., 2002, P 7 ACM S ACC CONTR, P57, DOI DOI 10.1145/507711.507722
Pearson S., 2009, P 1 INT C CLOUD COMP
Pearson S, 2009, LECT NOTES COMPUT SC, V5931, P90, DOI 10.1007/978-3-642-10665-1_9
Pretschner A, 2009, ELECTRON NOTES THEOR, V244, P109, DOI 10.1016/j.entcs.2009.07.042
Pretschner A, 2008, IEEE SECUR PRIV, V6, P44, DOI 10.1109/MSP.2008.101
Pretschner A, 2006, COMMUN ACM, V49, P39, DOI 10.1145/1151030.1151053
Roman S, 1992, CODING INFORM THEORY
Schneier B., 1993, APPL CRYPTOGRAPHY PR

```
   Schwarz T. S. J., 2006, 26 IEEE INT C DISTR, P12
   Squicciarini A., 2010, P IEEE INT C CLOUD C
   Sundareswaran S., 2011, P IEEE INT C CLOUD C
   Wang Q, 2009, LECT NOTES COMPUT SC, V5789, P355
   Weitzner DJ, 2008, COMMUN ACM, V51, P82, DOI 10.1145/1349026.1349043
   Wicker Stephen B, 1999, REED SOLOMON CODES T
   Xu M, 2007, SACMAT'07: PROCEEDINGS OF THE 12TH ACM SYMPOSIUM ON ACCESS
CONTROL MODELS AND TECHNOLOGIES, P71
NR 43
TC 44
Z9 48
U1 2
U2 19
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1314 USA
SN 1545-5971
EI 1941-0018
J9 IEEE T DEPEND SECURE
JI IEEE Trans. Dependable Secur. Comput.
PD JUL-AUG
PY 2012
VL 9
IS 4
BP 556
EP 568
DI 10.1109/TDSC.2012.26
PG 13
WC Computer Science, Hardware & Architecture; Computer Science, Information
   Systems; Computer Science, Software Engineering
SC Computer Science
GA 943TK
UT WOS:000304147900010
DA 2019-08-06
ER

PT J
AU Weitzman, ER
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   Mandl, KD
AF Weitzman, Elissa R.
   Kaci, Liljana
   Mandl, Kenneth D.
TI Sharing Medical Data for Health Research: The Early Personal Health
   Record Experience
SO JOURNAL OF MEDICAL INTERNET RESEARCH
LA English
DT Article
DE Medical records; personally controlled health records (PCHR); personal
   health records; data sharing; information altruism; HITECH; public
   health informatics
ID INFORMATION; CONSENT; ETHICS; ACCESS; COMMUNITY; PEOPLE
AB Background: Engaging consumers in sharing information from personally
controlled health records (PCHRs) for health research may promote goals of
improving care and advancing public health consistent with the federal Health
Information Technology for Economic and Clinical Health (HITECH) Act.
Understanding consumer willingness to share data is critical to advancing this
model.
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Objective: The objective was to characterize consumer willingness to share PCHR data for health research and the conditions and contexts bearing on willingness to share.

Methods: A mixed method approach integrating survey and narrative data was used. Survey data were collected about attitudes toward sharing PCHR information for health research from early adopters (n = 151) of a live PCHR populated with medical records and self-reported behavioral and social data. Data were analyzed using descriptive statistics and logistic regression to characterize willingness, conditions for sharing, and variations by sociodemographic factors. Narrative data were collected through semistructured focus group and one-on-one interviews with a separate sample of community members (n = 30) following exposure to PCHR demonstrations. Two independent analysts coded narrative data for major and minor themes using a shared rubric of a priori defined codes and an iterative inductive process. Findings were triangulated with survey results to identify patterns.

Results: Of PHCR users, 138 out of 151 (91%) were willing to share medical information for health research with 89(59%) favoring an opt-in sharing model. Willingness to share was conditioned by anonymity, research use, engagement with a trusted intermediary, transparency around PCHR access and use, and payment. Consumer-determined restrictions on content and timing of sharing may be prerequisites to sharing. Select differences in support for sharing under different conditions were observed across social groups. No gender differences were observed; however differences in age, role, and self-rated health were found. For example, students were more likely than nonstudents to favor an opt-out sharing default (unadjusted odds ratio [OR] = 2.89, 95% confidence interval [CI] 1.10 - 7.62, P =.03). Participants over age 50 were less likely than younger participants to report that payment would increase willingness to share (unadjusted OR = 0.94, 95% Cl 0.91 - 0.96, P < .001). Students were more likely than nonstudents to report that payment would increase their willingness to share (unadjusted OR 9.62, 95% CI 3.44 26.87, P < .001). Experiencing a public health emergency may increase willingness to share especially among persons over 50 (unadjusted OR 1.03, 95% CI 1.01 - 1.05, P = .02); however, students were less likely than non-students to report this attitude (unadjusted OR 0.13, 95% CI 0.05 - 0.36, P < .001). Finally, subjects with fair or poor self-rated health were less likely than those with good to excellent self-rated health to report that willingness to share would increase during a public health emergency (unadjusted OR 0.61, 95% CI 0.38 - 0.97, P = .04).

Conclusions: Strong support for sharing of PCHR information for health research existed among early adopters and focus group participants, with support varying by social group under different conditions and contexts. Allowing users to select their preferred conditions for sharing may be vital to supporting sharing and fostering trust as may be development of safety monitoring mechanisms.

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   AA016638-01A1 from the National Institute of Alcohol Abuse and
   Alcoholism (NIAAA), and by 1U54RR025224-01 from NCRR/NIH, and by the
   Manton Center for Orphan Disease Research.
CR Baird W, 2009, J MED ETHICS, V35, P92, DOI 10.1136/jme.2008.025304
   Barrett G, 2006, BRIT MED J, V332, P1068, DOI 10.1136/bmj.38805.473738.7C
   BOURGEOIS E, 2007, AMIA ANN S P, P881
   Detmer D, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-45
   Frost Jeana H, 2008, AMIA Annu Symp Proc, P217
   Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
   Harkonmaki K, 2008, PLOS ONE, V3, DOI 10.1371/journal.pone.0003402
   Hettema JM, 2001, AM J PSYCHIAT, V158, P1568, DOI
10.1176/appi.ajp.158.10.1568
   Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
   Mandl KD, 2007, BMC MED INFORM DECIS, V7, DOI 10.1186/1472-6947-7-25
   Mandl KD, 2008, NEW ENGL J MED, V358, P1732, DOI 10.1056/NEJMsb0800220
   Mazzeo SE, 2009, PSYCHOL MED, V39, P463, DOI 10.1017/S0033291708003310
   Miller FG, 2008, J LAW MED ETHICS, V36, P560, DOI 10.1111/j.1748-
720X.2008.304.x
   Navarro Robert, 2008, Inform Prim Care, V16, P257
   Scurrah KJ, 2006, GENET EPIDEMIOL, V30, P397, DOI 10.1002/gepi.20156
   Simons William W, 2006, AMIA Annu Symp Proc, P1099
   Taylor PL, 2007, NATURE, V450, P163, DOI 10.1038/450163a
   Taylor PL, 2007, NAT BIOTECHNOL, V25, P398, DOI 10.1038/nbt0407-398
   Terry Ken, 2008, Hosp Health Netw, V82, P36
   van Teijlingen ER, 2008, BMC PUBLIC HEALTH, V8, DOI 10.1186/1471-2458-8-396
   Weitzman ER, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1187
   Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI
10.1016/j.ijmedinf.2005.08.009
   Wiljer D, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1061
   Willison DJ, 2008, J MED ETHICS, V34, P308, DOI 10.1136/jme.2006.020032
   Willison Donald J, 2007, Healthc Policy, V2, P39
   Willison Donald J, 2008, BMC Med Ethics, V9, P18, DOI 10.1186/1472-6939-9-18
   Willison DJ, 2009, BMC MED ETHICS, V10, DOI 10.1186/1472-6939-10-10
NR 27
TC 44
Z9 46
U1 0
U2 24
PU JMIR PUBLICATIONS, INC
PI TORONTO
PA 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA
SN 1438-8871
J9 J MED INTERNET RES
JI J. Med. Internet Res.
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AU Paltoo, DN
   Rodriguez, LL
   Feolo, M
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   Bailey, A
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   Harris, EL
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AF Paltoo, Dina N.
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CA Natl Inst Hlth Genomic Data Sharin
TI Data use under the NIH GWAS Data Sharing Policy and future directions
SO NATURE GENETICS
LA English
DT Editorial Material
ID GENOME-WIDE ASSOCIATION; RISK LOCI; DISORDERS
AB In 2007, the US National Institutes of Health (NIH) introduced the Genome-
Wide Association Studies (GWAS) Policy and the database of Genotypes and
Phenotypes (dbGaP) to facilitate 'controlled' access to GWAS data based on
participants' informed consent. dbGaP has provided 2,221 investigators access to
304 studies, resulting in 924 publications and significant scientific advances.
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Following on this success, the 2014 Genomic Data Sharing Policy will extend the GWAS Policy to additional data types.
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FU Intramural NIH HHS [Z99 LM999999]
CR Adam D, 2013, NATURE, V496, P416, DOI 10.1038/496416a
Chen YX, 2013, BIOINFORMATICS, V29, P266, DOI 10.1093/bioinformatics/bts665
Gelernter J, 2014, MOL PSYCHIATR, V19, P41, DOI 10.1038/mp.2013.145
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hamza TH, 2010, NAT GENET, V42, P781, DOI 10.1038/ng.642
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Lee S, 2012, AM J HUM GENET, V91, P224, DOI 10.1016/j.ajhg.2012.06.007
Mailman MD, 2007, NAT GENET, V39, P1181
McCarthy SE, 2009, NAT GENET, V41, P1223, DOI 10.1038/ng.474
McMahon FJ, 2010, NAT GENET, V42, P128, DOI 10.1038/ng.523
Ramos EM, 2013, AM J HUM GENET, V92, P479, DOI 10.1016/j.ajhg.2012.08.034
Rodriguez LL, 2013, SCIENCE, V339, P275, DOI 10.1126/science.1234593
Smoller JW, 2013, LANCET, V381, P1371, DOI 10.1016/S0140-6736(12)62129-1
NR 13
TC 43
Z9 43
U1 0
U2 15
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1061-4036
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J9 NAT GENET
JI Nature Genet.
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AU Hassan, MM
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Yue, XJ
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AF Hassan, Mohammad Mehedi
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TI A multimedia healthcare data sharing approach through cloud-based body area network
SO FUTURE GENERATION COMPUTER SYSTEMS-THE INTERNATIONAL JOURNAL OF ESCIENCE
LA English
DT Article
DE Wireless body area network; Media healthcare; Data sharing; Cloud computing; Network architecture
ID ARCHITECTURE; MANAGEMENT
AB Wireless Body Area Network (WBAN), as, a dramatic platform for pervasive computing and communication, has been widely applied in healthcare domains. Since the patient-related data in the form of text, image, voice, etc. is significant in the process of healthcare services, efficiently managing these media data from various WBAN is vital for various applications. Recently, Cloud-assisted WBAN has become popular that can supply massive computing, flexible storage and various software services to WBAN. Still, there are some challenging issues exist in this platform to deliver and share the huge media healthcare data to remote terminals timely with guaranteed QoS support. In the paper, we propose an efficient network model that combines WBAN and Cloud for valid data sharing. The proposed network architecture is designed as four layers: perception layer, network layer, cloud computing layer, and application layer. In the network, the integration of TCP/IP and Zigbee in the coordinator devices is utilized. Consequently, WBAN coordinators can compatibility inter-operate with various local networks such as WiFi and LTE network to support high mobility of users. Besides, we integrate Content Centric Networking (CCN) with our proposed architecture to improve the ability of the WBAN coordinator. Thus, it can support uninterrupted media healthcare content delivery. In addition, adaptive streaming technique was also utilized to reduce packet loss. Various simulations were conducted using OPNET simulator to show the feasibility of the proposed architecture in terms of transmitting a huge amount of media healthcare data in real-time under traditional IP-based network. (C) 2016 Elsevier B.V. All rights reserved.
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CR Chen F, 2015, INT J DISTRIB SENS N, DOI 10.1155/2015/431047
Chen M., 2012, ACM SPRINGER MOBILE, V20, P704
Chen M., 2015, OPNET IOT SIMULATION
Chen M, 2015, IEEE COMMUN MAG, V53, P18, DOI 10.1109/MCOM.2015.7120041
Chen M, 2015, IEEE WIREL COMMUN, V22, P20, DOI 10.1109/MWC.2015.7054715
Chen M, 2014, INFORM SCIENCES, V284, P142, DOI 10.1016/j.ins.2014.06.023
Chen M, 2011, MOBILE NETW APPL, V16, P171, DOI 10.1007/s11036-010-0260-8
Chen M, 2010, IEEE WIREL COMMUN, V17, P37, DOI 10.1109/MWC.2010.5416348
Fortino G, 2014, WIREL NETW, V20, P1925, DOI 10.1007/s11276-014-0714-1
Fortino G, 2014, FUTURE GENER COMP SY, V35, P62, DOI 10.1016/j.future.2013.12.015
Fortino G, 2013, IEEE T HUM-MACH SYST, V43, P115, DOI 10.1109/TSMCC.2012.2215852
Ge XH, 2011, IEEE T WIREL COMMUN, V10, P3298, DOI 10.1109/TWC.2011.11.101551
Ge XH, 2012, MOBILE NETW APPL, V17, P29, DOI 10.1007/s11036-011-0296-4
Ghodsi A., 2011, PROC 10 ACM WORKSH H
Gonzalez-Valenzuela S, 2011, IEEE T INF TECHNOL B, V15, P539, DOI 10.1109/TITB.2010.2104326
Han B., 2013, IEEE INF WOM WORKSH
Hassan M.M., 2013, P 1 ACM MULT INT WOR, P15
Hassan MM, 2015, MULTIMED TOOLS APPL, V74, P5225, DOI 10.1007/s11042-014-2040-0
Hossain M. S., 2015, IEEE SYST J
Hossain MS, 2015, MOBILE NETW APPL, V20, P391, DOI 10.1007/s11036-015-0586-3
Hossain MS, 2013, MULTIMED TOOLS APPL, V67, P433, DOI 10.1007/s11042-012-1006-3
Hu L, 2015, J MED SYST, V39, DOI 10.1007/s10916-015-0336-x
Huang J., 2012, P 10 INT C MOB SYST, P225, DOI [10.1145/2307636.2307658, DOI 10.1145/2307636.2307658]
Humar I, 2011, IEEE NETWORK, V25, P40, DOI 10.1109/MNET.2011.5730527
Ibaida A, 2014, FUTURE GENER COMP SY, V35, P91, DOI 10.1016/j.future.2013.12.025
Iffat A., 2013, INT J DISTRIB SENS N, V2013
Islam MM, 2010, PROCEEDINGS OF THE 2010 INTERNATIONAL CONFERENCE ON COMPILERS, ARCHITECTURES AND SYNTHESIS FOR EMBEDDED SYSTEMS (CASES '10), P227, DOI 10.1145/1878921.1878955
Jacobson V, 2012, COMMUN ACM, V55, P117, DOI 10.1145/2063176.2063204
Li GJ, 2011, INFORMATION SCIENCE AND TECHNOLOGY IN CHINA: A ROADMAP TO 2050, P1

```
   Li J, 2012, PROCEEDINGS OF THE EIGHTH ACM/IEEE SYMPOSIUM ON ARCHITECTURES FOR
NETWORKING AND COMMUNICATIONS SYSTEMS (ANCS'12), P15
   Lounis A, 2016, FUTURE GENER COMP SY, V55, P266, DOI
10.1016/j.future.2015.01.009
   Lu CY, 2005, IEEE T PARALL DISTR, V16, P550, DOI 10.1109/TPDS.2005.73
   Masud M, 2012, IEEE T INF TECHNOL B, V16, P1015, DOI
10.1109/TITB.2012.2202244
   Min Chen, 2013, 2013 IEEE 15th International Conference on e-Health
Networking, Applications and Services (Healthcom 2013), P669, DOI
10.1109/HealthCom.2013.6720760
   Ming ZX, 2012, IEEE CONF COMPUT, P268, DOI 10.1109/INFCOMW.2012.6193504
   Monowar MM, 2014, INT J DISTRIB SENS N, DOI 10.1155/2014/676312
   Otal B., 2008, 3 ICST INT C BOD AR
   Riva G, 2000, CYBERPSYCHOL BEHAV, V3, P989, DOI 10.1089/109493100452255
   Ullah S, 2012, J MED SYST, V36, P3875, DOI 10.1007/s10916-012-9860-0
   Ullah S, 2012, J MED SYST, V36, P1065, DOI 10.1007/s10916-010-9571-3
   Wan JF, 2013, IEEE NETWORK, V27, P56, DOI 10.1109/MNET.2013.6616116
   Yang J, 2014, SPRINGERBRIEF COMPUT, P1, DOI 10.1007/978-3-319-07356-9
NR 42
TC 42
Z9 42
U1 4
U2 72
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
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SC Computer Science
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PT J
AU Adler-Milstein, J
   Jha, AK
AF Adler-Milstein, Julia
   Jha, Ashish K.
TI Sharing Clinical Data Electronically A Critical Challenge for Fixing the
   Health Care System
SO JAMA-JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION
LA English
DT Editorial Material
ID INFORMATION EXCHANGE; HOSPITALS
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CR Adler-Milstein J, 2011, AM J MANAG CARE, V17, P761
   Adler-Milstein J, 2009, HEALTH AFFAIR, V28, P483, DOI
10.1377/hlthaff.28.2.483
   Blumenthal D, 2011, NEW ENGL J MED, V365, P2426, DOI 10.1056/NEJMsr1112158
   Grossman Joy M, 2008, Res Brief, P1
   Health Information Technology Policy Committee, MEAN US WORKGR REQ C
   Kuperman GJ, 2011, J AM MED INFORM ASSN, V18, P678, DOI 10.1136/amiajnl-2010-
000021
   US Dept of Health and Human Services, STAT HLTH INF EXCH C
   Wolf L, 2012, HEALTH AFFAIR, V31, P505, DOI 10.1377/hlthaff.2011.0351
NR 8
TC 40
Z9 40
U1 0
U2 9
PU AMER MEDICAL ASSOC
PI CHICAGO
PA 330 N WABASH AVE, STE 39300, CHICAGO, IL 60611-5885 USA
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J9 JAMA-J AM MED ASSOC
JI JAMA-J. Am. Med. Assoc.
PD APR 25
PY 2012
VL 307
IS 16
BP 1695
EP 1696
DI 10.1001/jama.2012.525
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WC Medicine, General & Internal
SC General & Internal Medicine
GA 930OA
UT WOS:000303147500019
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ER

PT J
AU Lang, TD
AF Lang, Trudie
TI Advancing Global Health Research Through Digital Technology and Sharing
   Data
SO SCIENCE
LA English
DT Editorial Material
ID RESEARCH CAPACITY; MALARIA; COUNTRIES
AB The imperative for improving health in the world's poorest regions lies in
research, yet there is no question that low participation, a lack of trained
staff, and limited opportunities for data sharing in developing countries impede
advances in medical practice and public health knowledge. Extensive studies are
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essential to develop new treatments and to identify better ways to manage healthcare issues. Recent rapid advances in availability and uptake of digital technologies, especially of mobile networks, have the potential to overcome several barriers to collaborative research in remote places with limited access to resources. Many research groups are already taking advantage of these technologies for data sharing and capture, and these initiatives indicate that increasing acceptance and use of digital technology could promote rapid improvements in global medical science.
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CR Aikins AD, 2010, GLOBALIZATION HEALTH, V6, DOI 10.1186/1744-8603-6-5
Dondorp AM, 2010, LANCET, V376, P1647, DOI 10.1016/S0140-6736(10)61924-1
Fegan W, 2008, PLOS MED, V5, P347, DOI 10.1371/journal.pmed.0050006
Fischer BA, 2010, SCI ENG ETHICS, V16, P783, DOI 10.1007/s11948-010-9239-x
Guerin PJ, 2009, CURR OPIN INFECT DIS, V22, P593, DOI 10.1097/QCO.0b013e328332c4a7
Hay SI, 2006, PLOS MED, V3, P2204, DOI 10.1371/journal.pmed.0030473
Horton R, 2000, LANCET, V355, P2231, DOI 10.1016/S0140-6736(00)02414-4
Kanter AS, 2009, INT J MED INFORM, V78, P802, DOI 10.1016/j.ijmedinf.2009.08.002
Kowal P, 2010, GLOBAL HEALTH ACTION, V3, P11, DOI 10.3402/gha.v3i0.5302
Kwiatkowski D, 2008, NATURE, V456, P732, DOI 10.1038/nature07632
Lang TA, 2010, PLOS NEGLECT TROP D, V4, DOI 10.1371/journal.pntd.0000619
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
Mwaba P, 2010, LANCET, V375, P1874, DOI 10.1016/S0140-6736(10)60874-4
Noormohammad SF, 2010, INT J MED INFORM, V79, P204, DOI 10.1016/j.ijmedinf.2010.01.002
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Pirmohamed M, 2007, BRIT MED J, V335, P462, DOI 10.1136/bmj.39323.586123.BE
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
WENGER E, 2000, HARVARD BUSINESS JAN, P139
Wertheim HFL, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000231
Whitworth J, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.079202
NR 20
TC 39
Z9 42
U1 0
U2 24
PU AMER ASSOC ADVANCEMENT SCIENCE
PI WASHINGTON
PA 1200 NEW YORK AVE, NW, WASHINGTON, DC 20005 USA
SN 0036-8075
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J9 SCIENCE
JI Science
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA 719LH

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UT WOS:000287205700054
PM 21311011
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ER

PT J
AU Sun, JY
   Fang, YG
AF Sun, Jinyuan
   Fang, Yuguang
TI Cross-Domain Data Sharing in Distributed Electronic Health Record
   Systems
SO IEEE TRANSACTIONS ON PARALLEL AND DISTRIBUTED SYSTEMS
LA English
DT Article
DE Cross domain; delegation; electronic health record; privacy; security
AB Cross-organization or cross-domain cooperation takes place from time to time
in Electronic Health Record (EHR) system for necessary and high-quality patient
treatment. Cautious design of delegation mechanism must be in place as a
building block of cross-domain cooperation, since the cooperation inevitably
involves exchanging and sharing relevant patient data that are considered highly
private and confidential. The delegation mechanism grants permission to and
restricts access rights of a cooperating partner. Patients are unwilling to
accept the EHR system unless their health data are guaranteed proper use and
disclosure, which cannot be easily achieved without cross-domain authentication
and fine-grained access control. In addition, revocation of the delegated rights
should be possible at any time during the cooperation. In this paper, we propose
a secure EHR system, based on cryptographic constructions, to enable secure
sharing of sensitive patient data during cooperation and preserve patient data
privacy. Our EHR system further incorporates advanced mechanisms for fine-
grained access control, and on-demand revocation, as enhancements to the basic
access control offered by the delegation mechanism, and the basic revocation
mechanism, respectively. The proposed EHR system is demonstrated to fulfill
objectives specific to the cross-domain delegation scenario of interest.
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FU US National Science Foundation [CNS-0916391, CNS0716450, CNS-0721744];
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CR ABDALLA M, 2005, P INT CRYPT C CRYPTO
   ALRIYAMI SS, 2003, P 9 INT C THEOR APPL, P452
   BAEK J, 2005, 2005191 CRYPT
   Bao S.-D., 2005, P 28 IEEE EMBS ANN I, P58
   BOLDYREVA A, 2003, 2003096 CRYPT
   Boneh D, 2003, SIAM J COMPUT, V32, P586, DOI 10.1137/S0097539701398521
   Boneh D, 2001, LECT NOTES COMPUTER, V2248, P514, DOI DOI 10.1007/3-540-45682-
1_30
   Boneh D., 2004, P INT C THEOR APPL C
   Camenisch J., 2002, P 22 ANN INT CRYPT C, P61
```

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   EHR, 2009, ELECT HLTH RECORD
   GENTRY C, 2002, P 8 INT C THEOR APPL, P548
   GUPTA S, 2008, P MISS CRIT NETW WOR
   HESS F, 2002, SELECTED AREAS CRYPT, P310
   KATZAROVA M, 2006, P INF SEC C ISC 06
   Lee WB, 2008, IEEE T INF TECHNOL B, V12, P34, DOI 10.1109/TITB.2007.906101
   LIM HW, 2005, P 1 IEEE INT C E SCI
   Menezes AJ, 1996, HDB APPL CRYPTOGRAPH
   Mont M.C., 2003, P 14 INT WORKSH DAT
   Nguyen L, 2005, LECT NOTES COMPUT SC, V3531, P318
   *O EXSTENSIBLE ACC, 2009, XACML V2 0
   *O S S T COMM, 2009, SAML V2 0
   Pear R., 2007, NY TIMES        FEB
   Rash M. C., 2005, BUSINESS J GREAT APR
   RAY P, 2006, P 28 IEEE EMBS ANN I, P4686
   Ristenpart T., 2008, P 17 USENIX SEC S JU, P275
   SANDHU RS, 1996, IEEE COMPUT, V2, P38
   Sax U, 2005, J AM MED INFORM ASSN, V12, P263, DOI 10.1197/jamia.M1681
   Sun JY, 2008, P IEEE INFOCOM APR, P1687
   TAN CC, 2008, P ACM C WIR NETW SEC
   Thomlinson W, 1997, PHYS MEDICA, V13, P19
   *UD HLTH HUM SERV, 2009, HLTH INF TECHN
   Welch V., 2004, P 3 ANN PKI R D WORK
   Zhang L., 2003, ACM Transactions on Information and Systems Security, V6,
P404, DOI 10.1145/937527.937530
   2009, LIBERTY ALLIANCE PRO
NR 34
TC 38
Z9 39
U1 1
U2 11
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
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   Kiess, R
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AF Mielck, Andreas
   Kiess, Raphael
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   Stirbu, Irina
   Kunst, Anton E.
TI Association between forgone care and household income among the elderly
   in five Western European countries - analyses based on survey data from
   the SHARE-study
SO BMC HEALTH SERVICES RESEARCH
LA English
DT Article
ID HEALTH-CARE; INTERNATIONAL COMPARISONS; ADOLESCENTS; LAW; SERVICES;
   QUALITY; FINANCE; EQUITY

AB Background: Studies on the association between access to health care and household income have rarely included an assessment of 'forgone care', but this indicator could add to our understanding of the inverse care law. We hypothesize that reporting forgone care is more prevalent in low income groups.

Methods: The study is based on the 'Survey of Health, Ageing and Retirement in Europe (SHARE)', focusing on the non-institutionalized population aged 50 years or older. Data are included from France, Germany, Greece, Italy and Sweden. The dependent variable is assessed by the following question: During the last twelve months, did you forgo any types of care because of the costs you would have to pay, or because this care was not available or not easily accessible? The main independent variable is household income, adjusted for household size and split into quintiles, calculating the quintile limits for each country separately. Information on age, sex, self assessed health and chronic disease is included as well. Logistic regression models were used for the multivariate analyses.

Results: The overall level of forgone care differs considerably between the five countries (e. g. about 10 percent in Greece and 6 percent in Sweden). Low income groups report forgone care more often than high income groups. This association can also be found in analyses restricted to the subsample of persons with chronic disease. Associations between forgone care and income are particularly strong in Germany and Greece. Taking the example of Germany, forgone care in the lowest income quintile is 1.98 times (95% CI: 1.08-3.63) as high as in the highest income quintile.

Conclusion: Forgone care should be reduced even if it is not justified by an 'objective' need for health care, as it could be an independent stressor in its own right, and as patient satisfaction is a strong predictor of compliance. These efforts should focus on population groups with particularly high prevalence of forgone care, for example on patients with poor self assessed health, on women, and on low income groups. The inter-country differences point to the need to specify different policy recommendations for different countries.

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CR Arnold-Womer N, 2008, EXP CLIN ENDOCR DIAB, V116, P123, DOI 10.1055/s-2007-990297
BENZEVAL M, 1995, TACKLING INEQUALITIE
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
BRIDEVAUX IP, 2007, J PUBLIC HLTH, V15, P377
BUHMANN B, 1988, REV INCOME WEALTH, P115
Burstrom B, 2002, HEALTH POLICY, V62, P117, DOI 10.1016/S0168-8510(02)00016-7
Elliott BA, 2004, J ADOLESCENT HEALTH, V35, P303, DOI 10.1016/j.jadohealth.2003.09.015
Ford CA, 1999, JAMA-J AM MED ASSOC, V282, P2227, DOI 10.1001/jama.282.23.2227
GRAHAM H, 2001, UNDERSTANDING HLTH I
Gross DJ, 1999, HEALTH SERV RES, V34, P241
HART JT, 1971, LANCET, V1, P405, DOI 10.1016/S0140-6736(71)92410-X
Huang YG, 2001, EUR J PAIN-LONDON, V5, P67, DOI 10.1053/eujp.2001.0283
Jurges H, 2007, HEALTH ECON, V16, P163, DOI 10.1002/hec.1134
Kunst A, 1994, MEASURING SOCIOECONO
MARMOT M, 1999, SOCIAL DETERMINANTS
Mckee MD, 2006, J HEALTH CARE POOR U, V17, P759
Peytremann-Bridevaux I, 2008, J AFFECT DISORDERS, V105, P247, DOI 10.1016/j.jad.2007.04.011
Peytremann-Bridevaux I, 2007, PREV MED, V44, P442, DOI 10.1016/j.ypmed.2006.11.011
*RAND CORP, 2006, IMPR ACC NEED HLTH C
Rew L, 1999, J ADOLESCENT HEALTH, V25, P407, DOI 10.1016/S1054-139X(98)00159-1
Roger JP, 2007, AM J PUBLIC HEALTH, V97, P804, DOI 10.2105/AJPH.2005.080184
Sarmiento Olga L, 2005, J Immigr Health, V7, P305, DOI 10.1007/s10903-005-5128-9
Shmueli A, 2008, HEALTH POLICY, V87, P273, DOI 10.1016/j.healthpol.2008.02.008
Siegrist J., 2006, SOCIAL INEQUALITIES
Siegrist J, 2007, EUR J PUBLIC HEALTH, V17, P62, DOI 10.1093/eurpub/ckl084
Smaldone A, 2005, MATERN CHILD HLTH J, V9, pS75, DOI 10.1007/s10995-005-3859-9
*STAT OFF, 1998, ACH REO IND INQ IN H
Knesebeck OV, 2007, AGEING SOC, V27, P269, DOI 10.1017/S0144686X06005484
Wagstaff A, 1999, J HEALTH ECON, V18, P263, DOI 10.1016/S0167-6296(98)00044-7
WAGSTAFF A, 1992, J HEALTH ECON, V11, P361, DOI 10.1016/0167-6296(92)90012-P
Watt G, 2002, LANCET, V360, P252, DOI 10.1016/S0140-6736(02)09466-7
Whitehead M, 2006, LEVELLING 1

NR 33
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   Schroter, S
   Altman, DG
   Hemingway, H
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CA PROGRESS Grp
TI Improving the Transparency of Prognosis Research: The Role of Reporting,
   Data Sharing, Registration, and Protocols
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LA English
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CR Abo-Zaid G, 2012, BMC MED RES METHODOL, V12, DOI 10.1186/1471-2288-12-56
Altman DG, 2007, STAT IND TECHNOL, P3, DOI 10.1007/978-0-8176-4542-7_1
[Anonymous], 2010, EPIDEMIOLOGY, V21, P607, DOI 10.1097/EDE.0b013e3181eafbcf
Autier P, 2010, BRIT MED J, V341, DOI 10.1136/bmj.c3620
Benchimol EI, 2013, J CLIN EPIDEMIOL, V66, P703, DOI 10.1016/j.jclinepi.2012.09.006
Bouwmeester W, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001221
Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
Broeze KA, 2009, BMC MED RES METHODOL, V9, DOI 10.1186/1471-2288-9-22
Chambers C, 2013, J CORTEX LAUNCHES RE
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Chung SC, 2014, LANCET, V383, P1305, DOI 10.1016/S0140-6736(13)62070-X
Dal-Re R, 2014, SCI TRANSL MED, V6, DOI 10.1126/scitranslmed.3007513
Denaxas SC, 2012, INT J EPIDEMIOL, V41, P1625, DOI 10.1093/ije/dys188
DICKERSIN K, 1990, JAMA-J AM MED ASSOC, V263, P1385, DOI 10.1001/jama.263.10.1385
Dickersin K, 2012, JAMA-J AM MED ASSOC, V307, P1861, DOI 10.1001/jama.2012.4230
Gewin Virginia, 2012, Nature, V485, P137
Hemingway H, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.e5595
Hemingway H, 2009, BRIT MED J, V339, DOI 10.1136/bmj.b4184
Hill JC, 2011, LANCET, V378, P1560, DOI 10.1016/S0140-6736(11)60937-9
Hingorani AD, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.e5793
Holmes MV, 2011, JAMA-J AM MED ASSOC, V306, P2704, DOI 10.1001/jama.2011.1880
Institute of Medicine (IOM), 2012, EV TRANSL OM LESS LE
Ioannidis JPA, 2012, JAMA-J AM MED ASSOC, V308, P575, DOI 10.1001/jama.2012.8144
Kyzas PA, 2007, EUR J CANCER, V43, P2559, DOI 10.1016/j.ejca.2007.08.030
Laine C, 2007, ANN INTERN MED, V146, P450, DOI 10.7326/0003-4819-146-6-200703200-00154
Lash TL, 2012, EPIDEMIOLOGY, V23, P184, DOI 10.1097/EDE.0b013e318245c05b
LAU J, 1992, NEW ENGL J MED, V327, P248, DOI 10.1056/NEJM199207233270406
Lowrance W, 2006, ACCESS COLLECTIONS D
Malats W, 2005, LANCET ONCOL, V6, P678
Mallett S, 2010, BMC MED, V8
Manolio TA, 2012, AM J EPIDEMIOL, V175, P859, DOI 10.1093/aje/kwr453
Marmarou A, 2007, J NEUROTRAUM, V24, P239, DOI 10.1089/neu.2006.0036
McShane LM, 2005, JNCI-J NATL CANCER I, V97, P1180, DOI 10.1093/jnci/dji237
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Potti A, 2011, NEW ENGL J MED, V364, P1176, DOI 10.1056/NEJMc1101915
Rasmussen N, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-116
Riley RD, 2013, PLOS MED, V10, DOI 10.1371/journal.pmed.1001380
Roozenbeek B, 2012, CRIT CARE MED, V40, P1609, DOI 10.1097/CCM.0b013e31824519ce
Rossi D, 2013, BLOOD, V121, P1403, DOI 10.1182/blood-2012-09-458265
Simon R, 2001, PROGNOSTIC FACTORS C, P49
Sorensen HT, 2010, BMJ-BRIT MED J, V340, DOI 10.1136/bmj.c703
Steyerberg EW, 2013, PLOS MED, V10, DOI 10.1371/journal.pmed.1001381
The PLOS Medicine Editors, 2013, PLOS MED, V10
Thomas L, 2012, JAMA-J AM MED ASSOC, V308, P773, DOI 10.1001/jama.2012.9502
van Enst WA, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0042812
van Staa TP, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000194
Vandenbroucke JP, 2008, PLOS MED, V5, P339, DOI 10.1371/journal.pmed.0050067
Vandenbroucke JP, 2010, EPIDEMIOLOGY, V21, P619, DOI 10.1097/EDE.0b013e3181e942b8
Wager E, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f5248

```
   Wiener RS, 2011, ARCH INTERN MED, V171, P831, DOI
10.1001/archinternmed.2011.178
   Williams RJ, 2010, CAN MED ASSOC J, V182, P1638, DOI 10.1503/cmaj.092252
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AU Malin, B
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TI Never too old for anonymity: a statistical standard for demographic data
   sharing via the HIPAA Privacy Rule
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
ID GENOMIC DATA PRIVACY; PROTECTING PRIVACY; K-ANONYMITY; HEALTH;
   REIDENTIFICATION; CONFIDENTIALITY; ASSOCIATION; INFORMATION; TECHNOLOGY;
   DATABASES
AB Objective Healthcare organizations must de-identify patient records before
sharing data. Many organizations rely on the Safe Harbor Standard of the HIPAA
Privacy Rule, which enumerates 18 identifiers that must be suppressed (eg, ages
over 89). An alternative model in the Privacy Rule, known as the Statistical
Standard, can facilitate the sharing of more detailed data, but is rarely
applied because of a lack of published methodologies. The authors propose an
intuitive approach to de-identifying patient demographics in accordance with the
Statistical Standard.
   Design The authors conduct an analysis of the demographics of patient cohorts
in five medical centers developed for the NIH-sponsored Electronic Medical
Records and Genomics network, with respect to the US census. They report the re-
identification risk of patient demographics disclosed according to the Safe
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Harbor policy and the relative risk rate for sharing such information via alternative policies.

Measurements The re-identification risk of Safe Harbor demographics ranged from 0.01% to 0.19%. The findings show alternative de-identification models can be created with risks no greater than Safe Harbor. The authors illustrate that the disclosure of patient ages over the age of 89 is possible when other features are reduced in granularity.

Limitations The de-identification approach described in this paper was evaluated with demographic data only and should be evaluated with other potential identifiers.

Conclusion Alternative de-identification policies to the Safe Harbor model can be derived for patient demographics to enable the disclosure of values that were previously suppressed. The method is generalizable to any environment in which population statistics are available.

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CR ACQUISI A, 2005, P 1 ACM INT HLTH INF, V3, P26
BENITEZ K, 2010, P 1 ACM INT IN PRESS
Benitez K, 2010, J AM MED INFORM ASSN, V17, P169, DOI 10.1136/jamia.2009.000026
Cox LH, 1996, STAT MED, V15, P1895, DOI 10.1002/(SICI)1097-0258(19960915)15:17<1895::AID-SIM401>3.0.CO;2-W
DANKAR F, 2010, P EDBT ICDT WORKSH, P1
*DE ID DAT CORP, FREQ ASK QUEST
El Emam K, 2008, J AM MED INFORM ASSN, V15, P627, DOI 10.1197/jamia.M2716
El Emam K, 2006, J MED INTERNET RES, V8, DOI 10.2196/jmir.8.4.e28
El Emam K, 2009, J AM MED INFORM ASSN, V16, P670, DOI 10.1197/jamia.M3144
ELLIOT M., 2000, RISK MANAGEMENT, V2, P39, DOI DOI 10.1057/PALGRAVE.RM.8240067
Elliot MJ, 1998, RES OFF STAT, V1, P53
Ev mievski A., 2002, SIGKDD EXPLORATIONS, V4, P43
Federal Committee on Statistical Methodology, 2005, 22 FED COMM STAT MET
Golle P, 2006, P 5 ACM WORKSH PRIV, DOI [10.1145/1179601.1179615, DOI 10.1145/1179601.1179615]
Gostin LO, 2009, JAMA-J AM MED ASSOC, V301, P1373, DOI 10.1001/jama.2009.424
GOSTIN LO, 1993, JAMA-J AM MED ASSOC, V270, P2487
Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
Mailman MD, 2007, NAT GENET, V39, P1181
Malin B, 2004, J BIOMED INFORM, V37, P179, DOI 10.1016/j.jbi.2004.04.005
Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
Manolio TA, 2009, PHARMACOGENOMICS, V10, P235, DOI 10.2217/14622416.10.2.235
National Institutes of Health, 2003, NOTOD03032 NIH
Ness RB, 2007, JAMA-J AM MED ASSOC, V298, P2164, DOI 10.1001/jama.298.18.2164

```
   *NIH, NOTOD07088 NIH
   Ohm P, 2010, UCLA LAW REV, V57, P1701
   Ohno-Machado L, 2004, INT J MED INFORM, V73, P599, DOI
10.1016/j.ijmedinf.2004.05.002
   Ohrn A, 1999, ARTIF INTELL MED, V15, P235, DOI 10.1016/S0933-3657(98)00056-6
   Reiter JR, 2005, J R STAT SOC A STAT, V168, P185, DOI 10.1111/j.1467-
985X.2004.00343.x
   Roden DM, 2008, CLIN PHARMACOL THER, V84, P362, DOI 10.1038/clpt.2008.89
   RUDOLPH P, 2006, J PUBLIC HEALTH MAN, V12, P176
   Safran C, 2007, J AM MED INFORM ASSN, V14, P1, DOI 10.1197/jamia.M2273
   Sankararaman S, 2009, NAT GENET, V41, P965, DOI 10.1038/ng.436
   Skinner CJ, 2002, J ROY STAT SOC B, V64, P855, DOI 10.1111/1467-9868.00365
   Sparks R, 2008, COMPUT METH PROG BIO, V91, P208, DOI
10.1016/j.cmpb.2008.04.001
   Sweeney L, 1997, J LAW MED ETHICS, V25, P98, DOI 10.1111/j.1748-
720X.1997.tb01885.x
   Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI
10.1142/S0218488502001648
   SWEENEY L, 2000, LIDAPWP4 C MELL U DA
   TRUTA TM, 2003, P 15 INT C SCI STAT, P15
   2000, FED REG, V65, P82462
   VANDERBILT DEMOGRAPH
NR 40
TC 37
Z9 38
U1 1
U2 18
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD JAN
PY 2011
VL 18
IS 1
BP 3
EP 10
DI 10.1136/jamia.2010.004622
PG 8
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA 746BZ
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OA Bronze, Green Published
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AU Craft, D
   Bangert, M
   Long, T
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Papp, D
Unkelbach, J
AF Craft, David
Bangert, Mark
Long, Troy
Papp, David
Unkelbach, Jan
TI Shared data for intensity modulated radiation therapy (IMRT) optimization research: the CORT dataset
SO GIGASCIENCE
LA English
DT Article
DE IMRT; Optimization; Radiation therapy; Beam angle optimization; VMAT; Treatment plan optimization
ID DIRECT APERTURE OPTIMIZATION; BEAM ANGLE; ARC THERAPY; PENCIL BEAM; GENERATION; RADIOTHERAPY; NUMBER; PLANS

AB Background: We provide common datasets (which we call the CORT dataset: common optimization for radiation therapy) that researchers can use when developing and contrasting radiation treatment planning optimization algorithms. The datasets allow researchers to make one-to-one comparisons of algorithms in order to solve various instances of the radiation therapy treatment planning problem in intensity modulated radiation therapy (IMRT), including beam angle optimization, volumetric modulated arc therapy and direct aperture optimization.

Results: We provide datasets for a prostate case, a liver case, a head and neck case, and a standard IMRT phantom. We provide the dose-influence matrix from a variety of beam/couch angle pairs for each dataset. The dose-influence matrix is the main entity needed to perform optimizations: it contains the dose to each patient voxel from each pencil beam. In addition, the original Digital Imaging and Communications in Medicine (DICOM) computed tomography (CT) scan, as well as the DICOM structure file, are provided for each case.

Conclusions: Here we present an open dataset - the first of its kind - to the radiation oncology community, which will allow researchers to compare methods for optimizing radiation dose delivery.

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CR AHNESJO A, 1992, MED PHYS, V19, P263, DOI 10.1118/1.596856
Alber M, 2000, PHYS MED BIOL, V45, P49
Bangert M, 2012, PHYS MED BIOL, V57, P6707, DOI 10.1088/0031-9155/57/20/6707
Bokrantz R, 2012, MED PHYS, V39, P6712, DOI 10.1118/1.4754652
Breedveld S, 2006, PHYS MED BIOL, V51, P3569, DOI 10.1088/0031-9155/51/14/019
Breedveld S, 2012, MED PHYS, V39, P951, DOI 10.1118/1.3676689
Bzdusek K, 2009, MED PHYS, V36, P2328, DOI 10.1118/1.3132234
Carlsson F, 2008, MED PHYS, V35, P3828, DOI 10.1118/1.2964096
Cassioli A, 2013, PHYS MED BIOL, V58, P301, DOI 10.1088/0031-9155/58/2/301
Craft D., 2007, PHYS MED BIOL, V52, P127
Craft D, 2014, GIGASCIENCE DATABASE
Craft D, 2007, INT J RADIAT ONCOL, V67, P1596, DOI 10.1016/j.ijrobp.2006.11.034
Craft D, 2012, MED PHYS, V39, P686, DOI 10.1118/1.3675601
Deasy JO, 2003, MED PHYS, V30, P979, DOI 10.1118/1.1568978
Ezzell GA, 2009, MED PHYS, V36, P5359, DOI 10.1118/1.3238104
Hardemark B, 2003, DIRECT MACHINE PARAM

Jelen U, 2005, PHYS MED BIOL, V50, P1747, DOI 10.1088/0031-9155/50/8/009
Kalinin E, 2003, MED PHYS, V30, P1348
Khan F, 2014, PRACT RAD ONCOL
Men C, 2007, PHYS MED BIOL, V52, P7333, DOI 10.1088/0031-9155/52/24/009
Meng B, 2010, PHYS MED BIOL, V55, P521
Oelfke U, 2001, Med Dosim, V26, P113, DOI 10.1016/S0958-3947(01)00057-7
Otto K, 2008, MED PHYS, V35, P310, DOI 10.1118/1.2818738
Papp D, 2014, MED PHYS, V41, DOI 10.1118/1.4835435
Romeijn HE, 2005, SIAM J OPTIMIZ, V15, P838, DOI 10.1137/040606612
Salari E, 2013, PHYS MED BIOL, V58, P621, DOI 10.1088/0031-9155/58/3/621
Shepard DM, 2002, MED PHYS, V29, P1007, DOI 10.1118/1.1477415
Wang XC, 2004, INT J RADIAT ONCOL, V60, P1325, DOI
10.1016/j.ijrobp.2004.06.007
Webb S, 2001, PHYS MED BIOL, V46, P187
Yarmand H, 2013, PHYS MED BIOL, V58, P5931, DOI 10.1088/0031-9155/58/17/5931
Yu C, 2011, PHYS MED BIOL, V56, P31
NR 31
TC 36
Z9 36
U1 0
U2 2
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
EI 2047-217X
J9 GIGASCIENCE
JI GigaScience
PD DEC 12
PY 2014
VL 3
AR 37
DI 10.1186/2047-217X-3-37
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WC Biology; Multidisciplinary Sciences
SC Life Sciences & Biomedicine - Other Topics; Science & Technology - Other Topics
GA CX4HI
UT WOS:000365659600001
PM 25678961
OA DOAJ Gold, Green Published
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PT J
AU Haski-Leventhal, D
AF Haski-Leventhal, Debbie
TI Elderly Volunteering and Well-Being: A Cross-European Comparison Based on SHARE Data
SO VOLUNTAS
LA English
DT Article
DE Volunteering; Elderly; Well-being; Europe; SHARE
AB This paper, based on Survey of Health, Ageing and Retirement in Europe (SHARE) data, analyzes the relation between volunteering and well-being among 30,023 Europeans aged 50 and above in 12 countries. There is an overall positive correlation between volunteering and perceived health, life satisfaction, and self-life expectancy and a negative correlation to depression. However, in some countries the correlation is much stronger than in others.

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CR ABURAYYA HM, 2006, INTERNET J HLTH, V5, P8
Anheier HK, 1999, LAW CONTEMP PROBL, V62, P43, DOI [DOI 10.2307/1192266, 10.2307/1192266]
Aquino JA, 1996, J COUNS PSYCHOL, V43, P480, DOI 10.1037/0022-0167.43.4.480
ATCHLEY RC, 1989, GERONTOLOGIST, V29, P183, DOI 10.1093/geront/29.2.183
ATCHLEY RC, 1971, GERONTOLOGIST, V11, P13, DOI 10.1093/geront/11.1_Part_1.13
Bowen DJ, 2000, J APPL SOC PSYCHOL, V30, P1829, DOI 10.1111/j.1559-1816.2000.tb02470.x
Caro F. G., 1993, ACHIEVING PRODUCTIVE, P3
Clary EG, 1996, NONPROF VOLUNT SEC Q, V25, P485, DOI 10.1177/0899764096254006
Cnaan RA, 1999, J SOC SERV RES, V24, P1
Cumming E, 1961, GROWING OLD PROCESS
Demura Shinichi, 2003, Journal of Physiological Anthropology and Applied Human Science, V22, P159, DOI 10.2114/jpa.22.159
Erlinghagen M, 2006, AGEING SOC, V26, P567, DOI 10.1017/S0144686X06004818
Greenfield E. A., 2004, J GERONTOL B-PSYCHOL, V59, P258, DOI DOI 10.1093/GERONB/59.5.S258
Handy F., 2000, VOLUNTAS, V11, P45, DOI DOI 10.1023/A:1008903032393
Havighurst RJ, 1963, PROCESS AGING, P299
HERZOG AR, 1992, RES AGING, V14, P169, DOI 10.1177/0164027592142002
*IND SECT, 1998, AM SEN VOL
Independent Sector, 2001, GIV VOL US
Kovacs PJ, 1999, J GERONTOL SOC WORK, V32, P25
Kwong Kam P., 1996, COMMUNITY DEV J, V31, P230
Lum TY, 2005, RES AGING, V27, P31, DOI 10.1177/0164027504271349
LYONS M, 1996, NONPROFIT SECTOR CIV
Meijs L. C., 2003, VALUES VOLUNTEERING, P19
MOEN P, 1995, J HEALTH SOC BEHAV, V36, P259, DOI 10.2307/2137342
Morrow-Howell N., 2003, J GERONTOL B-PSYCHOL, V58, P137, DOI DOI 10.1093/GER0NB/58.3.S137
MORROWHOWELL N, 1989, J GERONTOL SOC WORK, V13, P21, DOI 10.1300/J083V13N03_03
Mostyn B., 1983, VOLUNTEERS PATTERNS, P24
Musick MA, 2003, SOC SCI MED, V56, P259, DOI 10.1016/S0277-9536(02)00025-4
Musick MA, 1999, J GERONTOL B-PSYCHOL, V54, P173, DOI DOI 10.1093/GERONB/54B.3.S173
Okun MA, 1998, PSYCHOL AGING, V13, P608, DOI 10.1037/0882-7974.13.4.608
Oman D, 1999, J Health Psychol, V4, P301, DOI 10.1177/135910539900400301
Pearce J. L, 1993, VOLUNTEERS ORG BEHAV
Putnam R., 2000, BOWLING ALONE COLLAP
SALAMON LM, 1998, VOLUNTAS, V9, P213, DOI DOI 10.1023/A:1022058200985
SMITH DH, 1994, NONPROF VOLUNT SEC Q, V23, P243, DOI 10.1177/089976409402300305
Thoits PA, 2001, J HEALTH SOC BEHAV, V42, P115, DOI 10.2307/3090173
Van Willigen M., 2000, J GERONTOL B-PSYCHOL, V55, P308, DOI DOI 10.1093/GERONB/55.5.S308
Wahrendorf Morten, 2006, Eur J Ageing, V3, P67, DOI 10.1007/s10433-006-0028-y
Wilson J, 1998, SOC SCI QUART, V79, P799
Wilson J, 2000, ANNU REV SOCIOL, V26, P215, DOI 10.1146/annurev.soc.26.1.215
WILSON J, 1999, LAW CONT PROBLEMS, V0062
Zrinscak S, 2008, VOLUNTAS, V19, P1, DOI [10.1007/s11266-008-9052-1, DOI 10.1007/S11266-008-9052-1]

```
NR 42
TC 36
Z9 36
U1 1
U2 23
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0957-8765
J9 VOLUNTAS
JI Voluntas
PD DEC
PY 2009
VL 20
IS 4
BP 388
EP 404
DI 10.1007/s11266-009-9096-x
PG 17
WC Social Issues
SC Social Issues
GA V17JT
UT WOS:000207934200004
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PT J
AU Pollack, CE
   Weissman, GE
   Lemke, KW
   Hussey, PS
   Weiner, JP
AF Pollack, Craig Evan
   Weissman, Gary E.
   Lemke, Klaus W.
   Hussey, Peter S.
   Weiner, Jonathan P.
TI Patient Sharing Among Physicians and Costs of Care: A Network Analytic
   Approach to Care Coordination Using Claims Data
SO JOURNAL OF GENERAL INTERNAL MEDICINE
LA English
DT Article
DE care coordination; performance measure; provider social networks; care
   density
ID HEALTH-CARE; ADMINISTRATIVE DATA; PERFORMANCE; CONTINUITY; MEDICARE;
   SYSTEM; PAY; COMMUNICATION; SPECIALISTS; DELIVERY
AB Improving care coordination is a national priority and a key focus of health
care reforms. However, its measurement and ultimate achievement is challenging.
   To test whether patients whose providers frequently share patients with one
another-what we term 'care density'aEuro"tend to have lower costs of care and
likelihood of hospitalization.
   Cohort study
   9,596 patients with congestive heart failure (CHF) and 52,688 with diabetes
who received care during 2009. Patients were enrolled in five large, private
insurance plans across the US covering employer-sponsored and Medicare Advantage
enrollees
   Costs of care, rates of hospitalizations
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The average total annual health care cost for patients with CHF was $29,456, and $14,921 for those with diabetes. In risk adjusted analyses, patients with the highest tertile of care density, indicating the highest level of overlap among a patient's providers, had lower total costs compared to patients in the lowest tertile ($3,310 lower for CHF and $1,502 lower for diabetes, p < 0.001). Lower inpatient costs and rates of hospitalization were found for patients with CHF and diabetes with the highest care density. Additionally, lower outpatient costs and higher pharmacy costs were found for patients with diabetes with the highest care density.

Patients treated by sets of physicians who share high numbers of patients tend to have lower costs. Future work is necessary to validate care density as a tool to evaluate care coordination and track the performance of health care systems.

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FU NIH National Cancer Institute; Office of Behavioral and Social Sciences Research [1K07CA151910-01A1]
FX Dr. Pollack's salary was supported by a career development award from the NIH National Cancer Institute and Office of Behavioral and Social Sciences Research (1K07CA151910-01A1). The funders had no role in the design and conduct off the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

CR [Anonymous], 2009, J HOPKINS ACG SYSTEM
[Anonymous], 2010, 2010 NATL HEALTHCARE
[Anonymous], 2011, REP C NAT STRAT QUAL
Barnett ML, 2011, HEALTH SERV RES, V46, P1592, DOI 10.1111/j.1475-6773.2011.01262.x
BICE TW, 1977, MED CARE, V15, P347, DOI 10.1097/00005650-197704000-00010
Bynum JPW, 2007, HEALTH SERV RES, V42, P45, DOI 10.1111/j.1475-6773.2006.00633.x
Chen AH, 2010, HEALTH AFFAIR, V29, P969, DOI 10.1377/hlthaff.2010.0027
Csardi G, 2006, INT C COMPL SYST 200
Fisher ES, 2009, HEALTH AFFAIR, V28, pW219, DOI 10.1377/hlthaff.28.2.w219
Foy R, 2010, ANN INTERN MED, V152, P247, DOI 10.7326/0003-4819-152-4-201002160-00010
Haggerty JL, 2003, BRIT MED J, V327, P1219, DOI 10.1136/bmj.327.7425.1219
*I MED, 2003, PRIOR AR NAT ACT TRA
Iezzoni LI, 1997, ANN INTERN MED, V127, P666, DOI 10.7326/0003-4819-127-8_Part_2-199710151-00048
Jee SH, 2006, MED CARE RES REV, V63, P158, DOI 10.1177/1077558705285294
Kim Y, 2009, J GEN INTERN MED, V24, P614, DOI 10.1007/s11606-009-0955-3
Liebhaber A, 2007, PHYS MOVING MIDSIZED
Luke DA, 2007, ANNU REV PUBL HEALTH, V28, P69, DOI 10.1146/annurev.publhealth.28.021406.144132
McDonald K, 2011, CARE COORDINATION ME
Miller HD, 2009, HEALTH AFFAIR, V28, P1418, DOI 10.1377/hlthaff.28.5.1418
National Priorities Partnership, 2008, NAT PRIOR GOALS AL O
National Quality Forum, NQF END DEF FRAM MEA
O'Malley AS, 2011, ARCH INTERN MED, V171, P56, DOI 10.1001/archinternmed.2010.480

Pham HH, 2007, NEW ENGL J MED, V356, P1130, DOI 10.1056/NEJMsa063979
Pham HH, 2009, ANN INTERN MED, V150, P236, DOI 10.7326/0003-4819-150-4-200902170-00004
Rittenhouse DR, 2009, NEW ENGL J MED, V361, P2301, DOI 10.1056/NEJMp0909327
Rosenthal MB, 2008, NEW ENGL J MED, V359, P1197, DOI 10.1056/NEJMp0804658
Saultz John W, 2003, Ann Fam Med, V1, P134, DOI 10.1370/afm.23
Singer SJ, 2011, MED CARE RES REV, V68, P112, DOI 10.1177/1077558710371485
Smith KP, 2008, ANNU REV SOCIOL, V34, P405, DOI 10.1146/annurev.soc.34.040507.134601
Starfield B, 2005, MILBANK Q, V83, P457, DOI 10.1111/j.1468-0009.2005.00409.x
Wasserman S., 1999, SOCIAL NETWORK ANAL
WEINER JP, 1991, MED CARE, V29, P452, DOI 10.1097/00005650-199105000-00006
NR 32
TC 35
Z9 35
U1 0
U2 20
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0884-8734
J9 J GEN INTERN MED
JI J. Gen. Intern. Med.
PD MAR
PY 2013
VL 28
IS 3
BP 459
EP 465
DI 10.1007/s11606-012-2104-7
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WC Health Care Sciences & Services; Medicine, General & Internal
SC Health Care Sciences & Services; General & Internal Medicine
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PM 22696255
OA Green Published
DA 2019-08-06
ER

PT J
AU Foster, MW
Sharp, RR
AF Foster, Morris W.
Sharp, Richard R.
TI Share and share alike: deciding how to distribute the scientific and social benefits of genomic data
SO NATURE REVIEWS GENETICS
LA English
DT Review
ID GENETIC RESEARCH; MEDICINE; PRIVACY; PATENTS; POLICY; LEGAL; US

AB Emerging technologies make genomic analyses more efficient and less expensive, enabling genome-wide association and gene-environment interaction studies. In anticipation of their results, funding agencies such as the US National Institutes of Health and the Wellcome Trust are formulating guidelines for sharing the large amounts of genomic data that are generated by the projects that they sponsor. Data-sharing policies can have varying implications for how disease susceptibility and drug-response research will be pursued by the

scientific community, and for who will benefit from the resulting medical discoveries. We suggest that the complex interplay of stakeholders and their interests, rather than single-issue and single-stakeholder perspectives, should be considered when deciding genomic data-sharing policies.
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CR Bennett ST, 2005, PHARMACOGENOMICS, V6, P373, DOI 10.1517/14622416.6.4.373
   Blumenthal D, 2006, ACAD MED, V81, P137, DOI 10.1097/00001888-200602000-00008
   Bookman EB, 2006, AM J MED GENET A, V140A, P1033, DOI 10.1002/ajmg.a.31195
   Botkin JR, 2001, JAMA-J AM MED ASSOC, V285, P207, DOI 10.1001/jama.285.2.207
   Boughman JA, 2007, AM J HUM GENET, V80, P581, DOI 10.1086/512166
   Cahill LS, 2001, KENNEDY INST ETHIC J, V11, P221, DOI 10.1353/ken.2001.0020
   Caulfield T, 2006, NAT BIOTECHNOL, V24, P1091, DOI 10.1038/nbt0906-1091
   Cho MK, 2004, NAT GENET, V36, pS8, DOI 10.1038/ng1434
   Clayton EW, 2003, NEW ENGL J MED, V349, P562, DOI 10.1056/NEJMra012577
   Foster MW, 2004, NAT REV GENET, V5, P790, DOI 10.1038/nrg1452
   Foster MW, 2000, TRENDS GENET, V16, P93, DOI 10.1016/S0168-9525(99)01895-8
   *GEN ALL, COMM NIH RESP THEIR
   Haddow G, 2007, SOC SCI MED, V64, P272, DOI 10.1016/j.socscimed.2006.08.028
   Heller MA, 1998, SCIENCE, V280, P698, DOI 10.1126/science.280.5364.698
   *INT GEN EP SOC, 2006, POS STAT INT GEN EP
   Kohane IS, 2006, JAMA-J AM MED ASSOC, V296, P212, DOI 10.1001/jama.296.2.212
   Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
   Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
   Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
   McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
   McGuire AL, 2006, J LAW MED ETHICS, V34, P809, DOI 10.1111/j.1748-720X.2006.00100.x
   Merz JF, 2002, AM J HUM GENET, V70, P965, DOI 10.1086/339767
   National Human Genome Research Institute, REAFF EXT NHGRI RAP
   Nelson RR, 2004, RES POLICY, V33, P455, DOI 10.1016/j.respol.2003.09.008
   *NIH, REQ INF RFI PROP POL
   Nisker J, 2006, PUBLIC UNDERST SCI, V15, P113, DOI 10.1177/0963662506053738
   Pressman L, 2006, NAT BIOTECHNOL, V24, P31, DOI 10.1038/nbt0106-31
   Rabino I, 2006, NEW GENET SOC, V25, P325, DOI 10.1080/14636770601032957
   Ravitsky V, 2006, AM J BIOETHICS, V6, P8, DOI 10.1080/15265160600934772
   Resnik DB, 1997, KENNEDY INST ETHIC J, V7, P43, DOI 10.1353/ken.1997.0008
   Sharp RR, 2004, NAT REV GENET, V5, P311, DOI 10.1038/nrg1320
   Terry SF, 2007, NAT REV GENET, V8, P157, DOI 10.1038/nrg1991
   The Wellcome Trust, SHAR DAT LARG SCAL B
   Tutton R, 2007, SCI TECHNOL HUM VAL, V32, P172, DOI 10.1177/0162243906296853
   *US DEP HHS, DOES HIPAA PRIV RULE
   WEIR RF, 1994, STORED TISSUE ISSUE
   Whitfield KE, 2003, J NATL MED ASSOC, V95, P539
   Williams G, 2004, NEW GENET SOC, V23, P89, DOI 10.1080/1463677042000189598
NR 38
TC 34
Z9 35
U1 0
U2 14
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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J9 NAT REV GENET
JI Nat. Rev. Genet.
PD AUG
PY 2007
VL 8
IS 8
BP 633
EP U8
DI 10.1038/nrg2124
PG 7
WC Genetics & Heredity
SC Genetics & Heredity
GA 191ZO
UT WOS:000248170700017
PM 17607307
DA 2019-08-06
ER

PT J
AU Zhu, YL
   Wang, AT
   Liu, MC
   Zwart, A
   Lee, RY
   Gallagher, A
   Wang, Y
   Miller, WR
   Dixon, JM
   Clarke, R
AF Zhu, Yuelin
   Wang, Antai
   Liu, Minetta C.
   Zwart, Alan
   Lee, Richard Y.
   Gallagher, Ann
   Wang, Yue
   Miller, William R.
   Dixon, J. Michael
   Clarke, Robert
TI Estrogen receptor alpha positive breast tumors and breast cancer cell
   lines share similarities in their transcriptome data structures
SO INTERNATIONAL JOURNAL OF ONCOLOGY
LA English
DT Article
DE breast cancer; bioinformatics; cell lines; data structure; genomics;
   microarray analysis; principal component analysis
ID FACTOR-KAPPA-B; GENE-EXPRESSION PATTERNS; REGULATORY-FACTOR-I;
   ORNITHINE-DECARBOXYLASE; MOLECULAR PHARMACOLOGY; GROWTH; MODELS; MICE;
   NUCLEOPHOSMIN; ICI-182,780
AB Established human breast cancer cell lines are widely used as experimental
models in breast cancer research. While these cell lines and their variants
share many phenotypic characteristics with human breast tumors, the extent to
which they reflect the underlying molecular biology of breast cancer remains
controversial. We explored this issue using a probabilistic rather than
heuristic approach. Data from gene expression microarrays were used to compare
the global structures of the transcriptomes of three estrogen receptor alpha
positive (ER+) human breast cancer cell lines (MCF-7, T47D, ZR-75-1) and 13
human breast tumors (11ER(+); 2ER(-)). Linear representations of the respective
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data structures were obtained by deriving those top principal components (PCs) required to capture >= 80% of the cumulative variance for each data set (M PCs). We then identified those genes most highly correlated with the M PCs (Pearson's correlation coefficient r >= 0.800) and identified a group of 36 genes commonly correlated with both the cell line (M = 5 PCs) and tumor (M = 6 PCs) data structures. All 36 common genes were correlated with PC1 from the breast tumor data: 21/36 genes were correlated with PC1, 14/36 genes correlated with PC2, and 1/36 genes correlated with PC3 from the cell line data. Genes important in defining the data structures include NF kappa B p65, IGFBP-6, ornithine decarboxylase-1, and paxillin. When data from MDA-MB-435 xenografts (ER-) were included in the analysis, we were unable to find any common genes between these xenografts and the breast tumors. These data clearly imply that MCF-7, T47D, and ZR-75-1 cells and ER+ breast tumors share substantial global similarities in the structures of their respective transcriptomes, and that these cell lines are good models in which to identify molecular events that are likely to be important in some ER+ human breast cancers.

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OI Clarke, Robert/0000-0002-9278-0854

FU NCI NIH HHS [R01-CA096483, P30-CA51008-14]

CR Alizadeh AA, 2000, NATURE, V403, P503, DOI 10.1038/35000501
Bach LA, 2005, GROWTH HORM IGF RES, V15, P185, DOI 10.1016/j.ghir.2005.04.001
Burdall SE, 2003, BREAST CANCER RES, V5, P89, DOI 10.1186/bcr577
CARTER CL, 1989, CANCER-AM CANCER SOC, V63, P181, DOI 10.1002/1097-0142(19890101)63:1<181::AID-CNCR2820630129>3.0.CO;2-H
CERIANI RL, 1992, IN VITRO CELL DEV-AN, V28A, P397
Clarke R, 1996, BREAST CANCER RES TR, V39, P69, DOI 10.1007/BF01806079
Clarke R, 2001, PHARMACOL REV, V53, P25
CLARKE R, 1992, CRIT REV ONCOL HEMAT, V12, P1, DOI 10.1016/1040-8428(92)90062-U
Ellis M, 2002, CLIN CANCER RES, V8, P1155
FISHER B, 1983, CANCER-AM CANCER SOC, V52, P1551, DOI 10.1002/1097-0142(19831101)52:9<1551::AID-CNCR2820520902>3.0.CO;2-3
Gu ZP, 2002, CANCER RES, V62, P3428
Guvakova MA, 1999, EXP CELL RES, V251, P244, DOI 10.1006/excr.1999.4566
Hahn WC, 2002, NAT REV CANCER, V2, P331, DOI 10.1038/nrc795
Hinneburg A, 1999, PROCEEDINGS OF THE TWENTY-FIFTH INTERNATIONAL CONFERENCE ON VERY LARGE DATA BASES, P506
Hotelling H, 1933, J EDUC PSYCHOL, V24, P498, DOI 10.1037/h0070888
James MR, 2001, ENDOCRINOLOGY, V142, P1497, DOI 10.1210/en.142.4.1497
Jolliffe I. T., 2002, PRINCIPAL COMPONENT
Kaulsay KK, 1999, EUR J ENDOCRINOL, V140, P164, DOI 10.1530/eje.0.1400164
Lacroix M, 2004, BREAST CANCER RES TR, V83, P249, DOI 10.1023/B:BREA.0000014042.54925.cc
Manni A, 2004, CLIN EXP METASTAS, V21, P461, DOI 10.1007/s10585-004-2724-3
Manni A, 2002, IN VIVO, V16, P493
Mimori K, 1998, INT J ONCOL, V12, P597

```
   Nakshatri H, 1997, MOL CELL BIOL, V17, P3629, DOI 10.1128/MCB.17.7.3629
   Osipo C, 2003, J NATL CANCER I, V95, P1597, DOI 10.1093/jnci/djg079
   Pawitan Y, 2005, BREAST CANCER RES, V7, pR953, DOI 10.1186/bcr1325
   Pratt MAC, 2003, MOL CELL BIOL, V23, P6887, DOI 10.1128/MCB.23.19.6887-
6900.2003
   PRICE JE, 1990, CANCER RES, V50, P717
   Qin CH, 2004, MOL CARCINOGEN, V40, P160, DOI 10.1002/mc.20030
   Rae JM, 2004, CLIN EXP METASTAS, V21, P543, DOI 10.1007/s10585-004-3759-1
   Rangarajan A, 2004, CANCER CELL, V6, P171, DOI 10.1016/j.ccr.2004.07.009
   Rangarajan A, 2003, NAT REV CANCER, V3, P952, DOI 10.1038/nrc1235
   Riggins RB, 2005, MOL CANCER THER, V4, P33
   Ross DT, 2000, NAT GENET, V24, P227, DOI 10.1038/73432
   Ross DT, 2001, DIS MARKERS, V17, P99, DOI 10.1155/2001/850531
   Sachdev D, 2001, ENDOCR-RELAT CANCER, V8, P197, DOI 10.1677/erc.0.0080197
   Satagopan JM, 2003, STAT MED, V22, P481, DOI 10.1002/sim.1350
   Scherf U, 2000, NAT GENET, V24, P236, DOI 10.1038/73439
   Sgroi DC, 1999, CANCER RES, V59, P5656
   Thykjaer T, 2001, CANCER RES, V61, P2492
   Van't Veer LJ, 2003, NAT MED, V9, P999, DOI 10.1038/nm0803-999b
   van't Veer LJ, 2002, NATURE, V415, P530, DOI 10.1038/415530a
   Wittes J, 1999, J NATL CANCER I, V91, P400, DOI 10.1093/jnci/91.5.400
   Zhu YL, 2006, INT J ONCOL, V28, P67
NR 43
TC 34
Z9 36
U1 0
U2 3
PU PROFESSOR D A SPANDIDOS
PI ATHENS
PA 1, S MERKOURI ST, EDITORIAL OFFICE,, ATHENS 116 35, GREECE
SN 1019-6439
J9 INT J ONCOL
JI Int. J. Oncol.
PD DEC
PY 2006
VL 29
IS 6
BP 1581
EP 1589
PG 9
WC Oncology
SC Oncology
GA 109MK
UT WOS:000242312100030
PM 17089000
DA 2019-08-06
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PT J
AU Roelofs, E
   Dekker, A
   Meldolesi, E
   van Stiphout, RGPM
   Valentini, V
   Lambin, P
AF Roelofs, Erik
   Dekker, Andre
   Meldolesi, Elisa
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van Stiphout, Ruud G. P. M.
Valentini, Vincenzo
Lambin, Philippe
TI International data-sharing for radiotherapy research: An open-source
based infrastructure for multicentric clinical data mining
SO RADIOTHERAPY AND ONCOLOGY
LA English
DT Article
DE Medical informatics; Knowledge engineering; Machine learning; Data
mining; Open source software
ID LUNG-CANCER PATIENTS; DECISION-SUPPORT-SYSTEMS; EXTERNAL VALIDATION;
PROGNOSTIC MODEL; ONCOLOGY TRIALS; RECTAL-CANCER; RADIATION; SURVIVAL;
PREDICTION; CARE

AB Extensive, multifactorial data sharing is a crucial prerequisite for current and future (radiotherapy) research. However, the cost, time and effort to achieve this are often a roadblock. We present an open-source based data-sharing infrastructure between two radiotherapy departments, allowing seamless exchange of de-identified, automatically translated clinical and biomedical treatment data. (C) 2013 Elsevier Ireland Ltd. All rights reserved.

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FU QuIC-ConCePT project; EFPI; Innovative Medicine Initiative Joint
Undertaking (IMI JU) [115151]; National Institutes of Health [NIH-USA
U01 CA 143062-01]; CTMM framework (AIRFORCE project) [030-103]; EU;
euroCAT (IVA Interreg); NGI [93612005]; Kankeronderzoekfonds Limburg
from the Health Foundation Limburg; Dutch Cancer Society [KWF UM
2008-4210, KWF UM 2011-5020]
FX Authors acknowledge financial support from the QuIC-ConCePT project,
which is partly funded by EFPI A companies and the Innovative Medicine
Initiative Joint Undertaking (IMI JU) under Grant Agreement No. 115151.
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framework (AIRFORCE project, Grant 030-103), EU 6th and 7th framework
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Pre-Seed Grant (no 93612005), Kankeronderzoekfonds Limburg from the
Health Foundation Limburg and the Dutch Cancer Society (KWF UM
2008-4210, KWF UM 2011-5020).

CR Abernethy AP, 2010, J CLIN ONCOL, V28, P4268, DOI 10.1200/JCO.2010.28.5478
Boulton G, 2011, LANCET, V377, P1633, DOI 10.1016/S0140-6736(11)60647-8
Buetow KH, 2009, DRUG DISCOV TODAY, V14, P605, DOI 10.1016/j.drudis.2009.03.011
Deasy JO, 2010, INT J RADIAT ONCOL, V76, pS151, DOI 10.1016/j.ijrobp.2009.06.094
Dehing-Oberije C, 2011, INT J RADIAT ONCOL, V81, P360, DOI 10.1016/j.ijrobp.2010.06.011
Dehing-Oberije C, 2010, RADIOTHER ONCOL, V97, P455, DOI 10.1016/j.radonc.2010.09.028
Dehing-Oberije C, 2009, INT J RADIAT ONCOL, V74, P355, DOI 10.1016/j.ijrobp.2008.08.052

```
   Egelmeer AGTM, 2011, RADIOTHER ONCOL, V100, P108, DOI
10.1016/j.radonc.2011.06.023
   European Medicines Agency, 2013, INSP GOOD CLIN PRACT
   Grand MM, 2012, J MED IMAG RADIAT ON, V56, P31, DOI 10.1111/j.1754-
9485.2011.02337.x
   International Health Terminology Standards Development Organization, SNOMED
CLIN TERMS SN
   Janssen MHM, 2010, INT J RADIAT ONCOL, V77, P392, DOI
10.1016/j.ijrobp.2009.04.030
   Lambin P, 2013, RADIOTHER ONCOL, V109, P159, DOI 10.1016/j.radonc.2013.07.007
   Lambin P, 2013, NAT REV CLIN ONCOL, V10, P27, DOI 10.1038/nrclinonc.2012.196
   Lambin P, 2012, EUR J CANCER, V48, P441, DOI 10.1016/j.ejca.2011.11.036
   Lambin P, 2010, RADIOTHER ONCOL, V96, P145, DOI 10.1016/j.radonc.2010.07.001
   Langella S, 2007, AMIA ANN S P, V2007, P433
   Movsas B, 2007, INT J RADIAT ONCOL, V68, P1145, DOI
10.1016/j.ijrobp.2007.01.051
   Murthy VH, 2004, JAMA-J AM MED ASSOC, V291, P2720, DOI
10.1001/jama.291.22.2720
   Oilers M, 2008, RADIOTHER ONCOL, V87, P142
   Oster S, 2008, J AM MED INFORM ASSN, V15, P138, DOI 10.1197/jamia.M2522
   Peters LJ, 2010, J CLIN ONCOL, V28, P2996, DOI 10.1200/JCO.2009.27.4498
   Roelofs E, 2013, RADIOTHER ONCOL, V108, P174, DOI
10.1016/j.radonc.2012.09.019
   Roelofs E, 2010, RADIOTHER ONCOL, V97, P567, DOI 10.1016/j.radonc.2010.08.009
   Valentini V, 2012, RADIOTHER ONCOL, V102, P1, DOI
10.1016/j.radonc.2011.12.001
   Valentini V, 2011, J CLIN ONCOL, V29, P3163, DOI 10.1200/JCO.2010.33.1595
   van Stiphout RGPM, 2011, RADIOTHER ONCOL, V98, P126, DOI
10.1016/j.radonc.2010.12.002
   Weber DC, 2012, RADIOTHER ONCOL, V105, P4, DOI 10.1016/j.radonc.2012.08.008
   Weber DC, 2011, RADIOTHER ONCOL, V100, P150, DOI 10.1016/j.radonc.2011.05.073
NR 29
TC 33
Z9 36
U1 2
U2 14
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
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SN 0167-8140
J9 RADIOTHER ONCOL
JI Radiother. Oncol.
PD FEB
PY 2014
VL 110
IS 2
BP 370
EP 374
DI 10.1016/j.radonc.2013.11.001
PG 5
WC Oncology; Radiology, Nuclear Medicine & Medical Imaging
SC Oncology; Radiology, Nuclear Medicine & Medical Imaging
GA AE5EI
UT WOS:000334010200025
PM 24309199
OA Green Accepted
DA 2019-08-06
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PT J
AU Palmateer, N
   Hutchinson, S
   McAllister, G
   Munro, A
   Cameron, S
   Goldberg, D
   Taylor, A
AF Palmateer, N.
   Hutchinson, S.
   McAllister, G.
   Munro, A.
   Cameron, S.
   Goldberg, D.
   Taylor, A.
TI Risk of transmission associated with sharing drug injecting
   paraphernalia: analysis of recent hepatitis C virus (HCV) infection
   using cross-sectional survey data
SO JOURNAL OF VIRAL HEPATITIS
LA English
DT Article
DE cross-sectional; hepatitis C; incidence; injecting paraphernalia;
   needles/syringes
ID DRIED BLOOD SPOTS; HEALTH-CARE WORKERS; PREPARATION EQUIPMENT;
   NATURAL-HISTORY; USERS; SEROCONVERSION; HIV; PREVALENCE; PEOPLE; COHORT
AB Sharing injecting paraphernalia (containers, filters and water) poses a risk of transmitting the hepatitis C virus (HCV). The prevalence of, and risk of HCV from, such behaviour has not been extensively reported in Europe. People who inject drugs (PWID) were recruited in cross-sectional surveys from services providing sterile injecting equipment across Scotland between 2008 and 2010. Participants completed a questionnaire and provided a blood spot for anonymous testing. Logistic regression was used to examine the association between recent HCV infection (anti-HCV negative and HCV-RNA positive) and self-reported measures of injecting equipment sharing in the 6months preceding interview. Twelve per cent of the sample reported sharing needles/syringes, and 40% reported sharing paraphernalia in the previous 6months. The adjusted odds ratios (AOR) for sharing needles/syringes (+/- paraphernalia), and sharing only paraphernalia in the last 6months were 6.7 (95% CI 2.6-17.1) and 3.0 (95% CI 1.2-7.5), respectively. Among those who reported not sharing needles/syringes, sharing containers and filters were both significantly associated with recent HCV infection (AOR 3.1, 95% CI 1.3-7.8 and 3.1, 95% CI 1.3-7.5, respectively); sharing water was not. We present the first study to apply a cross-sectional approach to the analysis of the association between sharing paraphernalia and incident HCV infection and demonstrate consistent results with previous longitudinal studies. The prevalence of paraphernalia sharing in our study population is high, representing significant potential for HCV transmission.
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FU Scottish Government
FX This work was supported by the Scottish Government. The authors are grateful to the following individuals and organizations: the respondents and services that participated in the NESI study; Cheryl Rees, Lauren Johnston, Julie Burza, Donald Falconer, Germana Vitrano and Alex Matheson for collecting the data; and Linda MacDonald, Tony Bimpson, and Samantha Shepherd at the West of Scotland Specialist Virology Centre for carrying out the testing of samples.

CR Allen EJ, 2012, INT J DRUG POLICY, V23, P346, DOI 10.1016/j.drugpo.2012.07.006
Alter MJ, 2007, WORLD J GASTROENTERO, V13, P2436, DOI 10.3748/wjg.v13.i17.2436
Aspinall E, 2012, DRUG ALCOHOL DEPEN, V126, P340, DOI 10.1016/j.drugalcdep.2012.05.041
Bennett S, 2012, J CLIN VIROL, V54, P106, DOI 10.1016/j.jcv.2012.02.004
Brunton C, 2000, NEW ZEAL MED J, V113, P98
COOK EF, 1988, AM J EPIDEMIOL, V127, P626, DOI 10.1093/oxfordjournals.aje.a114838
De P, 2008, J VIRAL HEPATITIS, V15, P279, DOI 10.1111/j.1365-2893.2007.00942.x
Des Jarlais DC, 1999, LANCET, V353, P1657
DiFranceisco W, 1998, AM J PUBLIC HEALTH, V88, P1068, DOI 10.2105/AJPH.88.7.1068
Doerrbecker J, 2013, J INFECT DIS, V207, P281, DOI 10.1093/infdis/jis677
Doerrbecker J, 2011, J INFECT DIS, V204, P1830, DOI 10.1093/infdis/jir535
Folch C, 2012, GAC SANIT, V26, P37, DOI 10.1016/j.gaceta.2011.07.022
GERBERDING JL, 1995, NEW ENGL J MED, V332, P444, DOI 10.1056/NEJM199502163320707
Glynn SA, 2005, TRANSFUSION, V45, P994, DOI 10.1111/j.1537-2995.2005.04390.x
Hagan H, 2001, AM J PUBLIC HEALTH, V91, P42
Hagan H, 2010, J INFECT DIS, V201, P378, DOI 10.1086/649783
Hahn JA, 2002, J INFECT DIS, V186, P1558, DOI 10.1086/345554
Health Protection Agency (HPA) Health Protection Scotland Public Health Wales and Public Health Agency Northern Ireland, 2012, SHOOT INF PEOPL WHO
Hope VD, 2011, J VIRAL HEPATITIS, V18, P262, DOI 10.1111/j.1365-2893.2010.01297.x
HPA, 2012, UNL AN MON SURV PEOP
ISD, 2012, INJ EQ PROV SCOTL SU
Judd A, 2003, J MED VIROL, V71, P49, DOI 10.1002/jmv.10463
Kapadia F, 2002, EPIDEMIOLOGY, V13, P738, DOI 10.1097/01.EDE.0000032363.40442.1
Lucidarme D, 2004, EPIDEMIOL INFECT, V132, P699, DOI 10.1017/S095026880400247X
Maher L., 2012, AUSTR NEEDLE SYRINGE
Maher L, 2006, ADDICTION, V101, P1499, DOI 10.1111/j.1360-0443.2006.01543.x
Metzger DS, 2000, AM J EPIDEMIOL, V152, P99, DOI 10.1093/aje/152.2.99
Netski DM, 2005, CLIN INFECT DIS, V41, P667, DOI 10.1086/432478
Page-Shafer K, 2008, J CLIN MICROBIOL, V46, P499, DOI 10.1128/JCM.01229-07
Palmateer NE, 2013, INT J DRUG POLICY, V24, P85, DOI 10.1016/j.drugpo.2012.08.006
Pouget ER, 2011, ADDICTION, V107, P1057
Rezza G, 1996, SCAND J INFECT DIS, V28, P27, DOI 10.3109/00365549609027145
Roy E, 2007, INT J STD AIDS, V18, P23, DOI 10.1258/095646207779949880
Scottish Government, 2008, HEP C ACT PLAN SCOTL

```
   Scottish Government, 2011, SEX HLTH BLOOD BORN
   Seeff LB, 2009, LIVER INT, V29, P89, DOI 10.1111/j.1478-3231.2008.01927.x
   Taylor A., 2004, EXAMINING INJECTING
   Thibault V, 2011, J INFECT DIS, V204, P1839, DOI 10.1093/infdis/jir650
   Thomson EC, 2011, J GEN VIROL, V92, P2227, DOI 10.1099/vir.0.033910-0
   Thomson EC, 2009, AIDS, V23, P89, DOI 10.1097/QAD.0b013e32831940a3
   Thorpe LE, 2002, AM J EPIDEMIOL, V155, P645, DOI 10.1093/aje/155.7.645
   Tomkins SE, 2012, J VIRAL HEPATITIS, V19, P199, DOI 10.1111/j.1365-
2893.2011.01543.x
   UWS HPS WoSSVC, 2010, NEEDL EXCH SURV IN N
   Yazdanpanah Y, 2005, CLIN INFECT DIS, V41, P1423, DOI 10.1086/497131
   Zule WA, 2009, DRUG ALCOHOL DEPEN, V100, P204, DOI
10.1016/j.drugalcdep.2008.08.017
NR 45
TC 33
Z9 33
U1 1
U2 8
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1352-0504
EI 1365-2893
J9 J VIRAL HEPATITIS
JI J. Viral Hepatitis
PD JAN
PY 2014
VL 21
IS 1
BP 25
EP 32
DI 10.1111/jvh.12117
PG 8
WC Gastroenterology & Hepatology; Infectious Diseases; Virology
SC Gastroenterology & Hepatology; Infectious Diseases; Virology
GA 267WY
UT WOS:000328130200004
PM 24329854
DA 2019-08-06
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PT J
AU Weitzman, ER
   Adida, B
   Kelemen, S
   Mandl, KD
AF Weitzman, Elissa R.
   Adida, Ben
   Kelemen, Skyler
   Mandl, Kenneth D.
TI Sharing Data for Public Health Research by Members of an International
   Online Diabetes Social Network
SO PLOS ONE
LA English
DT Article
ID GLOBAL BURDEN; MEDICINE; OBESITY; POWER
AB Background: Surveillance and response to diabetes may be accelerated through
engaging online diabetes social networks (SNs) in consented research. We tested
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the willingness of an online diabetes community to share data for public health research by providing members with a privacy-preserving social networking software application for rapid temporal-geographic surveillance of glycemic control.

Methods and Findings: SN-mediated collection of cross-sectional, member-reported data from an international online diabetes SN entered into a software applicaction we made available in a "Facebook-like" environment to enable reporting, charting and optional sharing of recent hemoglobin A1c values through a geographic display. Self-enrollment by 17% (n = 1,136) of n = 6,500 active members representing 32 countries and 50 US states. Data were current with 83.1% of most recent A1c values reported obtained within the past 90 days. Sharing was high with 81.4% of users permitting data donation to the community display. 34.1% of users also displayed their A1cs on their SN profile page. Users selecting the most permissive sharing options had a lower average A1c (6.8%) than users not sharing with the community (7.1%, p = .038). 95% of users permitted re-contact. Unadjusted aggregate A1c reported by US users closely resembled aggregate 2007-2008 NHANES estimates (respectively, 6.9% and 6.9%, p = 0.85).

Conclusions: Success within an early adopter community demonstrates that online SNs may comprise efficient platforms for bidirectional communication with and data acquisition from disease populations. Advancing this model for cohort and translational science and for use as a complementary surveillance approach will require understanding of inherent selection and publication (sharing) biases in the data and a technology model that supports autonomy, anonymity and privacy.

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CR Amer Diabet Assoc, 2010, DIABETES CARE, V33, pS11, DOI 10.2337/dc10-S011
Brownstein CA, 2009, NAT BIOTECHNOL, V27, P888, DOI 10.1038/nbt1009-888
Chou WYS, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1249
Christakis NA, 2007, NEW ENGL J MED, V357, P370, DOI 10.1056/NEJMsa066082
Cobb NK, 2010, AM J PUBLIC HEALTH, V100, P1282, DOI 10.2105/AJPH.2009.165449
Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053

```
   Gomez-Perez FJ, 2010, ARCH MED RES, V41, P302, DOI
10.1016/j.arcmed.2010.05.007
   Hammond RA, 2010, CURR OPIN ENDOCRINOL, V17, P467, DOI
10.1097/MED.0b013e32833d4687
   Hand E, 2010, NATURE, V466, P685, DOI 10.1038/466685a
   Heany C. A., 2002, HLTH BEHAV HLTH ED T, P185
   Hernandez M, 2010, COMMUNICATION   1012
   Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
   Kohane IS, 2007, SCIENCE, V316, P836, DOI 10.1126/science.1135489
   Mandl KD, 2007, BMC MED INFORM DECIS, V7, DOI 10.1186/1472-6947-7-25
   Mandl KD, 2008, NEW ENGL J MED, V358, P1732, DOI 10.1056/NEJMsb0800220
   Mercken L, 2009, SOC SCI MED, V69, P1506, DOI 10.1016/j.socscimed.2009.08.003
   Nathan DM, 2005, NEW ENGL J MED, V353, P2643
   Saaddine JB, 2002, ANN INTERN MED, V136, P565, DOI 10.7326/0003-4819-136-8-
200204160-00005
   Saudek CD, 2006, JAMA-J AM MED ASSOC, V295, P1688, DOI
10.1001/jama.295.14.1688
   Shaw JE, 2010, DIABETES RES CLIN PR, V87, P4, DOI
10.1016/j.diabres.2009.10.007
   van Dieren S, 2010, EUR J CARDIOV PREV R, V17, pS3, DOI
10.1097/01.hjr.0000368191.86614.5a
   van Noort S P, 2007, Euro Surveill, V12, pE5
   Vilhauer RP, 2009, WOMEN HEALTH, V49, P381, DOI 10.1080/03630240903238719
   Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
   Weitzman ER, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1187
   Weitzman ER, 2011, J AM MED INFORM ASS
   Wicks P, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1549
   Yach D, 2004, JAMA-J AM MED ASSOC, V291, P2616, DOI 10.1001/jama.291.21.2616
NR 28
TC 33
Z9 33
U1 1
U2 17
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD APR 27
PY 2011
VL 6
IS 4
AR e19256
DI 10.1371/journal.pone.0019256
PG 8
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA 756NO
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PM 21556358
OA DOAJ Gold, Green Published
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ER

PT J
AU Chokshi, DA
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Kwiatkowski, DP
AF Chokshi, Dave A.
Parker, Michael
Kwiatkowski, Dominic P.
TI Data sharing and intellectual property in a genomic epidemiology network: policies for large-scale research collaboration
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Article
ID PLASMODIUM-VIVAX; NEGLECTED DISEASES; HEMOGLOBIN-C; MALARIA; FALCIPARUM; HEALTH

AB Genomic epidemiology is a field of research that seeks to improve the prevention and management of common diseases through an understanding of their molecular origins. It involves studying thousands of individuals, often from different populations, with exacting techniques. The scale and complexity of such research has required the formation of research consortia. Members of these consortia need to agree on policies for managing shared resources and handling genetic data. Here we consider data-sharing and intellectual property policies for an international research consortium working on the genomic epidemiology of malaria. We outline specific guidelines governing how samples and data are transferred among its members; how results are released into the public domain; when to seek protection for intellectual property; and how intellectual property should be managed. We outline some pragmatic solutions founded on the basic principles of promoting innovation and access.

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CR Altshuler D, 2005, NATURE, V437, P1299, DOI 10.1038/nature04226
Arevalo-Herrera M, 2001, MOL IMMUNOL, V38, P443, DOI 10.1016/S0161-5890(01)00080-3
Ashley-Koch A, 2000, AM J EPIDEMIOL, V151, P839
CHITNIS CE, 1994, J EXP MED, V180, P497, DOI 10.1084/jem.180.2.497
Chokshi DA, 2005, NATURE, V435, P143, DOI 10.1038/435143a
CHOKSHI DA, 2005, GENOMICS SOC POLICY, V1, P1
DAVISS B, 2005, SCIENTIST, P42
*DIAB GEN CONS, 2004, T1DGC PUBL PRES POL
Eisenberg RS, 2003, SCIENCE, V299, P1018, DOI 10.1126/science.1081790
Fairhurst RM, 2005, NATURE, V435, P1117, DOI 10.1038/nature03631
GARDNER C, 2004, TECHNOLOGY LICENSING
*GAT FDN, 2005, GLOB ACC STRAT IP MA
Ghedin E, 2005, NATURE, V437, P1162, DOI 10.1038/nature04239
Kapczynski A., 2005, BERKELEY TECHNOLOGY, V20, P1031
MERZ JF, 2005, INTELLECTUAL PROPERT
MILLER LH, 1976, NEW ENGL J MED, V295, P302, DOI 10.1056/NEJM197608052950602
Modiano D, 2001, NATURE, V414, P305, DOI 10.1038/35104556
Moran M, 2005, PLOS MED, V2, P828, DOI 10.1371/journal.pmed.0020302
Mu JB, 2005, PLOS BIOL, V3, P1734, DOI 10.1371/journal.pbio.0030335
*NUFF COUNC BIOETH, 2002, ETHI PAT
Nwaka S, 2003, NAT REV DRUG DISCOV, V2, P919, DOI 10.1038/nrd1230
Risch NJ, 2000, NATURE, V405, P847, DOI 10.1038/35015718
SALLCRUP LA, 2005, INT MICROBIOL, V8, P1
The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
Trouiller P, 2002, LANCET, V359, P2188, DOI 10.1016/S0140-6736(02)09096-7
Varmus H, 2003, SCIENCE, V302, P398, DOI 10.1126/science.1091769
Webber D, 2001, B WORLD HEALTH ORGAN, V79, P735

```
   *WELLC TRUST CAS C, 2006, DAT REL ACC POL
   Widdus R., 2004, COMBATING DIS ASS PO
   Williams TN, 2005, PLOS MED, V2, P441, DOI 10.1371/journal.pmed.0020128
   Yazdani SS, 2004, VACCINE, V22, P3727, DOI 10.1016/j.vaccine.2004.03.030
   2000, LAW HUM GENOME REV, V12, P253
NR 32
TC 33
Z9 33
U1 1
U2 19
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
EI 1564-0604
J9 B WORLD HEALTH ORGAN
JI Bull. World Health Organ.
PD MAY
PY 2006
VL 84
IS 5
BP 382
EP 387
DI 10.2471/BLT.06.029843
PG 6
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 041ZL
UT WOS:000237496100016
PM 16710548
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ER

PT J
AU Modjarrad, K
   Moorthy, VS
   Millett, P
   Gsell, PS
   Roth, C
   Kieny, MP
AF Modjarrad, Kayvon
   Moorthy, Vasee S.
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TI Developing Global Norms for Sharing Data and Results during Public
   Health Emergencies
SO PLOS MEDICINE
LA English
DT Article
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OI Kieny, Marie-Paule/0000-0002-5943-6488; Moorthy,
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FU World Health Organization [001]; Wellcome Trust
CR Agnandji ST, 2016, NEW ENGL J MED, V374, P1647, DOI 10.1056/NEJMoa1502924
   Ledgerwood JE, 2017, NEW ENGL J MED, V376, P928, DOI 10.1056/NEJMoa1410863
   Marshall E, 2001, SCIENCE, V291, P1192, DOI 10.1126/science.291.5507.1192
   Moorthy VS, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001819
   Rampling T, 2015, NEW ENGL J MED, DOI [10.1056/NEJMoa1411627, DOI
10.1056/NEJMOA1411627, 10.1056/NEJMoa1411627(2015)]
   Regules JA, 2015, NEW ENGL J MED, DOI [10.1056/EJMoa1414216, DOI
10.1056/EJMOA1414216]
   World Health Organization, 2014, 12 GEN PROGR WORK 20
   Yozwiak NL, 2015, NATURE, V518, P477, DOI 10.1038/518477a
NR 8
TC 32
Z9 32
U1 0
U2 5
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1549-1676
J9 PLOS MED
JI PLos Med.
PD JAN
PY 2016
VL 13
IS 1
AR e1001935
DI 10.1371/journal.pmed.1001935
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WC Medicine, General & Internal
SC General & Internal Medicine
GA DC7AL
UT WOS:000369370600004
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OA DOAJ Gold, Green Published
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PT J
AU Perrino, T
   Howe, G
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   Pantin, H
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   Cruden, G
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   Brown, CH
AF Perrino, Tatiana
   Howe, George
   Sperling, Anne
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   Sandler, Irwin
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   Bandiera, Frank
   Brown, C. Hendricks
TI Advancing Science Through Collaborative Data Sharing and Synthesis
SO PERSPECTIVES ON PSYCHOLOGICAL SCIENCE
LA English
DT Article
DE collaborative research; data sharing; data synthesis; scientific equity;
   integrative data analysis
ID RANDOMIZED CONTROLLED-TRIAL; INTEGRATIVE DATA-ANALYSIS; DEPRESSIVE
   SYMPTOMS; PREVENTIVE INTERVENTION; SUBSTANCE USE; CHILDREN; ADOLESCENTS;
   FAMILY; EFFICACY; RISK
AB The demand for researchers to share their data has increased dramatically in
recent years. There is a need to replicate and confirm scientific findings to
bolster confidence in many research areas. Data sharing also serves the critical
function of allowing synthesis of findings across trials. As innovative
statistical methods have helped resolve barriers to synthesis analyses, data
sharing and synthesis can help answer research questions that cannot be answered
by individual trials alone. However, the sharing of data among researchers
remains challenging and infrequent. This article aims to (a) increase support
for data sharing and synthesis collaborations among researchers to advance
scientific knowledge and (b) provide a model for establishing these
collaborations using the example of the ongoing National Institute of Mental
Health's Collaborative Data Synthesis on Adolescent Depression Trials. This
study brings together datasets from existing prevention and treatment trials in
adolescent depression, as well as researchers and stakeholders, to answer
questions about for whom interventions work and by what pathways interventions
have their effects. This is critical to improving interventions, including
increasing knowledge about intervention efficacy among minority populations, or
what we call scientific equity. The collaborative model described is relevant to
fields with research questions that can only be addressed by synthesizing
individual-level data.
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CR Bauer DJ, 2009, PSYCHOL METHODS, V14, P101, DOI 10.1037/a0015583
   Beardslee WR, 2003, PEDIATRICS, V112, pE119, DOI 10.1542/peds.112.2.e119
   Berlin JA, 2002, STAT MED, V21, P371, DOI 10.1002/sim.1023
   Brent DA, 1997, ARCH GEN PSYCHIAT, V54, P877
   Brown C. H., 2011, PREVENTION SCI OFFIC
   Brown CH, 2008, CHILD DEV PERSPECT, V2, P198
   CARDEMIL EV, 2002, PREVENTION TREATMENT, V5
   Chan ME, 2012, PERSPECT PSYCHOL SCI, V7, P79, DOI 10.1177/1745691611429355
```

Clarke GN, 2001, ARCH GEN PSYCHIAT, V58, P1127, DOI 10.1001/archpsyc.58.12.1127
Compas BE, 2009, J CONSULT CLIN PSYCH, V77, P1007, DOI 10.1037/a0016930
Cooper H., 2012, AM PSYCHOL
Curran PJ, 2009, PSYCHOL METHODS, V14, P81, DOI 10.1037/a0015914
Dagne G., 2013, MODERATED NETW UNPUB
Dishion Thomas J, 2002, Prev Sci, V3, P191, DOI 10.1023/A:1019994500301
Garber J, 2009, JAMA-J AM MED ASSOC, V301, P2215, DOI 10.1001/jama.2009.788
Gibbons RD, 2012, ARCH GEN PSYCHIAT
Gillham JE, 2007, J CONSULT CLIN PSYCH, V75, P9, DOI 10.1037/0022-006x.75.1.9
Guttmacher AE, 2009, P NATL ACAD SCI USA, V106, P16894, DOI 10.1073/pnas.0910378106
Hernan MA, 2009, EPIDEMIOLOGY, V20, P167, DOI 10.1097/EDE.0b013e318196784a
Higgins JPT, 2001, STAT MED, V20, P2219, DOI 10.1002/sim.918
Hofer SM, 2009, PSYCHOL METHODS, V14, P150, DOI 10.1037/a0015566
Horowitz JL, 2006, J CONSULT CLIN PSYCH, V74, P401, DOI 10.1037/0022-006X.74.3.401
Howe G. H., 2012, S 2012 SOC PREV RES
Israel B., 2005, METHODS COMMUNITY BA
Kell DB, 2008, NATURE, V456, P29, DOI 10.1038/456029c
MacKinnon D. P., 2012, NEW APPROACH I UNPUB
MacKinnon DP, 2008, HEALTH PSYCHOL, V27, pS99, DOI 10.1037/0278-6133.27.2(Suppl.).S99
MacKinnon DP, 2008, INTRO STAT MEDIATION
March J, 2004, JAMA-J AM MED ASSOC, V292, P807
Merry SN, 2011, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD003380.pub3
National Research Council and Institute of Medicine, 2009, PREVENTING MENTAL EM
National Research Council/Institute of Medicine, 2009, DEPR PAR PAR CHILDR
Nosek BA, 2012, PERSPECT PSYCHOL SCI, V7, P615, DOI 10.1177/1745691612459058
Pashler H, 2012, PERSPECT PSYCHOL SCI, V7, P528, DOI 10.1177/1745691612465253
Perrino T., 2012, PREVENTING INT UNPUB
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Prado G, 2007, J CONSULT CLIN PSYCH, V75, P914, DOI 10.1037/0022-006X.75.6.914
Rose BM, 2004, J DEV BEHAV PEDIATR, V25, P58, DOI 10.1097/00004703-200402000-00013
Rossello J, 1999, J CONSULT CLIN PSYCH, V67, P734, DOI 10.1037/0022-006X.67.5.734
Sandler IN, 2003, J CONSULT CLIN PSYCH, V71, P587, DOI 10.1037/0022-006X.71.3.587
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Spoth R, 2009, J CONSULT CLIN PSYCH, V77, P620, DOI 10.1037/a0016029
Stice E, 2009, J CONSULT CLIN PSYCH, V77, P486, DOI 10.1037/a0015168
Wicherts JM, 2006, AM PSYCHOL, V61, P726, DOI 10.1037/0003-066X.61.7.726
Young JF, 2006, J CHILD PSYCHOL PSYC, V47, P1254, DOI 10.1111/j.1469-7610.2006.01667.x
NR 45
TC 32
Z9 32
U1 1
U2 18
PU SAGE PUBLICATIONS LTD
PI LONDON
PA 1 OLIVERS YARD, 55 CITY ROAD, LONDON EC1Y 1SP, ENGLAND
SN 1745-6916
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J9 PERSPECT PSYCHOL SCI

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JI Perspect. Psychol. Sci.
PD JUL
PY 2013
VL 8
IS 4
BP 433
EP 444
DI 10.1177/1745691613491579
PG 12
WC Psychology, Multidisciplinary
SC Psychology
GA 179BU
UT WOS:000321493400007
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OA Green Accepted
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ER

PT J
AU Watson, MS
AF Watson, Michael S.
CA ACMG Board Directors
TI Laboratory and clinical genomic data sharing is crucial to improving
   genetic health care: a position statement of the American College of
   Medical Genetics and Genomics
SO GENETICS IN MEDICINE
LA English
DT Article
DE genomic data sharing; genomic databases; gene variant databases;
   genotype: phenotype correlations
AB Disclaimer: These recommendations are designed primarily as an educational
resource for medical geneticists and other health-care providers, to help them
provide quality medical genetic services. Adherence to these recommendations
does not necessarily assure a successful medical outcome. These recommendations
should not be considered inclusive of all proper procedures and tests or
exclusive of other procedures and tests that are reasonably directed to
obtaining the same results. In determining the propriety of any specific
procedure or test, the geneticist should apply his or her own professional
judgment to the specific clinical circumstances presented by the individual
patient or specimen. It may be prudent, however, to document in the patient's
record the rationale for any significant deviation from these recommendations.
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CR National Institutes of Health, NIH GEN DAT SHAR POL
   Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
NR 2
TC 31
Z9 31
U1 0
U2 3
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1098-3600
EI 1530-0366
J9 GENET MED
JI Genet. Med.
PD JUL
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PY 2017
VL 19
IS 7
BP 721
EP 722
DI 10.1038/gim.2016.196
PG 2
WC Genetics & Heredity
SC Genetics & Heredity
GA FA4AA
UT WOS:000405385000001
PM 28055021
OA Bronze
DA 2019-08-06
ER

PT J
AU Garrison, NA
   Sathe, NA
   Antommaria, AHM
   Holm, IA
   Sanderson, SC
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   Clayton, EW
AF Garrison, Nanibaa' A.
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   Smith, Maureen E.
   McPheeters, Melissa L.
   Clayton, Ellen W.
TI A systematic literature review of individuals' perspectives on broad
   consent and data sharing in the United States
SO GENETICS IN MEDICINE
LA English
DT Review
DE biobank; broad consent; data sharing; systematic review; tiered consent
ID STORED BIOLOGICAL SAMPLES; INFORMED-CONSENT; PUBLIC PERSPECTIVES;
   PATIENTS ATTITUDES; MICHIGAN BIOTRUST; GENETIC RESEARCH; GENOMIC
   RESEARCH; BIOBANK CONSENT; CANCER-PATIENTS; COMMUNITY
AB proposed that de-identified human data and specimens be included in biobanks
only if patients provide consent. The National Institutes of Health Genomic Data
Sharing policy went into effect in 2015, requiring broad consent from almost all
research participants.
   Methods: We conducted a systematic literature review of attitudes toward
biobanking, broad consent, and data sharing. Bibliographic databases included
MEDLINE, Web of Science, EthxWeb, and GenETHX. Study screening was conducted
using DistillerSR.
   Results: The final 48 studies included surveys (n = 23), focus groups (n = 8),
mixed methods (n = 14), interviews (n = 1), and consent form analyses (n = 2).
Study quality was characterized as good (n = 19), fair (n = 27), and poor (n =
2). Although many participants objected, broad consent was often preferred over
tiered or study-specific consent, particularly when broad consent was the only
option, samples were de-identified, logistics of biobanks were communicated, and
privacy was addressed. Willingness for data to be shared was high, but it was
lower among individuals from under-represented minorities, individuals with
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privacy and confidentiality concerns, and when pharmaceutical companies had access to data.

Conclusions: Additional research is needed to understand factors affecting willingness to give broad consent for biobank research and data sharing in order to address concerns to enhance acceptability.

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CR Beskow LM, 2008, CANCER EPIDEM BIOMAR, V17, P1440, DOI 10.1158/1055-9965.EPI-08-0086
Braun KL, 2014, BIOPRESERV BIOBANK, V12, P106, DOI 10.1089/bio.2013.0083
Brothers KB, 2013, PERS MED, V10, P349, DOI [10.2217/PME.13.34, 10.2217/pme.13.34]
Brothers KB, 2011, AM J MED GENET A, V155A, P2982, DOI 10.1002/ajmg.a.34304
Chen DT, 2005, ARCH INTERN MED, V165, P652, DOI 10.1001/archinte.165.6.652

Conley JM, 2012, J LAW MED ETHICS, V40, P612, DOI 10.1111/j.1748-720X.2012.00694.x
Duquette D, 2012, PUBLIC HEALTH GENOM, V15, P146, DOI 10.1159/000336565
Fong Megan, 2004, Pac Health Dialog, V11, P154
Fong M, 2006, J CANCER EDUC, V21, pS47, DOI 10.1207/s15430154jce2101s_10
Goddard KAB, 2009, BIOPRESERV BIOBANK, V7, P119, DOI 10.1089/bio.2009.0006
Goldenberg AJ, 2009, J PEDIATR-US, V155, P578, DOI 10.1016/j.jpeds.2009.04.034
Gornick MC, 2014, J EMPIR RES HUM RES, V9, P22, DOI 10.1177/1556264614544277
Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162
Haga SB, 2011, PUBLIC HEALTH GENOM, V14, P319, DOI 10.1159/000324705
Helft PR, 2007, J EMPIR RES HUM RES, V2, P15, DOI [10.1525/jer.2007.2.3.15, 10.1525/JERHRE.2007.2.3.15]
Hiratsuka V, 2012, PROG COMM HLTH PARTN, V6, P131, DOI 10.1353/cpr.2012.0025
Hiratsuka VY, 2012, INT J CIRCUMPOL HEAL, V71, DOI 10.3402/ijch.v71i0.18642
Hofmann B, 2009, J MED ETHICS, V35, P125, DOI 10.1136/jme.2008.024851
Hoop JG, 2009, GENET TEST MOL BIOMA, V13, P331, DOI 10.1089/gtmb.2008.0117
Hull SC, 2008, AM J BIOETHICS, V8, P62, DOI 10.1080/15265160802478404
Huston P, 1996, CAN MED ASSOC J, V154, P1695
Kaphingst KA, 2006, CLIN GENET, V69, P393, DOI 10.1111/j.1399-0004.2006.00614.x
Kaufman D, 2012, GENET MED, V14, P787, DOI 10.1038/gim.2012.45
Kaufman D, 2009, GENET MED, V11, P329, DOI 10.1097/GIM.0b013e31819994f8
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Kelley K, 2003, INT J QUAL HEALTH C, V15, P261, DOI 10.1093/intqhc/mzg031
Kern MH, 2010, THESIS
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Lemke AA, 2012, AM J MED GENET A, V158A, P1029, DOI 10.1002/ajmg.a.34414
Long MD, 2015, INFLAMM BOWEL DIS, V21, P132, DOI 10.1097/MIB.0000000000000263
Ludman EJ, 2010, J EMPIR RES HUM RES, V5, P9, DOI 10.1525/jer.2010.5.3.9
Luque JS, 2012, J CANCER EDUC, V27, P91, DOI 10.1007/s13187-011-0275-2
Master Z, 2012, NAT METHODS, V9, P885, DOI 10.1038/nmeth.2142
McCarty CA, 2011, AM J MED GENET A, V155A, P737, DOI 10.1002/ajmg.a.33896
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
McQuillan GM, 2003, GENET MED, V5, P35, DOI 10.1097/01.GIM.0000048372.64172.15
Murphy J, 2009, AM J PUBLIC HEALTH, V99, P2128, DOI 10.2105/AJPH.2008.157099
National Cancer Institute/National Action Plan on Breast Cancer, NCI NAPBC MOD INF CO
Neidich AB, 2008, AM J MED GENET A, V146A, P297, DOI 10.1002/ajmg.a.32145
Pentz RD, 2006, AM J MED GENET A, V140A, P733, DOI 10.1002/ajmg.a.31154
Pereira S, 2014, GENES-BASEL, V5, P739, DOI 10.3390/genes5030739
Platt J, 2014, GENET MED, V16, P11, DOI 10.1038/gim.2013.59
Platt T, 2014, J COMMUN GENET, V5, P349, DOI 10.1007/s12687-014-0190-4
Pulley JM, 2008, CELL TISSUE BANK, V9, P55, DOI 10.1007/s10561-007-9051-2
Rahm AK, 2013, J COMMUN GENET, V4, P445, DOI 10.1007/s12687-013-0146-0
Ridgeway JL, 2013, PUBLIC HEALTH GENOM, V16, P118, DOI 10.1159/000349924
Rogith D, 2014, J AM MED INFORM ASSN, V21, pE320, DOI 10.1136/amiajnl-2013-002579
Schwartz MD, 2001, AM J MED GENET, V98, P336, DOI 10.1002/1096-8628(20010201)98:4<336::AID-AJMG1100>3.0.CO;2-7
Scott EA, 2010, TRANSFUSION, V50, P1943, DOI 10.1111/j.1537-2995.2010.02667.x
Simon CM, 2011, GENET MED, V13, P821, DOI 10.1097/GIM.0b013e31821d2f88
Stein DT, 2013, GENET TEST MOL BIOMA, V17, P855, DOI 10.1089/gtmb.2013.1550
Storr CL, 2014, J COMMUN GENET, V5, P363, DOI 10.1007/s12687-014-0191-3
Taualii M, 2014, J CANCER EDUC, V29, P570, DOI 10.1007/s13187-014-0638-6
Thiel DB, 2014, J COMMUN GENET, V5, P125, DOI 10.1007/s12687-013-0162-0

```
   Tomlinson T, 2015, JAMA-J AM MED ASSOC, V313, P417, DOI
10.1001/jama.2014.16363
   Tomlinson T, 2013, HASTINGS CENT REP, V43, P41, DOI 10.1002/hast.115
   Tong A, 2007, INT J QUAL HEALTH C, V19, P349, DOI 10.1093/intqhc/mzm042
   Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
   Truven Health Analytics, 2014, HLTH POLL DAT PRIV
   Valle-Mansilla JI, 2010, CANCER INVEST, V28, P726, DOI
10.3109/07357907.2010.494320
   Wang S S, 2001, Community Genet, V4, P18, DOI 10.1159/000051152
   Wendler D, 2002, ARCH INTERN MED, V162, P1457, DOI
10.1001/archinte.162.13.1457
   Williams H, 2015, JMIR MED INF, V3, DOI 10.2196/medinform.3525
NR 63
TC 31
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U2 22
PU NATURE PUBLISHING GROUP
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TI Facilitating a culture of responsible and effective sharing of cancer
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SO NATURE MEDICINE
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ID GLOBAL ALLIANCE; PRIVACY; CONSENT; LEGAL; CARE; CONSORTIUM; PROTECTION;
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AB Rapid and affordable tumor molecular profiling has led to an explosion of
clinical and genomic data poised to enhance the diagnosis, prognostication and
treatment of cancer. A critical point has now been reached at which the analysis
and storage of annotated clinical and genomic information in unconnected silos
will stall the advancement of precision cancer care. Information systems must be
harmonized to overcome the multiple technical and logistical barriers to data
sharing. Against this backdrop, the Global Alliance for Genomic Health (GA4GH)
was established in 2013 to create a common framework that enables responsible,
voluntary and secure sharing of clinical and genomic data. This Perspective from
the GA4GH Clinical Working Group Cancer Task Team highlights the data-
aggregation challenges faced by the field, suggests potential collaborative
solutions and describes how GA4GH can catalyze a harmonized data-sharing culture.
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CR Alizadeh AA, 2015, NAT MED, V21, P846, DOI 10.1038/nm.3915
American Association for Cancer Research, PROJ GENIE GEN EV NE
Andre F, 2014, ANN ONCOL, V25, P2295, DOI 10.1093/annonc/mdu478
Andre F, 2014, LANCET ONCOL, V15, P267, DOI 10.1016/S1470-2045(13)70611-9
Aparicio S, 2013, NEW ENGL J MED, V368, P842, DOI 10.1056/NEJMra1204892
Boutros PC, 2014, NAT GENET, V46, P318, DOI 10.1038/ng.2932
Christensen KD, 2016, CLIN GENET, V89, P228, DOI 10.1111/cge.12626
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Conley BA, 2014, SEMIN ONCOL, V41, P297, DOI 10.1053/j.seminoncol.2014.05.002
Denny JC, 2013, NAT BIOTECHNOL, V31, P1102, DOI 10.1038/nbt.2749
Eggermont AMM, 2014, EUR J CANCER, V50, P2745, DOI 10.1016/j.ejca.2014.07.025
Erlich Y, 2014, NAT REV GENET, V15, P409, DOI 10.1038/nrg3723

European Commission, 2012, PROP REG EUR PARL CO
Ewing AD, 2015, NAT METHODS, V12, P623, DOI [10.1038/NMETH.3407, 10.1038/nmeth.3407]
Gargis AS, 2015, NAT BIOTECHNOL, V33, P689, DOI 10.1038/nbt.3237
Girdea M, 2013, HUM MUTAT, V34, P1057, DOI 10.1002/humu.22347
Global Al liance for Genomics and Health, 2016, DAT SHAR LEX
Global Alliance for Genomics and Health, 2015, CONS POL
Global Alliance for Genomics and Health, SEC INFR STAND IMPL
Global Alliance for Genomics and Health, 2016, ACC POL
Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN H
Global Alliance for Genomics and Health, 2014, GA P3G IPAC CONS TOO
Global Alliance for Genomics and Health, 2013, WHIT PAP CREAT GLOB
Global Alliance for Genomics and Health, 2015, PRIV SEC POL
Green RC, 2015, NEW ENGL J MED, V372, P397, DOI 10.1056/NEJMp1404776
Groza T, 2015, AM J HUM GENET, V97, P111, DOI 10.1016/j.ajhg.2015.05.020
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Haga SB, 2008, ADV GENET, V60, P505, DOI 10.1016/S0065-2660(07)00418-X
Hamosh A, 2013, HUM MUTAT, V34, P566, DOI 10.1002/humu.22283
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Hudson TJ, 2010, NATURE, V464, P993, DOI 10.1038/nature08987
Husedzinovic A, 2015, EUR J HUM GENET, V23, P1607, DOI 10.1038/ejhg.2015.27
Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
Kaye J, 2015, INT LIBR ETH LAW TEC, V14, P101, DOI 10.1007/978-94-017-9573-9_8
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Knoppers BM, 2014, GENOME MED, V6, DOI 10.1186/gm530
Kohler S, 2014, NUCLEIC ACIDS RES, V42, pD966, DOI 10.1093/nar/gkt1026
Kosseim P, 2014, GENOME BIOL, V15, DOI 10.1186/s13059-014-0430-2
Lacombe D, 2014, NAT REV CLIN ONCOL, V11, P492, DOI 10.1038/nrclinonc.2014.98
Lawler M, 2015, CANCER DISCOV, V5, P1133, DOI 10.1158/2159-8290.CD-15-0821
Lawler M, 2014, ONCOLOGIST, V19, P217, DOI 10.1634/theoncologist.2013-0452
Lawler M, 2014, LANCET ONCOL, V15, P258, DOI 10.1016/S1470-2045(13)70552-7
Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
Lolkema MP, 2013, J CLIN ONCOL, V31, P1842, DOI 10.1200/JCO.2012.45.2789
Lunshof JE, 2008, NAT REV GENET, V9, P406, DOI 10.1038/nrg2360
Mancini Julien, 2011, J Natl Cancer Inst, V103, P154, DOI 10.1093/jnci/djq498
McCarthy M, 2016, BMJ-BRIT MED J, V352, DOI 10.1136/bmj.i213
McCarty CA, 2011, BMC MED GENOMICS, V4, DOI 10.1186/1755-8794-4-13
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
Meric-Bernstam F, 2015, J CLIN ONCOL, V33, P2753, DOI 10.1200/JCO.2014.60.4165
O'Doherty KC, 2011, SOC SCI MED, V73, P367, DOI 10.1016/j.socscimed.2011.05.046
Paten B, 2015, J AM MED INFORM ASSN, V22, P1143, DOI 10.1093/jamia/ocv047
Pillai U, 2014, BIOPRESERV BIOBANK, V12, P409, DOI 10.1089/bio.2014.0039
Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
Rogith D, 2014, J AM MED INFORM ASSN, V21, pE320, DOI 10.1136/amiajnl-2013-002579
Schilsky RL, 2014, J CLIN ONCOL, V32, P2373, DOI 10.1200/JCO.2014.56.2124
Schilsky RL, 2014, NAT REV CLIN ONCOL, V11, P432, DOI 10.1038/nrclinonc.2014.54
Sioutos N, 2007, J BIOMED INFORM, V40, P30, DOI 10.1016/j.jbi.2006.02.013
Siva N, 2015, LANCET, V385, P103, DOI 10.1016/S0140-6736(14)62453-3
Stein LD, 2015, NATURE, V523, P149, DOI 10.1038/523149a
Tejpar S., 2012, 37 EUR SOC MED ONC C, p1382P
Tryka KA, 2014, NUCLEIC ACIDS RES, V42, pD975, DOI 10.1093/nar/gkt1211
US National Institutes of Health, 2014, NAT I HLTH GEN DAT S
Van Allen EM, 2014, NAT MED, V20, P682, DOI 10.1038/nm.3559

```
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Weinstein JN, 2013, NAT GENET, V45, P1113, DOI 10.1038/ng.2764
   Wolf Leslie E, 2004, IRB, V26, P1, DOI 10.2307/3563696
   Zika E, 2008, PHARMACOGENOMICS, V9, P773, DOI 10.2217/14622416.9.6.773
NR 68
TC 31
Z9 31
U1 3
U2 15
PU NATURE PUBLISHING GROUP
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TI Anonymising and sharing individual patient data
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DT Article
ID CLINICAL-TRIALS; MEDICAL-RECORDS; ACCESS; PRIVACY; CONSENT; BIAS
AB There is a strong movement to share individual patient data for secondary
purposes, particularly for research. A major obstacle to broad data sharing has
been the concern for patient privacy. One of the methods for protecting the
privacy of patients in accordance with privacy laws and regulations is to
anonymise the data before it is shared. This article describes the key concepts
and principles for anonymising health data while ensuring it remains suitable
for meaningful analysis.
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CR [Anonymous], 2014, ARTICLE 29 DATA PROT
Arbuckle L, 2013, ANONYMIZING HLTH DAT
Bhattacharjee Y, 2012, SCIENCE, V338, P29, DOI 10.1126/science.338.6103.29
Castellani J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1881
Duncan GT, 2011, STAT SOC BEHAV SC, P1, DOI 10.1007/978-1-4419-7802-8
Eguale Tewodros, 2005, AMIA Annu Symp Proc, P947
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
El Emam K, 2013, GUIDE DEIDENTIFICATI
El Emam K, 2007, PAN CANADIAN DEIDENT
El Emam K, 2015, INT DATA PRIV LAW, V5, P73, DOI 10.1093/idpl/ipu033
El Emam K, 2013, BMC MED INFORM DECIS, V13, DOI 10.1186/1472-6947-13-114
El Emam K, 2013, AM J BIOETHICS, V13, P42, DOI 10.1080/15265161.2013.767958
El Emam K, 2012, J MED INTERNET RES, V14, DOI 10.2196/jmir.2001
El Emam K, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0028071
El Emam K, 2009, J AM MED INFORM ASSN, V16, P670, DOI 10.1197/jamia.M3144
European Medicines Agency, 2014, EUR MED AG POL PUBL
European Medicines Agency, 2013, REL DAT CLIN TRIALS
Gkoulalas-Divanis A, 2014, J BIOMED INFORM, V50, P4, DOI 10.1016/j.jbi.2014.06.002
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Haggie E, 2013, PLOS BIOL
Harrison C, 2012, NAT REV DRUG DISCOV, V11, P891, DOI 10.1038/nrd3907
Health System Use Technical Advisory Committee Data De-identification Working Group, 2010, BEST PRACT GUID MAN
Hede K, 2013, JNCI-J NATL CANCER I, V105, P1159, DOI 10.1093/jnci/djt232
Hrynaszkiewicz I, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-9
Hughes S, 2014, PHARM STAT, V13, P179, DOI 10.1002/pst.1615
Information Commissioner's Office, 2012, AN MAN DAT PROT RISK
Kho ME, 2009, BMJ-BRIT MED J, V338, DOI 10.1136/bmj.b866
Krumholz HM, 2011, JAMA-J AM MED ASSOC, V306, P1593, DOI 10.1001/jama.2011.1459
Malin BA, 2013, J AM MED INFORM ASSN, V20, P2, DOI 10.1136/amiajnl-2012-001509
Medical Research Council, 2015, RES POL ETH DAT SHAR
*NIH, 2003, FIN NIH STAT SHAR RE
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Olson S., 2013, SHAR CLIN RES DAT WO
Phrma, 2013, PRINC RESP CLIN TRIA
Robertson J, 2013, BLOOMBERG NEWS
Sandercock PAG, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-101
Shostak J, 2006, DEIDENTIFICATION CLI
Sweeney L., 2013, MATCHING KNOWN PATIE
US Department of Health and Human Services, 2012, GUID REG METH DEID P
Vallance P, 2013, LANCET, V382, P1073, DOI 10.1016/S0140-6736(13)62001-2
Wellcome Trust, 2011, SHAR RES DAT IMPR PU

```
   Willenborg L., 1996, STAT DISCLOSURE CONT
   Willison DJ, 2008, J MED ETHICS, V34, P308, DOI 10.1136/jme.2006.020032
   Yale School of Medicine, YODA PROJ
NR 44
TC 31
Z9 31
U1 0
U2 10
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1756-1833
J9 BMJ-BRIT MED J
JI BMJ-British Medical Journal
PD MAR 20
PY 2015
VL 350
AR h1139
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PG 6
WC Medicine, General & Internal
SC General & Internal Medicine
GA CE1KX
UT WOS:000351571600001
PM 25794882
OA Green Published, Bronze
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PT J
AU Freymann, JB
   Kirby, JS
   Perry, JH
   Clunie, DA
   Jaffe, CC
AF Freymann, John B.
   Kirby, Justin S.
   Perry, John H.
   Clunie, David A.
   Jaffe, C. Carl
TI Image Data Sharing for Biomedical Research-Meeting HIPAA Requirements
   for De-identification
SO JOURNAL OF DIGITAL IMAGING
LA English
DT Article
DE Data sharing; De-identification; Anonymization; Cross-disciplinary
   research; Open access; Open source; DICOM; Supplement 142; Image
   archive; HIPAA; PHI; Common rule
ID RADIOLOGY
AB Data sharing is increasingly recognized as critical to cross-disciplinary
research and to assuring scientific validity. Despite National Institutes of
Health and National Science Foundation policies encouraging data sharing by
grantees, little data sharing of clinical data has in fact occurred. A principal
reason often given is the potential of inadvertent violation of the Health
Insurance Portability and Accountability Act privacy regulations. While
regulations specify the components of private health information that should be
protected, there are no commonly accepted methods to de-identify clinical data
objects such as images. This leads institutions to take conservative risk-averse
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positions on data sharing. In imaging trials, where images are coded according to the Digital Imaging and Communications in Medicine (DICOM) standard, the complexity of the data objects and the flexibility of the DICOM standard have made it especially difficult to meet privacy protection objectives. The recent release of DICOM Supplement 142 on image de-identification has removed much of this impediment. This article describes the development of an open-source software suite that implements DICOM Supplement 142 as part of the National Biomedical Imaging Archive (NBIA). It also describes the lessons learned by the authors as NBIA has acquired more than 20 image collections encompassing over 30 million images.
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OI Clunie, David A/0000-0002-2406-1145
FU National Cancer Institute, National Institutes of Health
   [HHSN261200800001E]
FX This project has been funded in whole or in part with federal funds from
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CR Branstetter BF, 2007, RADIOGRAPHICS, V27, DOI 10.1148/rg.275065139
   Hrynaszkiewicz I, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-9
   Lien CY, 2011, PROC SPIE, V7967, DOI 10.1117/12.877989
   National Cancer Institute, 2011, CANCER
   Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
   Noumeir R, 2007, J DIGIT IMAGING, V20, P284, DOI 10.1007/s10278-006-1051-4
   Ohm P., 2009, 0912 U COL
   Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
   Gonzalez DR, 2010, EUR RADIOL, V20, P1896, DOI 10.1007/s00330-010-1745-3
   Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
NR 10
TC 31
Z9 31
U1 0
U2 21
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0897-1889
J9 J DIGIT IMAGING
JI J. Digit. Imaging
PD FEB
PY 2012
VL 25
IS 1
BP 14
EP 24
DI 10.1007/s10278-011-9422-x
PG 11

WC Radiology, Nuclear Medicine & Medical Imaging
SC Radiology, Nuclear Medicine & Medical Imaging
GA 943IF
UT WOS:000304113400004
PM 22038512
OA Green Published
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PT J
AU Pearce, N
Smith, AH
AF Pearce, Neil
Smith, Allan H.
TI Data sharing: not as simple as it seems
SO ENVIRONMENTAL HEALTH
LA English
DT Editorial Material
DE epidemiology; ethics; data sharing
ID NEW-ZEALAND; PRESCRIBED FENOTEROL; SPERM COUNTS; DATA RESPONSIBILITY; CERVICAL-CANCER; BETA-AGONISTS; ASTHMA; DEATH; EPIDEMIOLOGY; DIAGNOSIS

AB In recent years there has been a major change on the part of funders, particularly in North America, so that data sharing is now considered to be the norm rather than the exception. We believe that data sharing is a good idea. However, we also believe that it is inappropriate to prescribe exactly when or how researchers should preserve and share data, since these issues are highly specific to each study, the nature of the data collected, who is requesting it, and what they intend to do with it. The level of ethical concern will vary according to the nature of the information, and the way in which it is collected - analyses of anonymised hospital admission records may carry a quite different ethical burden than analyses of potentially identifiable health information collected directly from the study participants. It is striking that most discussions about data sharing focus almost exclusively on issues of ownership (by the researchers or the funders) and efficiency (on the part of the funders). There is usually little discussion of the ethical issues involved in data sharing, and its implications for the study participants. Obtaining prior informed consent from the participants does not solve this problem, unless the informed consent process makes it completely clear what is being proposed, in which case most study participants would not agree. Thus, the undoubted benefits of data sharing does not remove the obligations and responsibilities that the original investigators hold for the people they invited to participate in the study.

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CR Alsheikh-Ali AA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0024357
[Anonymous], 2003, NIHODOS032
[Anonymous], 2011, NOTES11009 NIEHS
Blair A, 2009, ENVIRON HEALTH PERSP, V117, P1809, DOI 10.1289/ehp.0901194
Blakely T, 2011, J EPIDEMIOL COMMUN H, V65, pA33, DOI 10.1136/jech.2011.142976a.89

Blakely T, 2000, AUST NZ J PUBL HEAL, V24, P92, DOI 10.1111/j.1467-842X.2000.tb00732.x
Boffetta P, 2008, JNCI-J NATL CANCER I, V100, P988, DOI 10.1093/jnci/djn191
Bonde JP, 2011, EPIDEMIOLOGY, V22, P617, DOI 10.1097/EDE.0b013e318223442c
Brewer N, 2008, 26 CPHR
Brewer N, 2008, 23 CPHR
Brewer N, 2011, BMC CANC, V11
Brewer N, 2008, 24 CPHR
Brewer N, 2007, 17 CPHR
Brewer N, 2010, INT J EPIDEMIOL, V39, P156, DOI 10.1093/ije/dyp303
Brewer N, 2009, J WOMENS HEALTH, V18, P955, DOI 10.1089/jwh.2008.1163
CRANE J, 1989, LANCET, V1, P917
Davis Devra, 2002, SMOKE RAN WATER
DUFFY AP, 2001, REPORT MINISTERIAL I
Egilman D, 2006, INT J OCCUP ENV HEAL, V12, P169, DOI 10.1179/oeh.2006.12.2.169
Foliaki S, 2008, 28 CTR PUBL HLTH RES
Foliaki Sunia, 2004, Pac Health Dialog, V11, P199
GRAINGER J, 1991, THORAX, V46, P105, DOI 10.1136/thx.46.2.105
Greenland Sander, 2004, WAKE FOREST LAW REV, V39, P291
Hardell L, 2007, AM J IND MED, V50, P227, DOI 10.1002/ajim.20357
Infante PF, 2006, INT J OCCUP ENV HEAL, V12, P268, DOI 10.1179/oeh.2006.12.3.268
Michaels D, 2005, AM J PUBLIC HEALTH, V95, pS39, DOI 10.2105/AJPH.2004.043059
Michaels D, 2006, ENV HLTH, V5, DOI [10.1186/476-069X-5-5, DOI 10.1186/476-069X-5-5]
Monforton C, 2006, AM J PUBLIC HEALTH, V96, P271, DOI 10.2105/AJPH.2005.064410
Neutra RR, 2006, EPIDEMIOLOGY, V17, P335, DOI 10.1097/01.ede.0000209464.97895.bf
Parkin L, 2011, J EPIDEMIOL COMMUN H, V65, P150, DOI 10.1136/jech.2009.097436
PEARCE N, 1990, THORAX, V45, P170, DOI 10.1136/thx.45.3.170
Pearce N, 1998, EPIDEMIOL REV, V20, P173, DOI 10.1093/oxfordjournals.epirev.a017979
Pearce N, 2007, ADVERSE REACTIONS FE
Pearce N, 2008, INT J EPIDEMIOL, V37, P46, DOI 10.1093/ije/dym270
Pearce N, 2011, OCCUP ENVIRON MED, V68, P86, DOI 10.1136/oem.2010.058917
Pearce N, 2009, J CLIN EPIDEMIOL, V62, P582, DOI 10.1016/j.jclinepi.2009.01.004
Reiter JP, 2011, EPIDEMIOLOGY, V22, P632, DOI 10.1097/EDE.0b013e318225c44b
Skakkebaek NE, 2011, EPIDEMIOLOGY, V22, P620, DOI 10.1097/EDE.0b013e318229ec01
Wilcox AJ, 2011, EPIDEMIOLOGY, V22, P615, DOI 10.1097/EDE.0b013e318225036d
NR 39
TC 31
Z9 31
U1 0
U2 11
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1476-069X
J9 ENVIRON HEALTH-GLOB
JI Environ. Health
PD DEC 21
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VL 10
AR 107

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DI 10.1186/1476-069X-10-107
PG 7
WC Environmental Sciences; Public, Environmental & Occupational Health
SC Environmental Sciences & Ecology; Public, Environmental & Occupational
   Health
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UT WOS:000299255600001
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PT J
AU Spencer, K
   Sanders, C
   Whitley, EA
   Lund, D
   Kaye, J
   Dixon, WG
AF Spencer, Karen
   Sanders, Caroline
   Whitley, Edgar A.
   Lund, David
   Kaye, Jane
   Dixon, William Gregory
TI Patient Perspectives on Sharing Anonymized Personal Health Data Using a
   Digital System for Dynamic Consent and Research Feedback: A Qualitative
   Study
SO JOURNAL OF MEDICAL INTERNET RESEARCH
LA English
DT Article
DE eHealth; data sharing; public trust; consent
ID PUBLIC-ATTITUDES; RECORDS; TRUST; INFORMATION; AWARENESS; ADOPTION;
   PEOPLE
AB Background: Electronic health records are widely acknowledged to provide an
important opportunity to anonymize patient-level health care data and collate
across populations to support research. Nonetheless, in the wake of public and
policy concerns about security and inappropriate use of data, conventional
approaches toward data governance may no longer be sufficient to respect and
protect individual privacy. One proposed solution to improve transparency and
public trust is known as Dynamic Consent, which uses information technology to
facilitate a more explicit and accessible opportunity to opt out. In this case,
patients can tailor preferences about whom they share their data with and can
change their preferences reliably at any time. Furthermore, electronic systems
provide opportunities for informing patients about data recipients and the
results of research to which their data have contributed.
   Objective: To explore patient perspectives on the use of anonymized health
care data for research purposes. To evaluate patient perceptions of a Dynamic
Consent model and electronic system to enable and implement ongoing
communication and collaboration between patients and researchers.
   Methods: A total of 26 qualitative interviews and three focus groups were
conducted that included a video presentation explaining the reuse of anonymized
electronic patient records for research. Slides and tablet devices were used to
introduce the Dynamic Consent system for discussion. A total of 35 patients with
chronic rheumatic disease with varying levels of illness and social deprivation
were recruited from a rheumatology outpatient clinic; 5 participants were
recruited from a patient and public involvement health research network.
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Results: Patients were supportive of sharing their anonymized electronic patient record for research, but noted a lack of transparency and awareness around the use of data, making it difficult to secure public trust. While there were general concerns about detrimental consequences of data falling into the wrong hands, such as insurance companies, 39 out of 40 (98%) participants generally considered that the altruistic benefits of sharing health care data outweighed the risks. Views were mostly positive about the use of an electronic interface to enable greater control over consent choices, although some patients were happy to share their data without further engagement. Participants were particularly enthusiastic about the system as a means of enabling feedback regarding data recipients and associated research results, noting that this would improve trust and public engagement in research. This underlines the importance of patient and public involvement and engagement throughout the research process, including the reuse of anonymized health care data for research. More than half of patients found the touch screen interface easy to use, although a significant minority, especially those with limited access to technology, expressed some trepidation and felt they may need support to use the system.

Conclusions: Patients from a range of socioeconomic backgrounds viewed a digital system for Dynamic Consent positively, in particular, feedback about data recipients and research results. Implementation of a digital Dynamic Consent system would require careful interface design and would need to be located within a robust data infrastructure; it has the potential to improve trust and engagement in electronic medical record research.

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OI Dixon, William/0000-0001-5881-4857; Whitley, Edgar/0000-0003-1779-0814; Spencer, Karen/0000-0003-2038-2600; Kaye, Jane/0000-0002-7311-4725; Sanders, Caroline/0000-0002-0539-928X

FU Arthritis Research UK; Wellcome Trust [096599/2/11/Z]; Medical Research Council (MRC) Clinician Scientist Fellowship [G0902272]; Technology Strategy Board; Engineering and Physical Sciences Research Council; Economic and Social Research Council [EP/G002541/1]; Engineering and Physical Sciences Research Council [EP/G002541/1]; Medical Research Council [G0902272, MR/K006665/1, MC_PC_13042]

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Research Council, and the Economic and Social Research Council (grant number EP/G002541/1) for JK, DL, and EAW.

CR American Thoracic Society, 2002, Am J Respir Crit Care Med, V165, P277
[Anonymous], 2014, PROM RES ACT NAT
[Anonymous], 2014, BETT INF MEANS BETT
[Anonymous], 2014, IND INF GOV OV PAN R
[Anonymous], 2014, BIG DAT PUBL VIEWS C
Bachmann R, 2015, ORGAN STUD, V36, P1123, DOI 10.1177/0170840615599334
Buckley BS, 2011, J MED ETHICS, V37, P50, DOI 10.1136/jme.2010.037903
Caldicott F, 2013, INFORM GOVERNANCE RE
Carter P, 2015, J MED ETHICS, V41, P404, DOI 10.1136/medethics-2014-102374
Department for Business Innovation and Skills (BIS) Office for Life Sciences, 2011, STRAT UK LIF SCI
Dixon-Woods M, 2009, SOC SCI MED, V68, P2215, DOI 10.1016/j.socscimed.2009.03.034
Dougados M, 2014, ANN RHEUM DIS, V73, P62, DOI 10.1136/annrheumdis-2013-204223
Gilson L, 2003, SOC SCI MED, V56, P1453, DOI 10.1016/S0277-9536(02)00142-9
Greenhalgh T, 2010, BMJ-BRIT MED J, V341, DOI 10.1136/bmj.c5814
Hill EM, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-72
Ipsos MORI, 2011, PUBL SUPP RES NHS
Kass NE, 2003, J LAW MED ETHICS, V31, P429, DOI 10.1111/j.1748-720X.2003.tb00105.x
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kjeken I, 2010, PHYS THER, V90, P450, DOI 10.2522/ptj.20080381
Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
MAYER RC, 1995, ACAD MANAGE REV, V20, P709, DOI 10.2307/258792
Nuffield Council on Bioethics, 2015, COLL LINK US DAT BIO
Patton M. Q., 2002, QUALITATIVE EVALUATI
Riordan F, 2015, INT J MED INFORM, V84, P237, DOI 10.1016/j.ijmedinf.2015.01.008
Rousseau DM, 1998, ACAD MANAGE REV, V23, P393, DOI 10.5465/AMR.1998.926617
Sanders C, 2012, BMC HEALTH SERV RES, V12, DOI 10.1186/1472-6963-12-220
Sheather J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f7042
Strauss A. L, 1987, QUALITATIVE ANAL SOC
Taylor Mark J, 2014, Life Sci Soc Policy, V10, P15, DOI 10.1186/s40504-014-0015-6
Teare HJA, 2015, DIGIT HEALTH, V1, DOI 10.1177/2055207615605644
Williams H, 2015, JMIR MED INF, V3, DOI 10.2196/medinform.3525
Willison DJ, 2009, BMC MED ETHICS, V10, DOI 10.1186/1472-6939-10-10
YouTube: Health eResearch Centre. Manchester UK: University of Manchester, 2014, HLTH REC RES YOUR DA

NR 33
TC 30
Z9 30
U1 6
U2 34
PU JMIR PUBLICATIONS, INC
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PA 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA
SN 1438-8871
J9 J MED INTERNET RES
JI J. Med. Internet Res.
PD APR
PY 2016
VL 18
IS 4
AR e66

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DI 10.2196/jmir.5011
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA EC9VZ
UT WOS:000388493700014
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PT J
AU Sanderson, SC
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   Mercaldo, ND
   Clayton, EW
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   Aufox, SA
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   Horowitz, CR
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   Shrubsole, MJ
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   Smith, ME
   Hom, IA
AF Sanderson, Saskia C.
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   Clayton, Ellen Wright
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   Campos, Diego
   Carrell, David S.
   Connolly, John
   Conway, Pat
   Fullerton, Stephanie M.
   Garrison, Nanibaa' A.
   Horowitz, Carol R.
   Jarvik, Gail P.
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Li, Rongling
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McCormick, Jennifer B.
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Myers, Melanie F.
Scro, Aaron
Williams, Janet L.
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Schildcrout, Jonathan S.
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TI Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-site Experimental Survey in the US

SO AMERICAN JOURNAL OF HUMAN GENETICS

LA English

DT Article

ID GENOME-WIDE ASSOCIATION; RESEARCH PARTICIPANTS; BROAD CONSENT; INFORMED-CONSENT; PERSPECTIVES; INFORMATION; NANOTECHNOLOGY; PREFERENCES; POPULATION; TUSKEGEE

AB Individuals participating in biobanks and other large research projects are increasingly asked to provide broad consent for open-ended research use and widespread sharing of their biosamples and data. We assessed willingness to participate in a biobank using different consent and data sharing models, hypothesizing that willingness would be higher under more restrictive scenarios. Perceived benefits, concerns, and information needs were also assessed. In this experimental survey, individuals from 11 US healthcare systems in the Electronic Medical Records and Genomics (eMERGE) Network were randomly allocated to one of three hypothetical scenarios: tiered consent and controlled data sharing; broad consent and controlled data sharing; or broad consent and open data sharing. Of 82,328 eligible individuals, exactly 13,000 (15.8%) completed the survey. Overall, 66% (95% CI: 63%-69%) of population-weighted respondents stated they would be willing to participate in a biobank; willingness and attitudes did not differ between respondents in the three scenarios. Willingness to participate was associated with self-identified white race, higher educational attainment, lower religiosity, perceiving more research benefits, fewer concerns, and fewer information needs. Most (86%, CI: 84%-87%) participants would want to know what would happen if a researcher misused their health information; fewer (51%, CI: 47%-55%) would worry about their privacy. The concern that the use of broad consent and open data sharing could adversely affect participant recruitment is not supported by these findings. Addressing potential participants' concerns and information needs and building trust and relationships with communities may increase acceptance of broad consent and wide data sharing in biobank research.

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CR American Association for Public Opinion Research, 2011, STAND DEF FIN DISP C
Ashley EA, 2015, JAMA-J AM MED ASSOC, V313, P2119, DOI 10.1001/jama.2015.3595
Bates BR, 2004, J NATL MED ASSOC, V96, P1051
Brossard D, 2009, PUBLIC UNDERST SCI, V18, P546, DOI 10.1177/0963662507087304
Brothers KB, 2011, AM J MED GENET A, V155A, P2982, DOI 10.1002/ajmg.a.34304
Bustamante CD, 2011, NATURE, V475, P163, DOI 10.1038/475163a
Chen DT, 2005, ARCH INTERN MED, V165, P652, DOI 10.1001/archinte.165.6.652
Chen H, 2012, BIOMETRICS, V68, P1278, DOI 10.1111/j.1541-0420.2012.01761.x
Chowdhury S., 2007, P SURV RES METH SECT, P2651
Collins FS, 2007, NATURE, V445, P259, DOI 10.1038/445259a
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
De Vries Raymond G, 2016, Life Sci Soc Policy, V12, P3, DOI 10.1186/s40504-016-0036-4
Department of Health and Human Services, 2016, FED REGISTER, V81, P4036
Department of Homeland Security, 2015, FED REGISTER, V80
*FETZ I, 1999, MULT MEAS REL SPIR U
Fullerton Stephanie Malia, 2011, ACHIEVING JUSTICE GE, P40
Garrison NA, 2016, GENET MED, V18, P663, DOI 10.1038/gim.2015.138
Gaskell G, 2011, NAT BIOTECHNOL, V29, P113, DOI 10.1038/nbt.1771
Gottesman O, 2013, GENET MED, V15, P761, DOI 10.1038/gim.2013.72
Hall MA, 2006, MED CARE, V44, P1048, DOI 10.1097/01.mlr.0000228023.37087.cb
Hamilton CM, 2011, AM J EPIDEMIOL, V174, P253, DOI 10.1093/aje/kwr193
Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
Hartzler A, 2013, GENET MED, V15, P792, DOI 10.1038/gim.2013.127
Helft PR, 2007, J EMPIR RES HUM RES, V2, P15, DOI [10.1525/jer.2007.2.3.15, 10.1525/JERHRE.2007.2.3.15]
Ho SS, 2013, PUBLIC UNDERST SCI, V22, P606, DOI 10.1177/0963662511417936
Hudson KLR, 2015, PRECISION MED INITIA
Johnson DR, 2015, SOCIOL SCI, V2, P106, DOI 10.15195/v2.a7
Kaufman D, 2009, GENET MED, V11, P329, DOI 10.1097/GIM.0b013e31819994f8
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Ludman EJ, 2010, J EMPIR RES HUM RES, V5, P9, DOI 10.1525/jer.2010.5.3.9
Manolio TA, 2007, NAT GENET, V39, P1045, DOI 10.1038/ng2127
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
McQuillan GM, 2003, GENET MED, V5, P35, DOI 10.1097/01.GIM.0000048372.64172.15
Murphy J, 2009, AM J PUBLIC HEALTH, V99, P2128, DOI 10.2105/AJPH.2008.157099
National Institutes of Health, 2014, FED REGISTER, V79, P51345
Need AC, 2009, TRENDS GENET, V25, P489, DOI 10.1016/j.tig.2009.09.012
Platt J, 2014, GENET MED, V16, P11, DOI 10.1038/gim.2013.59
Potter F., 1988, P SURV RES METH SECT, P2651
ROSENBAUM PR, 1983, BIOMETRIKA, V70, P41, DOI 10.2307/2335942
Rosenberg NA, 2010, NAT REV GENET, V11, P356, DOI 10.1038/nrg2760
Rubin DB, 2004, MULTIPLE IMPUTATION
Scheufele DA, 2009, NAT NANOTECHNOL, V4, P91, DOI [10.1038/nnano.2008.361, 10.1038/NNANO.2008.361]
Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI 10.1586/14737159.2014.961917
Shavers VL, 2000, J NATL MED ASSOC, V92, P563
Shea JA, 2008, J GEN INTERN MED, V23, P727, DOI 10.1007/s11606-008-0575-3
Simon CM, 2011, GENET MED, V13, P821, DOI 10.1097/GIM.0b013e31821d2f88
Smith ME, 2016, BMC MED RES METHODOL, V16, DOI 10.1186/s12874-016-0263-7
Steinsbekk KS, 2013, EUR J HUM GENET, V21, P897, DOI 10.1038/ejhg.2012.282

```
   Terry AL, 2008, HEALTH POLICY, V85, P293, DOI 10.1016/j.healthpol.2007.08.002
   Trinidad SB, 2011, SCIENCE, V331, P287, DOI 10.1126/science.1199000
   Ware JE, 1996, MED CARE, V34, P220, DOI 10.1097/00005650-199603000-00003
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TC 29
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U2 14
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ID HEMAGGLUTININ CLEAVAGE SITE; A VIRUSES; H5N1 INFLUENZA; HONG-KONG; WILD
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AB Avian influenza (AI) is a listed disease of the World Organisation for Animal
Health (OIE) that has become a disease of great importance both for animal and
human health. Until recent times, AI was considered a disease of birds with
zoonotic implications of limited significance. The emergence and spread of the
Asian lineage highly pathogenic AI H5N1 virus has dramatically changed this
perspective; not only has it been responsible of the death or culling of
millions of birds, but this virus has also been able to infect a variety of non-
avian hosts including human beings. The implications of such a panzootic reflect
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themselves in animal health issues, notably in the reduction of a protein source for developing countries and in the management of the pandemic potential. Retrospective studies have shown that avian progenitors play an important role in the generation of pandemic viruses for humans, and therefore these infections in the avian reservoir should be subjected to control measures aiming at eradication of the Asian H5N1 virus from all sectors rather than just eliminating or reducing the impact of the disease in poultry. Collection and analysis of information in a transparent environment and close collaboration between the medical and veterinary scientific community are crucial to support the global AI crisis.

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CR Alexander DJ, 2007, AVIAN DIS, V51, P161, DOI 10.1637/7602-041306R.1
Alexander DJ, 2000, VET MICROBIOL, V74, P3, DOI 10.1016/S0378-1135(00)00160-7
Alexander DJ, 2003, AVIAN DIS, V47, P792, DOI 10.1637/0005-2086-47.s3.792
ALEXANDER DJ, 1986, AVIAN PATHOL, V15, P647, DOI 10.1080/03079458608436328
Alexander DJ, 2001, EMERGENCE AND CONTROL OF ZOONOTIC ORTHO- AND PARAMYXOVIRUS DISEASES, P25
Banks J, 2000, AVIAN PATHOL, V29, P353, DOI 10.1080/03079450050118485
Banks J, 1998, ARCH VIROL, V143, P781, DOI 10.1007/s007050050329
Banks J, 2000, ARCH VIROL, V145, P1047, DOI 10.1007/s007050050695
BEARE AS, 1991, ARCH VIROL, V119, P37, DOI 10.1007/BF01314321
BECKER WB, 1966, J HYG-CAMB, V64, P309, DOI 10.1017/S0022172400040596
BERG M, 1990, ARCH VIROL, V113, P61, DOI 10.1007/BF01318353
Bridges CB, 2002, J INFECT DIS, V185, P1005, DOI 10.1086/340044
CALLAN RJ, 1995, J GEN VIROL, V76, P199, DOI 10.1099/0022-1317-76-1-199
Campbell G., 1998, P JOINT 4 ANN M NAT, P13
Capua I, 2000, AVIAN PATHOL, V29, P537, DOI 10.1080/03079450020016779
Capua I, 2003, AVIAN DIS, V47, P839, DOI 10.1637/0005-2086-47.s3.839
Capua I, 2004, AVIAN PATHOL, V33, P393, DOI 10.1080/0307945041000l724085
Capua I, 2007, VACCINE, V25, P4987, DOI 10.1016/j.vaccine.2007.01.113
CHAMBERS TM, 1989, VIROLOGY, V172, P180, DOI 10.1016/0042-6822(89)90119-0
Chen H, 2005, NATURE, V436, P191, DOI 10.1038/nature03974
Choi YK, 2005, J VIROL, V79, P10821, DOI 10.1128/JVI.79.16.10821-10825.2005
EFSA, 2005, EFSA J, V266, P1
Ellis TM, 2004, AVIAN PATHOL, V33, P492, DOI 10.1080/03079450400003601
FIORETTI A, 1997, P JOINT 4 ANN M NAT, P17
Fouchier RAM, 2004, P NATL ACAD SCI USA, V101, P1356, DOI 10.1073/pnas.0308352100
GETHING MJ, 1980, NATURE, V287, P301, DOI 10.1038/287301a0
GLASS SE, 1981, AVIAN DIS, V25, P545, DOI 10.2307/1589950
Guan Y, 1996, J VIROL, V70, P8041
GUO YJ, 1992, VIROLOGY, V188, P245, DOI 10.1016/0042-6822(92)90754-D
HALVORSON D, 1983, AVIAN DIS, V27, P77, DOI 10.2307/1590374
Halvorson DA, 1998, PROCEEDINGS OF THE FORTH INTERNATIONAL SYMPOSIUM ON AVIAN INFLUENZA, P36
HALVORSON DA, 1992, P 3 INT S AV INFL, P33
Halvorson DA, 1987, P 2 INT S AV INFL 19, P155
HINSHAW VS, 1986, J VIROL, V58, P655
HINSHAW VS, 1981, ARCH VIROL, V67, P191, DOI 10.1007/BF01318130
HINSHAW VS, 1981, INFECT IMMUN, V34, P354

HOMME PJ, 1970, AVIAN DIS, V14, P240, DOI 10.2307/1588468
Humberd J, 2006, J VIROL, V80, P2151, DOI 10.1128/JVI.80.5.2151-2161.2006
Isoda N, 2006, ARCH VIROL, V151, P1267, DOI 10.1007/s00705-005-0723-6
JOHNSON DC, 1984, BROILER IND, V47, P58
KARANOVIC T, 2004, CRUSTACEANA MONOGRAP, V3, P1
Karasin AI, 2000, J VIROL, V74, P9322, DOI 10.1128/JVI.74.19.9322-9327.2000
KAWAOKA Y, 1988, VIROLOGY, V163, P247, DOI 10.1016/0042-6822(88)90260-7
KAWAOKA Y, 1989, J VIROL, V63, P4603
Keawcharoen J, 2004, EMERG INFECT DIS, V10, P2189, DOI 10.3201/eid1012.040759
KIDA H, 1994, J GEN VIROL, V75, P2183, DOI 10.1099/0022-1317-75-9-2183
KING LJ, 1984, BROILER IND, V47, P44
KLINGEBORN B, 1985, ARCH VIROL, V86, P347, DOI 10.1007/BF01309839
Kuiken T, 2004, SCIENCE, V306, P241, DOI 10.1126/science.1102287
Kurtz J, 1996, LANCET, V348, P901, DOI 10.1016/S0140-6736(05)64783-6
LANG G, 1981, ARCH VIROL, V68, P189, DOI 10.1007/BF01314571
Lang G., 1982, P 1 INT S AV INFL 19, P21
LI SQ, 1990, J VIROL, V64, P3297
Liu J, 2005, SCIENCE, V309, P1206, DOI 10.1126/science.1115273
LOEFFEN W, P IN BETW C INT SOC, P329
LOEFFEN W, 2003, P ESVV C ST MAL FRAN
LUDWIG S, 1994, VIROLOGY, V202, P281, DOI 10.1006/viro.1994.1344
Lvov D. K., 1978, Viruses and environment, P351
MARAROVA NV, 2003, VIROLOGY, V310, P8
Mo IP, 1998, PROCEEDINGS OF THE FORTH INTERNATIONAL SYMPOSIUM ON AVIAN INFLUENZA, P379
MOHAN R, 1981, AVIAN DIS, V25, P11, DOI 10.2307/1589822
NARAYAN O, 1969, ARCH GES VIRUSFORSCH, V26, P166, DOI 10.1007/BF01241185
*OIE, 2006, UPD AV INFL AN TYP H
OKAZAKI K, 1983, ARCH VIROL, V77, P265, DOI 10.1007/BF01309274
Olsen B, 2006, SCIENCE, V312, P384, DOI 10.1126/science.1122438
Pasick J, 2005, J GEN VIROL, V86, P727, DOI 10.1099/vir.0.80478-0
Peiris JSM, 2001, J VIROL, V75, P9679, DOI 10.1128/JVI.75.20.9679-9686.2001
PENSAERT M, 1981, B WORLD HEALTH ORGAN, V59, P75
Perdue M, 1998, PROCEEDINGS OF THE FORTH INTERNATIONAL SYMPOSIUM ON AVIAN INFLUENZA, P182
Perez DR, 2003, AVIAN DIS, V47, P1114, DOI 10.1637/0005-2086-47.s3.1114
POMEROY BS, 1982, P 1 INT S AV INFL 19, P13
Pomeroy BS, 1987, P 2 INT S AV INFL 19, P14
ROHM C, 1995, VIROLOGY, V209, P664, DOI 10.1006/viro.1995.1301
SCHOLTISSEK C, 1978, VIROLOGY, V91, P79, DOI 10.1016/0042-6822(78)90356-2
Senne DA, 2003, AVIAN DIS, V47, P798, DOI 10.1637/0005-2086-47.s3.798
Senne DA, 2006, DEV BIOLOGICALS, V124, P37
Senne DA, 1996, AVIAN DIS, V40, P425, DOI 10.2307/1592241
SHARP GB, 1993, EPIDEMIOL INFECT, V110, P161, DOI 10.1017/S0950268800050780
Shortridge KF, 1998, VIROLOGY, V252, P331, DOI 10.1006/viro.1998.9488
Sims LD, 2005, VET REC, V157, P159, DOI 10.1136/vr.157.6.159
Songer JG, 2006, ANAEROBE, V12, P1, DOI 10.1016/j.anaerobe.2005.09.001
Songserm T, 2006, EMERG INFECT DIS, V12, P681, DOI 10.3201/eid1204.051396
Songserm T, 2006, EMERG INFECT DIS, V12, P1744, DOI 10.3201/eid1211.060542
STALLKNECHT DE, 1988, VET RES COMMUN, V12, P125, DOI 10.1007/BF00362792
Stallknecht DE, 1998, PROCEEDINGS OF THE FORTH INTERNATIONAL SYMPOSIUM ON AVIAN INFLUENZA, P61
STIENEKEGROBER A, 1992, EMBO J, V11, P2407, DOI 10.1002/j.1460-2075.1992.tb05305.x
Suarez DL, 2004, EMERG INFECT DIS, V10, P693, DOI 10.3201/eid1004.030396
Taubenberger JK, 2005, ARCH VIROL, P101
Thanawongnuwech R, 2005, EMERG INFECT DIS, V11, P699, DOI 10.3201/eid1105.050007

TUMOVA B, 1980, COMP IMMUNOL MICROB, V3, P45, DOI 10.1016/0147-9571(80)90038-7
Utterback W., 1984, Proceedings of the 33rd Western Poultry Conference, Davis, California, P4
Van Borm S, 2005, EMERG INFECT DIS, V11, P702, DOI 10.3201/eid1105.050211
Van Reeth K, 2007, VET RES, V38, P243, DOI 10.1051/vetres:2006062
VEY M, 1992, VIROLOGY, V188, P408, DOI 10.1016/0042-6822(92)90775-K
WEBSTER RG, 1981, VIROLOGY, V113, P712, DOI 10.1016/0042-6822(81)90200-2
WEBSTER RG, 1992, MICROBIOL REV, V56, P152
Wells R. J. H., 1963, Veterinary Record, V75, P783
WERNER O, 1999, P JOINT 5 ANN M NAT, P10
Werner O., 1998, P JOINT 4 ANN M NAT, P9
WESTBURY HA, 1981, AVIAN PATHOL, V10, P481, DOI 10.1080/03079458108418498
WESTBURY HA, 1979, VET MICROBIOL, V4, P223, DOI 10.1016/0378-1135(79)90058-0
Wood GW, 1997, AVIAN PATHOL, V26, P347, DOI 10.1080/03079459708419217
WOOD GW, 1993, ARCH VIROL, V130, P209, DOI 10.1007/BF01319010
WRIGHT SM, 1992, AM J EPIDEMIOL, V136, P488, DOI 10.1093/oxfordjournals.aje.a116522
Xu XY, 1999, VIROLOGY, V261, P15, DOI 10.1006/viro.1999.9820
Yingst SL, 2006, EMERG INFECT DIS, V12, P1295, DOI 10.3201/eid1708.060264
Yuen KY, 1998, LANCET, V351, P467, DOI 10.1016/S0140-6736(98)01182-9
NR 107
TC 29
Z9 29
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U2 9
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   Hugh-Jones, Charles
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CR Geifman N, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.27
   Guinney J, 2017, LANCET ONCOL, V18, P132, DOI 10.1016/S1470-2045(16)30560-5
   Murthy VH, 2004, JAMA-J AM MED ASSOC, V291, P2720, DOI
10.1001/jama.291.22.2720
   Pitcher B, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0170544
   Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
   Siegel RL, 2016, CA-CANCER J CLIN, V66, P7, DOI 10.3322/caac.21332
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   Wilkerson J, 2017, LANCET ONCOL, V18, P143, DOI 10.1016/S1470-2045(16)30633-7
NR 8
TC 28
Z9 28
U1 2
U2 14
PU MASSACHUSETTS MEDICAL SOC
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TI Comparison of consumers' views on electronic data sharing for healthcare
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DE privacy; patient-centered; distributed research network; health
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ID PERSONAL INFORMATION; RECORD DATA; ATTITUDES; CONSENT; PREFERENCES;
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AB New models of healthcare delivery such as accountable care organizations and
patient-centered medical homes seek to improve quality, access, and cost. They
rely on a robust, secure technology infrastructure provided by health
information exchanges (HIEs) and distributed research networks and the
willingness of patients to share their data. There are few large, in-depth
studies of US consumers' views on privacy, security, and consent in electronic
data sharing for healthcare and research together. Objective This paper
addresses this gap, reporting on a survey which asks about California consumers'
views of data sharing for healthcare and research together.
   Materials and Methods The survey conducted was a representative, random-digit
dial telephone survey of 800 Californians, performed in Spanish and English.
   Results There is a great deal of concern that HIEs will worsen privacy (40.3%)
and security (42.5%). Consumers are in favor of electronic data sharing but
elements of transparency are important: individual control, who has access, and
the purpose for use of data. Respondents were more likely to agree to share
deidentified information for research than to share identified information for
healthcare (76.2% vs 57.3%, p<.001).
   Discussion While consumers show willingness to share health information
electronically, they value individual control and privacy. Responsiveness to
these needs, rather than mere reliance on Health Insurance Portability and
Accountability Act (HIPAA), may improve support of data networks.
   Conclusion Responsiveness to the public's concerns regarding their health
information is a pre-requisite for patient-centeredness. This is one of the
first in-depth studies of attitudes about electronic data sharing that compares
attitudes of the same individual towards healthcare and research.
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   [U54HL108460]; Office of National Coordinator for Health Information
   Technology, U.S. Department of Health and Human Services [90HT0029]
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CR Agaku IT, 2014, J AM MED INFORM ASSN, V21, P374, DOI 10.1136/amiajnl-2013-002079
American Association for Public Opinion Research, 2011, STAND DEF FIN DISP C
Ancker JS, 2013, J AM MED INFORM ASSN, V20, P152, DOI 10.1136/amiajnl-2012-001062
Ancker JS, 2012, AM J PREV MED, V43, P76, DOI 10.1016/j.amepre.2012.02.027
Blumberg SJ, 2012, WIRELESS SUBSTITUTIO
Brown J, 2009, HHSA290200500331T05
Brown JS, 2010, MED CARE, V48, pS45, DOI 10.1097/MLR.0b013e3181d9919f
CaleConnect, 2012, EN EXCH ASS COMM ENT
California Health and Human Services Agency, 2014, REP LEG DEM PROJ SPE
California HealthCare Foundation, 2010, CONS HLTH INF TECHN
Collins FS, 2014, J AM MED INFORM ASSN, V21, P576, DOI 10.1136/amiajnl-2014-002864
Daugherty SE, 2014, J AM MED INFORM ASSN, V21, P583, DOI 10.1136/amiajnl-2014-002758
eHealthInitiative, 2012, 2012 REP HLTH INF EX
Fox S., 2011, SOCIAL LIFE HLTH INF
Fox Susannah, 2000, ONLINE HLTH CARE REV
GOLDSTEIN MM, 2010, CONSUMER CONSENT OPT
Grande D, 2013, JAMA INTERN MED, V173, P1798, DOI 10.1001/jamainternmed.2013.9166
Hansen MH, 1943, ANN MATH STAT, V14, P333, DOI 10.1214/aoms/1177731356
Holmes JH, 2014, J AM MED INFORM ASSN, V21, P730, DOI 10.1136/amiajnl-2013-002370
Horrigan J., 2009, MOBILE DIFFERENCE PE
Hripcsak G, 2014, J AM MED INFORM ASSN, V21, P204, DOI 10.1136/amiajnl-2013-002117
Kim KK, 2014, J AM MED INFORM ASSN, V21, P714, DOI 10.1136/amiajnl-2013-002308
Kim KK, 2013, J AM MED INFORM ASSN, V21, P714
Lauer MS, 2013, NEW ENGL J MED, V369, P1579, DOI 10.1056/NEJMp1310102
Mamo Laura A, 2013, AMIA Annu Symp Proc, V2013, P920
McGraw D, 2013, J AM MED INFORM ASSN, V20, P29, DOI 10.1136/amiajnl-2012-000936
Medical Research Council, 2007, US PERS HLTH INF MED
National Partnership for Women & Families, 2012, MAK IT MEAN CONS VAL, P32
Ohno-Machado L, 2013, TECHNICAL REPORT
Ohno-Machado L, 2014, J AM MED INFORM ASSN, V21, P621, DOI 10.1136/amiajnl-2014-002751
Perera G, 2011, INT J MED INFORM, V80, P94, DOI 10.1016/j.ijmedinf.2010.11.005
Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
Rogith D, 2014, J AM MED INFORM ASSN, V21, pE320, DOI 10.1136/amiajnl-2013-002579
Selby JV, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3006298

```
   Shoenbill K, 2014, J AM MED INFORM ASSN, V21, P171, DOI 10.1136/amiajnl-2013-
001694
   Smith M., 2012, BEST CARE LOWER COST
   Teixeira Paul A, 2011, Patient Educ Couns, V84, pe9, DOI
10.1016/j.pec.2010.07.013
   Weitzman ER, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-39
   Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
   Wen K-Y, J MED INTERNET RES, pe73
   Westin Alan F, 2005, AHIP Cover, V46, P22
   Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI
10.1016/j.ijmedinf.2005.08.009
   Willison DJ, 2003, BRIT MED J, V326, P373, DOI 10.1136/bmj.326.7385.373
   Willison DJ, 2007, J AM MED INFORM ASSN, V14, P706, DOI 10.1197/jamia.M2457
   Willison DJ, 2009, BMC MED ETHICS, V10, DOI 10.1186/1472-6939-10-10
NR 45
TC 27
Z9 27
U1 6
U2 34
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD JUL
PY 2015
VL 22
IS 4
BP 821
EP 830
DI 10.1093/jamia/ocv014
PG 10
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
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SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
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OA Green Published
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PT J
AU Kaye, J
   Hawkins, N
AF Kaye, Jane
   Hawkins, Naomi
TI Data sharing policy design for consortia: challenges for sustainability
SO GENOME MEDICINE
LA English
DT Article
ID OMICS DATA; GENOME
AB The field of human genomics has led advances in the sharing of data with a
view to facilitating translation of research into innovations for human health.
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This change in scientific practice has been implemented through new policy developed by many principal investigators, project managers and funders, which has ultimately led to new forms of practice and innovative governance models for data sharing. Here, we examine the development of the governance of data sharing in genomics, and explore some of the key challenges associated with the design and implementation of these policies. We examine how the incremental nature of policy design, the perennial problem of consent, the gridlock caused by multiple and overlapping access systems, the administrative burden and the problems with incentives and acknowledgment all have an impact on the potential for data sharing to be maximized. We conclude by proposing ways in which the scientific community can address these problems, to improve the sustainability of data sharing into the future.
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FU Wellcome Trust [096599/2/11/Z]; EU F7 project BIOSHARE
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CR Ankeny RA, 2003, ENDEAVOUR, V27, P87, DOI 10.1016/S0160-9327(03)00061-9
[Anonymous], 2011, NAT MED, V17, P137, DOI 10.1038/nm0211-137
[Anonymous], 2013, NAT GENET, V45, P843
Berman H, 2003, NAT STRUCT BIOL, V10, P980, DOI 10.1038/nsb1203-980
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Burton PR, 2007, NATURE, V447, P661, DOI 10.1038/nature05911
Cambon-Thomsen A, 2011, NAT GENET, V43, P503, DOI 10.1038/ng.831
Cook-Deegan Robert, 1994, GENE WARS SCI POLITI
Creating a Global Alliance to Enable Responsible Sharing of Genomic and Clinical Data, 2013, CREATING GLOBAL ALLI
Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
Fortin S, 2011, PUBLIC HEALTH GENOM, V14, P104, DOI 10.1159/000309852
Ft. Lauderdale Agreement, 2003, SHARING DATA LARGE S
Gibbs RA, 2003, NATURE, V426, P789, DOI 10.1038/nature02168
Guttmacher AE, 2009, P NATL ACAD SCI USA, V106, P16894, DOI 10.1073/pnas.0910378106
Hayden EC, 2013, NATURE, V498, P16, DOI 10.1038/498017a
Henderson M, J SULSTON HUMAN GENO
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Hudson TJ, 2010, NATURE, V464, P993, DOI 10.1038/nature08987
Human Genome Organization (HUGO), 1996, PRINC AGR 1 INT STRA
Im HK, 2012, AM J HUM GENET, V90, P591, DOI 10.1016/j.ajhg.2012.02.008
Jasny BR, 2013, EPJ DATA SCI, V2, DOI 10.1140/epjds13
Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
Kaiser J, 2008, SCIENCE, V319, P395, DOI 10.1126/science.319.5862.395
Kaye J, 2011, BMJ-BRIT MED J, V343, pd6900, DOI DOI 10.1136/BMJ.D6900
Kaye J, 2012, SCIENCE, V336, P673, DOI 10.1126/science.1218015
Kaye J, 2012, NAT REV GENET, V13, P371, DOI 10.1038/nrg3218
Kaye J, 2011, HUM GENET, V130, P377, DOI 10.1007/s00439-011-1063-0
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Kwiatkowski D, 2008, NATURE, V456, P732, DOI 10.1038/nature07632
Louis KS, 2002, AM SCI, V90, P304, DOI 10.1511/2002.4.304
Mailman MD, 2007, NAT GENET, V39, P1181
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143

```
   Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
   Pryor G, 2009, INT J DIGITAL CURATI, V4, P71, DOI DOI 10.2218/IJDC.V4I3.115
   Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
   Schekman R, 2009, P NATL ACAD SCI USA, V106, P16893, DOI
10.1073/pnas.0910317106
   Stein DT, 2013, GENET TEST MOL BIOMA, V17, P855, DOI 10.1089/gtmb.2013.1550
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   Thorisson GA, 2011, ORCID DATA PUBLICATI
   Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI
10.1038/461168a
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Yuille M, 2010, CELL TISSUE BANK, V11, P241, DOI 10.1007/s10561-009-9150-3
NR 43
TC 27
Z9 27
U1 0
U2 14
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1756-994X
J9 GENOME MED
JI Genome Med.
PD JAN 29
PY 2014
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AR 4
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WC Genetics & Heredity
SC Genetics & Heredity
GA 297VM
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OA DOAJ Gold, Green Published
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PT J
AU Ma, XL
   Wu, YJ
   Wang, YH
AF Ma, Xiaolei
   Wu, Yao-Jan
   Wang, Yinhai
TI DRIVE Net E-Science Transportation Platform for Data Sharing,
   Visualization, Modeling, and Analysis
SO TRANSPORTATION RESEARCH RECORD
LA English
DT Article
ID MASS
AB In past decades, transportation research has been driven by mathematical
equations and has relied on scarce data. With increasing amounts of data being
collected from intelligent transportation system sensors, data-driven or data-
based research is expected to expand soon. Most online systems are designed to
handle one type of data, such as from freeway or arterial sensors. Even if
transportation data are ubiquitous, data usability is difficult to improve. A
framework is proposed for a regionwide web-based transportation decision system
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that adopts digital roadway maps as the base and provides data layers for integrating multiple data sources (e.g., traffic sensor, incident, accident, and travel time). This system, called the Digital Roadway Interactive Visualization and Evaluation Network (DRIVE Net), provides a practical method for facilitating data retrieval and integration and enhances data usability. Moreover, DRIVE Net offers a platform for optimizing transportation decisions that also serves as an ideal tool for visualizing historical observations spatially and temporally. Not only can DRIVE Net be used as a practical tool for various transportation analyses, with the use of its online computation engine, DRIVE Net can also help evaluate the benefit of a specific transportation solution. In its current implementation, DRIVE Net demonstrates potential to be used soon as a standard tool to incorporate more data sets from different fields (e.g., health and household data) and offer a platform for real-time decision making.

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CR Athol P., 1965, HIGHWAY RES REC, V72, P58
Bertini RL, 2005, TRANSPORT RES REC, P90
Cambridge Systematics Inc. Texas Transportation Institute, 2005, TRAFF CONG REL TREND
Cheevarunothai P, 2006, TRANSPORT RES REC, P73
Chen C., 2003, PUBLICATION U CALIFO
Chiu YC, 2008, IEEE T INTELL TRANSP, V9, P264, DOI 10.1109/TITS.2008.922878
CODD EF, 1970, COMMUN ACM, V13, P377, DOI 10.1145/362384.362685
Council F. M., 2009, HIGHWAY SAFETY INFOR
Eckerson W. W., 1995, OPEN INFORMATION SYS, V3, P1
Filippova D., 2009, 88 ANN M TRANSP RES
Garrett J. J., 2005, AJAX NEW APPROACH WE
Google Inc., GOOGL WEB TOOLK
Google Inc., GOOGL CHART TOOLS
Google Inc., GOOGL MAPS API
GRUBER TR, 1993, KNOWL ACQUIS, V5, P199, DOI 10.1006/knac.1993.1008
Haghani A, 2004, TRANSPORT RES REC, P176, DOI 10.3141/1882-21
Hastie T., 2009, ELEMENTS STAT LEARNI
Hey T, 2002, FUTURE GENER COMP SY, V18, P1017, DOI 10.1016/S0167-739X(02)00082-1
Jarke M, 2003, FUNDAMENTALS DATA WA
Listgarten J, 2007, PLOS COMPUT BIOL, V3, P1879, DOI 10.1371/journal.pcbi.0030188
Lund AS, 2010, TRANSPORT RES REC, P1, DOI 10.3141/2174-01
Ma X., 2011, 90 ANN M TRANSP RES
Malinovskiy Y., 2010, 89 ANN M TRANSP RES
May A. D., 1990, TRAFFIC FLOW FUNDAME
Miller M, 2008, CLOUD COMPUTING WEB
Murray-Tuite P., 2005, SWUTC051675281 COLL
Pack M. L., 2008, 87 ANN M TRANSP RES
Pack ML, 2005, TRANSPORT RES REC, P152
Petty K., 2006, 85 ANN M TRANSP RES
PIPES LA, 1967, TRANSPORT RES, V1, P21, DOI 10.1016/0041-1647(67)90092-5
Rahm E., 2000, IEEE DATA ENG B, V23, P3, DOI DOI 10.1145/1317331.1317341
Ran B., 1999, TRANSPORT RES REC, V1660, P114
Russel Stuart J., 1995, ARTIFICIAL INTELLIGE

```
   Seymour E. J., 2007, 86 ANN M TRANSP RES
   Singh V., 2006, MSRTR2006190 MICR CO
   Smith MC, 2008, J TRANSP ENG-ASCE, V134, P273, DOI 10.1061/(ASCE)0733-
947X(2008)134:7(273)
   Szlavecz K., 2006, MSRTR200690 MICR COR
   The Eclipse Foundation, ECL
   Tulle K. A., 2010, 89 ANN M TRANSP RES
   Van Hee VC, 2009, AM J RESP CRIT CARE, V179, P827, DOI 10.1164/rccm.200808-
1344OC
   VanDaniker M. R., 2009, 88 ANN M TRANSP RES
   Wang Y., 2009, QUANTIFYING INCIDENT
   Wang Y., 2009, DEV STATEWIDE ONLINE
   Wongsuphasawat K, 2009, TRANSPORT RES REC, P135, DOI 10.3141/2138-18
   Wu Y.-J., 2009, INT J WEB APPL, V1, P241
   Wu Y.-J., 2011, 90 ANN M TRANSP RES
   Wu Y.-J., 2010, 89 ANN M TRANSP RES
   Wu YJ, 2011, TRANSPORT RES REC, P24, DOI 10.3141/2215-03
   Wu YJ, 2010, TRANSPORT RES REC, P128, DOI 10.3141/2160-14
   Yao-Jan Wu, 2007, 2007 IEEE Intelligent Transportation Systems Conference,
P968
   Yu R., 2011, 90 ANN M TRANSP RES
NR 51
TC 27
Z9 27
U1 0
U2 20
PU NATL ACAD SCIENCES
PI WASHINGTON
PA 2101 CONSTITUTION AVE NW, WASHINGTON, DC 20418 USA
SN 0361-1981
EI 2169-4052
J9 TRANSPORT RES REC
JI Transp. Res. Record
PY 2011
IS 2215
BP 37
EP 49
DI 10.3141/2215-04
PG 13
WC Engineering, Civil; Transportation; Transportation Science & Technology
SC Engineering; Transportation
GA 831RM
UT WOS:000295748800004
DA 2019-08-06
ER

PT J
AU Hopkins, C
   Sydes, M
   Murray, G
   Woolfall, K
   Clarke, M
   Williamson, P
   Smith, CT
AF Hopkins, Carolyn
   Sydes, Matthew
   Murray, Gordon
   Woolfall, Kerry
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   Clarke, Mike
   Williamson, Paula
   Smith, Catrin Tudur
TI UK publicly funded Clinical Trials Units supported a controlled access
   approach to share individual participant data but highlighted concerns
SO JOURNAL OF CLINICAL EPIDEMIOLOGY
LA English
DT Article
DE Data sharing; Individual participant data; IPD; Clinical trial; Publicly
   funded; Clinical trial unit
ID OPEN SCIENCE; RAW DATA; PREVENTION; PROTOCOL; HEALTH
AB Objectives: Evaluate current data sharing activities of UK publicly funded Clinical Trial Units (CTUs) and identify good practices and barriers.

Study Design and Setting: Web-based survey of Directors of 45 UK Clinical Research Collaboration (UKCRC)-registered CTUs.

Results: Twenty-three (51%) CTUs responded: Five (22%) of these had an established data sharing policy and eight (35%) specifically requested consent to use patient data beyond the scope of the original trial. Fifteen (65%) CTUs had received requests for data, and seven (30%) had made external requests for data in the previous 12 months. CTUs supported the need for increased data sharing activities although concerns were raised about patient identification, misuse of data, and financial burden. Custodianship of clinical trial data and requirements for a CTU to align its policy to their parent institutes were also raised. No CTUs supported the use of an open access model for data sharing.

Conclusion: There is support within the publicly funded UKCRC-registered CTUs for data sharing, but many perceived barriers remain. CTUs are currently using a variety of approaches and procedures for sharing data. This survey has informed further work, including development of guidance for publicly funded CTUs, to promote good practice and facilitate data sharing. (C) 2016 The Authors. Published by Elsevier Inc.

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FU MRC Network of Hubs for Trials Methodology Research [MR/L004933/1- R39];
   Medical Research Council [MC_UU_12023/24, MR/L004933/1, MR/K025635/1,
   G0901530, G0800803, G0800792]
FX This work was supported by the MRC Network of Hubs for Trials Methodology Research (MR/L004933/1- R39). The views expressed are those of the authors and not necessarily those of the MRC. The funders played no role in the study design; collection, analysis, and interpretation of data; writing of the report; or the decision to submit the article for publication. Researchers were independent of influence from study

funders.
CR [Anonymous], 2014, EUR MED AG POL PUBL
Association of the British Pharmaceutical Industry, 2013, CLIN TRIAL TRANSP TE
Carrillo MC, 2012, ALZHEIMERS DEMENT, V8, P337, DOI 10.1016/j.jalz.2012.04.007
Chan AW, 2013, ANN INTERN MED, V158, P200, DOI 10.7326/0003-4819-158-3-201302050-00583
Cooper NJ, 2009, STAT MED, V28, P1861, DOI 10.1002/sim.3594
Cuticchia A Jamie, 2006, BMC Med Inform Decis Mak, V6, P19, DOI 10.1186/1472-6947-6-19
Doshi P, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001201
European Forum for Good Clinical Practice, 2014, MULT ROUNDT M SHAR C
Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7888
Gotzsche PC, 2012, CIRC-CARDIOVASC QUAL, V5, P236, DOI 10.1161/CIRCOUTCOMES.112.965277
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
GUEYFFIER F, 1995, THERAPIE, V50, P353
Hede K, 2013, JNCI-J NATL CANCER I, V105, P1159, DOI 10.1093/jnci/djt232
Institute of Medicine, 2014, DISC FRAM CLIN TRIAL, DOI 10.17226/18610
Lemmens T, 2012, AM J LAW MED, V38, P63
Little RJ, 2012, NEW ENGL J MED, V367, P1355, DOI 10.1056/NEJMsr1203730
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Perera D, 2013, INTERV CARDIOL, V5, P619
PRO ACT, POOL RES OP ACC ALS
Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI 10.1161/CIRCOUTCOMES.112.965798
Sandercock PAG, 2011, TRIALS, V12, P24
Sid Nair C, 2013, J QUAL PARTICIPATION, V35, P19
Smith CT, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0097886
Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
Tudur Smith C, 2015, GOOD PRACTICE PRINCI
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
NR 28
TC 26
Z9 31
U1 0
U2 14
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0895-4356
EI 1878-5921
J9 J CLIN EPIDEMIOL
JI J. Clin. Epidemiol.
PD FEB
PY 2016
VL 70
BP 17
EP 25
DI 10.1016/j.jclinepi.2015.07.002
PG 9
WC Health Care Sciences & Services; Public, Environmental & Occupational Health
SC Health Care Sciences & Services; Public, Environmental & Occupational Health

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UT WOS:000370676900003
PM 26169841
OA Green Published, Other Gold
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ER

PT J
AU Weitzman, ER
   Kelemen, S
   Kaci, L
   Mandl, KD
AF Weitzman, Elissa R.
   Kelemen, Skyler
   Kaci, Liljana
   Mandl, Kenneth D.
TI Willingness to share personal health record data for care improvement
   and public health: a survey of experienced personal health record users
SO BMC MEDICAL INFORMATICS AND DECISION MAKING
LA English
DT Article
ID ELECTRONIC MEDICAL-RECORDS; FACTOR SURVEILLANCE SYSTEM; QUALITY-OF-CARE;
   SOCIOECONOMIC-STATUS; UNITED-STATES; INFORMATION; ATTITUDES;
   PROFESSIONALS; MANAGEMENT; COMMUNICATION
AB Background: Data stored in personally controlled health records (PCHRs) may
hold value for clinicians and public health entities, if patients and their
families will share them. We sought to characterize consumer willingness and
unwillingness (reticence) to share PCHR data across health topics, and with
different stakeholders, to advance understanding of this issue.
   Methods: Cross-sectional 2009 Web survey of repeat PCHR users who were
patients over 18 years old or parents of patients, to assess willingness to
share their PCHR data with an-out-of-hospital provider to support care, and the
state/local public health authority to support monitoring; the odds of reticence
to share PCHR information about ten exemplary health topics were estimated using
a repeated measures approach.
   Results: Of 261 respondents (56% response rate), more reported they would
share all information with the state/local public health authority (63.3%) than
with an out-of-hospital provider (54.1%) (OR 1.5, 95% CI 1.1, 1.9; p = .005);
few would not share any information with these parties (respectively, 7.9% and
5.2%). For public health sharing, reticence was higher for most topics compared
to contagious illness (ORs 4.9 to 1.4, all p-values < .05), and reflected
concern about anonymity (47.2%), government insensitivity (41.5%),
discrimination (24%). For provider sharing, reticence was higher for all topics
compared to contagious illness (ORs 6.3 to 1.5, all p-values < .05), and
reflected concern for relevance (52%), disclosure to insurance (47.6%) and/or
family (20.5%).
   Conclusions: Pediatric patients and their families are often willing to share
electronic health information to support health improvement, but remain cautious.
Robust trust models for PCHR sharing are needed.
C1 [Weitzman, Elissa R.; Kelemen, Skyler; Kaci, Liljana; Mandl, Kenneth D.]
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CR Baird W, 2009, J MED ETHICS, V35, P92, DOI 10.1136/jme.2008.025304
Bays HE, 2007, BMC PUBLIC HEALTH, V7, DOI 10.1186/1471-2458-7-277
Beckles GLA, 2007, MED CARE, V45, P876, DOI 10.1097/MLR.0b013e3180ca95fa
Benton Tami, 2007, Ann Clin Psychiatry, V19, P289, DOI 10.1080/10401230701653542
Boonstra A, 2010, BMC HEALTH SERV RES, V10, DOI 10.1186/1472-6963-10-231
Bourgeois FC, 2008, J AM MED INFORM ASSN, V15, P737, DOI 10.1197/jamia.M2865
Boyle MJ, 2010, BMC MED EDUC, V10, DOI 10.1186/1472-6920-10-71
Britt TW, 2007, MIL MED, V172, P157, DOI 10.7205/MILMED.172.2.157
Buckley BS, 2011, J MED ETHICS, V37, P50, DOI 10.1136/jme.2010.037903
Burke Darrell, 2005, J Healthc Qual, V27, P24
Chowdhury Pranesh, 2010, Morbidity and Mortality Weekly Report, V59, P1
Clark AM, 2009, NAT REV CARDIOL, V6, P712, DOI 10.1038/nrcardio.2009.163
Dawood N, 2008, ARCH INTERN MED, V168, P1961, DOI 10.1001/archinte.168.18.1961
Detmer D, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-45
Ebell M, 2010, MED DECIS MAKING, V30, P712, DOI 10.1177/0272989X10386232
Eiser C, 2001, ARCH DIS CHILD, V84, P205, DOI 10.1136/adc.84.3.205
Gaylin DS, 2011, HEALTH SERV RES, V46, P920, DOI 10.1111/j.1475-6773.2010.01233.x
Hampton T, 2008, JAMA-J AM MED ASSOC, V299, P1888, DOI 10.1001/jama.299.16.1888
Heisler M, 2003, DIABETES CARE, V26, P738, DOI 10.2337/diacare.26.3.738
Hood JE, 2011, SEX HEALTH, V8, P159, DOI 10.1071/SH10070
Horwitz AV, 2010, MILBANK Q, V88, P112, DOI 10.1111/j.1468-0009.2010.00591.x
Hou JR, 2010, J HEALTH COMMUN, V15, P186, DOI 10.1080/10810730.2010.522691
Huppert Jill S, 2003, Curr Womens Health Rep, V3, P451
Jeffreys MD, 2010, MIL MED, V175, P719, DOI 10.7205/MILMED-D-10-00054
Koch T, 2010, BMC FAM PRACT, V11, DOI 10.1186/1471-2296-11-52
Kohane IS, 2005, NEW ENGL J MED, V353, P2074, DOI 10.1056/NEJMsb051220
LANDGRAF JM, 2005, ASSESSING QUALITY LI, P339
Lichtenstein B, 2005, SEX TRANSM DIS, V32, P281, DOI 10.1097/01.olq.0000163597.44078.19
Mandl KD, 2001, BMJ-BRIT MED J, V322, P283, DOI 10.1136/bmj.322.7281.283
Mandl KD, 2007, BMC MED INFORM DECIS, V7, DOI 10.1186/1472-6947-7-25
Mann MY, 2006, PEDIATRICS, V117, pS315, DOI 10.1542/peds.2005-2633K
Mojtabai R, 2007, PSYCHIAT SERV, V58, P642, DOI 10.1176/appi.ps.58.5.642
O'Malley AS, 2010, J GEN INTERN MED, V25, P177, DOI 10.1007/s11606-009-1195-2
[PCAST The White House Office of Science and Technology Policy], 2010, REP PRES REAL FULL P
Ramsey Fred, 2008, Morbidity and Mortality Weekly Report, V57, P1
Ramsey SD, 2007, J UROLOGY, V177, P1992, DOI 10.1016/j.juro.2007.01.138
Rathore SS, 2008, ARCH GEN PSYCHIAT, V65, P1402, DOI 10.1001/archpsyc.65.12.1402

```
   Roush S, 1999, JAMA-J AM MED ASSOC, V282, P164, DOI 10.1001/jama.282.2.164
   Silk BJ, 2005, J PUBLIC HEALTH MAN, V11, P191
   Sprinson JE, 2006, BMC PUBLIC HEALTH, V6, DOI 10.1186/1471-2458-6-217
   Tang PC, 2006, J AM MED INFORM ASSN, V13, P121, DOI 10.1197/jamia.M2025
   Teh CF, 2010, PSYCHOSOM MED, V72, P61, DOI 10.1097/PSY.0b013e3181c2a7a8
   Walker J, 2011, ANN INTERN MED, V155, P811, DOI 10.7326/0003-4819-155-12-
201112200-00003
   Weitzman ER, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0019256
   Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
   Weitzman ER, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1187
   Willison DJ, 2009, BMC MED ETHICS, V10, DOI 10.1186/1472-6939-10-10
   Yamin CK, 2011, ARCH INTERN MED, V171, P568, DOI
10.1001/archinternmed.2011.34
NR 48
TC 25
Z9 25
U1 0
U2 24
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1472-6947
J9 BMC MED INFORM DECIS
JI BMC Med. Inform. Decis. Mak.
PD MAY 22
PY 2012
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AR 39
DI 10.1186/1472-6947-12-39
PG 10
WC Medical Informatics
SC Medical Informatics
GA 977ZL
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PT J
AU Stokes, TH
   Torrance, JT
   Li, H
   Wang, MD
AF Stokes, Todd H.
   Torrance, J. T.
   Li, Henry
   Wang, May D.
TI ArrayWiki: an enabling technology for sharing public microarray data
   repositories and meta-analyses
SO BMC BIOINFORMATICS
LA English
DT Article; Proceedings Paper
CT Symposium of Computations in Bioinformatics and Bioscience (SCBB07)
CY AUG 13-15, 2007
CL Iowa City, IA
ID EXPRESSION PROFILES; CDNA MICROARRAYS; CANCER; BIOINFORMATICS;
   WIKIPEDIA; BIOLOGY; WIKI; ANNOTATION; SIGNATURES; PLATFORMS
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AB Background: A survey of microarray databases reveals that most of the repository contents and data models are heterogeneous (i.e., data obtained from different chip manufacturers), and that the repositories provide only basic biological keywords linking to PubMed. As a result, it is difficult to find datasets using research context or analysis parameters information beyond a few keywords. For example, to reduce the "curse-of-dimension" problem in microarray analysis, the number of samples is often increased by merging array data from different datasets. Knowing chip data parameters such as pre-processing steps (e.g., normalization, artefact removal, etc), and knowing any previous biological validation of the dataset is essential due to the heterogeneity of the data. However, most of the microarray repositories do not have meta-data information in the first place, and do not have a a mechanism to add or insert this information. Thus, there is a critical need to create "intelligent" microarray repositories that (1) enable update of metadata with the raw array data, and (2) provide standardized archiving protocols to minimize bias from the raw data sources.

Results: To address the problems discussed, we have developed a community maintained system called ArrayWiki that unites disparate meta-data of microarray meta-experiments from multiple primary sources with four key features. First, ArrayWiki provides a user-friendly knowledge management interface in addition to a programmable interface using standards developed by Wikipedia. Second, ArrayWiki includes automated quality control processes (caCORRECT) and novel visualization methods (BioPNG, Gel Plots), which provide extra information about data quality unavailable in other microarray repositories. Third, it provides a user-curation capability through the familiar Wiki interface. Fourth, ArrayWiki provides users with simple text-based searches across all experiment meta-data, and exposes data to search engine crawlers (Semantic Agents) such as Google to further enhance data discovery.

Conclusions: Microarray data and meta information in ArrayWiki are distributed and visualized using a novel and compact data storage format, BioPNG. Also, they are open to the research community for curation, modification, and contribution. By making a small investment of time to learn the syntax and structure common to all sites running MediaWiki software, domain scientists and practioners can all contribute to make better use of microarray technologies in research and medical practices.

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CR *AFF INC, 2005, GUID PROB LOG INT ER
Arshinoff BI, 2007, NUCLEIC ACIDS RES, V35, pD422, DOI 10.1093/nar/gkl881
Ball CA, 2005, NUCLEIC ACIDS RES, V33, pD580
Barrett T, 2005, NUCLEIC ACIDS RES, V33, pD562
Baumgartner W. A., 2007, BIOINFORMATICS, V23, P141
Churchill GA, 2002, NAT GENET, V32, P490, DOI 10.1038/ng1031
Day A, 2007, GENOME BIOL, V8, DOI 10.1186/gb-2007-8-6-r112
Duggan DJ, 1999, NAT GENET, V21, P10, DOI 10.1038/4434
Fernandez-Garcia N, 2006, LECT NOTES ARTIF INT, V4253, P580
Gentleman RC, 2004, GENOME BIOL, V5, DOI 10.1186/gb-2004-5-10-r80
Giles J, 2007, NATURE, V445, P691, DOI 10.1038/445691a
Giustini D, 2006, BRIT MED J, V333, P1283, DOI 10.1136/bmj.39062.555405.80

Hanauer DA, 2007, CURR MOL MED, V7, P133, DOI 10.2174/156652407779940431
Hepp M, 2007, IEEE INTERNET COMPUT, V11, P54, DOI 10.1109/MIC.2007.110
Hucka M, 2003, BIOINFORMATICS, V19, P524, DOI 10.1093/bioinformatics/btg015
Irizarry RA, 2005, NAT METHODS, V2, P345, DOI 10.1038/nmeth756
Lamb J, 2006, SCIENCE, V313, P1929, DOI 10.1126/science.1132939
Luciano JS, 2005, DRUG DISCOV TODAY, V10, P937, DOI 10.1016/S1359-6446(05)03501-4
Luo Y, 2005, DRUG DISCOV TODAY, V10, P1689, DOI 10.1016/S1359-6446(05)03647-0
MILLENAAR FF, 2006, BMC BIOINFORMATICS, V7
Oster S., 2007, J AM MED INFORM ASS
Parkinson H, 2005, NUCLEIC ACIDS RES, V33, pD553
Pearson H, 2006, NATURE, V441, P678, DOI 10.1038/441678a
PFEIL U, 2006, J COMPUTER MEDIATED, V12
Rhodes DR, 2007, NEOPLASIA, V9, P166, DOI 10.1593/neo.07112
Rhodes DR, 2004, NEOPLASIA, V6, P1, DOI 10.1016/S1476-5586(04)80047-2
Salzberg SL, 2007, GENOME BIOL, V8, DOI 10.1186/gb-2007-8-1-102
Schuetz AN, 2005, J MOL DIAGN, V7, P206, DOI 10.1016/S1525-1578(10)60547-8
Segal E, 2005, NAT GENET, V37, pS38, DOI 10.1038/ng1561
SEO J, 2006, BMC BIOINFORMATICS, V7
Shen LH, 2005, NUCLEIC ACIDS RES, V33, pD614
Shi LM, 2006, NAT BIOTECHNOL, V24, P1151, DOI 10.1038/nbt1239
Shippy R, 2006, NAT BIOTECHNOL, V24, P1123, DOI 10.1038/nbt1241
Stokes TH, 2007, ANN BIOMED ENG, V35, P1068, DOI 10.1007/s10439-007-9313-y
Stromback L, 2005, BIOINFORMATICS, V21, P4401, DOI 10.1093/bioinformatics/bti718
Tapscott D, 2006, WIKINOMICS MASS COLL
TORRANCE JT, 2007, LIF SCI SYST APPL WO, P196
Whetzel PL, 2006, BIOINFORMATICS, V22, P866, DOI 10.1093/bioinformatics/btl005
Young AN, 2008, ADV ANAT PATHOL, V15, P28, DOI 10.1097/PAP.0b013e3181594720
Zhang TT, 2006, NANO LETT, V6, P800, DOI 10.1021/nl0603350
NR 40
TC 25
Z9 25
U1 0
U2 17
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1471-2105
J9 BMC BIOINFORMATICS
JI BMC Bioinformatics
PY 2008
VL 9
SU 6
AR S18
DI 10.1186/1471-2105-9-S6-S18
PG 14
WC Biochemical Research Methods; Biotechnology & Applied Microbiology; Mathematical & Computational Biology
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology; Mathematical & Computational Biology
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PT J
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AF Tamm, Marcus
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TI Elasticities of market shares and social health insurance choice in
   Germany: A dynamic panel data approach
SO HEALTH ECONOMICS
LA English
DT Article
DE competition; generalized method of moments; health insurance
ID MANAGED COMPETITION; MODELS; DEMAND; ESTIMATORS; CARE
AB In 1996, free choice of health insurers was introduced to the German social health insurance system. One objective was to increase efficiency through competition. A crucial precondition for effective competition among health insurers is that consumers search for lower-priced health insurers. We test this hypothesis by estimating the price elasticities of insurers' market shares. We use unique panel data and specify a dynamic panel model to explain changes in market shares. Estimation results suggest that short-run price elasticities are smaller than previously found by other studies. In the long-run, however, estimation results suggest substantial price effects. Copyright (c) 2006 John Wiley & Sons, Ltd.
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CR ARELLANO M, 1991, REV ECON STUD, V58, P277, DOI 10.2307/2297968
   ARELLANO M, 1995, J ECONOMETRICS, V68, P29, DOI 10.1016/0304-4076(94)01642-D
   Baltagi B. H., 2001, ECONOMETRIC ANAL PAN
   Beck K., 2004, RISIKO KRANKENVERSIC
   BEHREND C, 2004, J PUBLIC HLTH, V12, P20
   BERRY S, 1995, ECONOMETRICA, V63, P841, DOI 10.2307/2171802
   BERRY ST, 1994, RAND J ECON, V25, P242, DOI 10.2307/2555829
   Blundell R, 1998, J ECONOMETRICS, V87, P115, DOI 10.1016/S0304-4076(98)00009-8
   BOND S, 2005, 0705 CEMMAP CWP I FI
   Bond S. R., 2002, PORT ECON J, V1, P141, DOI DOI 10.1007/S10258-002-0009-9
   BREITUNG J, 1994, APPL ECON, V26, P353, DOI 10.1080/00036849400000081
   Chintagunta PK, 2001, MARKET SCI, V20, P442, DOI 10.1287/mksc.20.4.442.9751
   De Ven V, 2000, HDB HLTH EC, P755
   ENTHOVEN AC, 1993, HEALTH AFFAIR, V12, P24, DOI 10.1377/hlthaff.12.suppl_1.24
   FELDMAN R, 1989, J HUM RESOUR, V24, P115, DOI 10.2307/145935
   Gress S, 2002, HEALTH POLICY, V60, P235, DOI 10.1016/S0168-8510(01)00193-2
   Gress S, 2004, J HEALTH POLIT POLIC, V29, P679, DOI 10.1215/03616878-29-4-5-679
   GRESS S, 2005, HLTH CARE COVERAGE D, P115
   Gress S, 2006, HEALTH POLICY, V78, P295, DOI 10.1016/j.healthpol.2005.11.011
   HANSEN LP, 1982, ECONOMETRICA, V50, P1029, DOI 10.2307/1912775
   Hoppner K., 2004, GESUNDHEITSMONITOR 2, P24
   Jacobs K., 2002, SCHRIFTENREIHE BUNDE, V140
   McFadden D., 1974, FRONTIERS ECONOMETRI, P105, DOI DOI 10.1108/EB028592

```
   McKenzie D.J., 2001, ECONOMET J, V4, P89, DOI DOI 10.1111/ECTJ.2001.4.ISSUE-1
   Nevo A, 2000, J ECON MANAGE STRAT, V9, P513, DOI 10.1162/105864000567954
   Nuscheler R, 2005, HEALTH ECON, V14, P1253, DOI 10.1002/hec.1005
   Roodman D., 2005, XTABOND2 STATA MODUL
   Royalty AB, 1999, J HUM RESOUR, V34, P1, DOI 10.2307/146301
   SARGAN JD, 1958, ECONOMETRICA, V26, P393, DOI 10.2307/1907619
   Scanlon DP, 2002, J HEALTH ECON, V21, P19, DOI 10.1016/S0167-6296(01)00111-4
   Schut Frederik T, 2003, Int J Health Care Finance Econ, V3, P117, DOI
10.1023/A:1023369231291
   Schut FT, 2002, J HEALTH ECON, V21, P1009, DOI 10.1016/S0167-6296(02)00055-3
   Schwarze J, 2001, SCHMOLLERS JB, V121, P581
   Windmeijer F, 2005, J ECONOMETRICS, V126, P25, DOI
10.1016/j.jeconom.2004.02.005
   Wooldridge J. M., 2002, ECONOMETRIC ANAL CRO
NR 35
TC 25
Z9 26
U1 0
U2 6
PU JOHN WILEY & SONS LTD
PI CHICHESTER
PA THE ATRIUM, SOUTHERN GATE, CHICHESTER PO19 8SQ, W SUSSEX, ENGLAND
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J9 HEALTH ECON
JI Health Econ.
PD MAR
PY 2007
VL 16
IS 3
BP 243
EP 256
DI 10.1002/hec.1167
PG 14
WC Economics; Health Care Sciences & Services; Health Policy & Services
SC Business & Economics; Health Care Sciences & Services
GA 145YH
UT WOS:000244901200003
PM 16981190
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ER

PT J
AU Aitken, M
   Jorre, JD
   Pagliari, C
   Jepson, R
   Cunningham-Burley, S
AF Aitken, Mhairi
   Jorre, Jenna de St.
   Pagliari, Claudia
   Jepson, Ruth
   Cunningham-Burley, Sarah
TI Public responses to the sharing and linkage of health data for research
   purposes: a systematic review and thematic synthesis of qualitative
   studies
SO BMC MEDICAL ETHICS
LA English
DT Article
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DE Data linkage; Data sharing; Public engagement; Health informatics

ID PRIVACY; CONSENT; INFORMATION; RECORDS; CARE; CONFIDENTIALITY; MORTALITY; ATTITUDES; DISEASE; PEOPLE

AB Background: The past 10 years have witnessed a significant growth in sharing of health data for secondary uses. Alongside this there has been growing interest in the public acceptability of data sharing and data linkage practices. Public acceptance is recognised as crucial for ensuring the legitimacy of current practices and systems of governance. Given the growing international interest in this area this systematic review and thematic synthesis represents a timely review of current evidence. It highlights the key factors influencing public responses as well as important areas for further research.

Methods: This paper reports a systematic review and thematic synthesis of qualitative studies examining public attitudes towards the sharing or linkage of health data for research purposes. Twenty-five studies were included in the review. The included studies were conducted primarily in the UK and North America, with one study set in Japan, another in Sweden and one in multiple countries. The included studies were conducted between 1999 and 2013 (eight studies selected for inclusion did not report data collection dates). The qualitative methods represented in the studies included focus groups, interviews, deliberative events, dialogue workshops and asynchronous online interviews.

Results: Key themes identified across the corpus of studies related to the conditions necessary for public support/acceptability, areas of public concern and implications for future research. The results identify a growing body of evidence pointing towards widespread general-though conditional-support for data linkage and data sharing for research purposes. Whilst a variety of concerns were raised (e.g. relating to confidentiality, individuals' control over their data, uses and abuses of data and potential harms arising) in cases where participants perceived there to be actual or potential public benefits from research and had trust in the individuals or organisations conducting and/or overseeing data linkage/sharing, they were generally supportive. The studies also find current low levels of awareness about existing practices and uses of data.

Conclusions: Whilst the results indicate widespread (conditional) public support for data sharing and linkage for research purposes, a range of concerns exist. In order to ensure public support for future research uses of data greater awareness raising combined with opportunities for public engagement and deliberation are needed. This will be essential for ensuring the legitimacy of future health informatics research and avoiding further public controversy.

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FU Farr Institute of Health Informatics Research; Arthritis Research UK; British Heart Foundation; Cancer Research UK; Economic and Social Research Council; Engineering and Physical Sciences Research Council; Medical Research Council; National Institute of Health Research; National Institute for Social Care and Health Research (Welsh Assembly Government); Chief Scientist Office (Scottish Government Health Directorates); Wellcome Trust, (MRC) [MR/M501633/2]; Engineering and Physical Sciences Research Council [EP/J017728/1, EP/J017728/2]; Medical Research Council [MR/K007017/1, MR/K023209/1]

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CR Aitken M, 2016, SCI PUBL POLICY, V43, P713, DOI 10.1093/scipol/scv075
Barbour RS, 2003, J EVAL CLIN PRACT, V9, P179, DOI 10.1046/j.1365-2753.2003.00371.x
Booth A, 2001, COCHRANE COCK EYED S
Bradwell & Gallagher, 2007, FYI NEW POL PERS INF
Britten Nicky, 2002, J Health Serv Res Policy, V7, P209, DOI 10.1258/135581902320432732
Buckley BS, 2011, J MED ETHICS, V37, P50, DOI 10.1136/jme.2010.037903
Campbell B, 2007, QUAL SAF HEALTH CARE, V16, P404, DOI 10.1136/qshc.2006.020313
Chalmers J, 2003, BMJ-BRIT MED J, V326, P725, DOI 10.1136/bmj.326.7392.725
Critical Appraisal Skills Programme (CASP), 2013, CASP QUAL CHECKL
Damschroder LJ, 2007, SOC SCI MED, V64, P223, DOI 10.1016/j.socscimed.2006.08.045
Davidson S., 2013, SOCIAL RES SERIES
Devers K, 2013, FEASIBILITY USING EL
Fischbacher CM, 2007, BMC PUBLIC HEALTH, V7, DOI 10.1186/1471-2458-7-142
Gross AG, 1994, PUBLIC UNDERST SCI, V3, P3, DOI DOI 10.1088/0963-6625/3/1/001
Haddow G, 2011, J EVAL CLIN PRACT, V17, P1140, DOI 10.1111/j.1365-2753.2010.01488.x
Hartz SM, 2011, AM J EPIDEMIOL, V174, P336, DOI 10.1093/aje/kwr084
Holman CDJ, 2008, AUST HEALTH REV, V32, P766, DOI 10.1071/AH080766
Information Commissioner's Office (ICO), 2012, AN MAN DAT PROT RISK
Ishikawa H, 2005, INT J JPN SOCIOL, V14, P84, DOI 10.1111/j.1475-6781.2005.00070.x
Jutte DP, 2011, ANNU REV PUBL HEALTH, V32, P91, DOI 10.1146/annurev-publhealth-031210-100700
Kariminia A, 2007, INT J EPIDEMIOL, V36, P310, DOI 10.1093/ije/dyl225
King T, 2012, INT J MED INFORM, V81, P279, DOI 10.1016/j.ijmedinf.2012.01.005
Mezuk B, 2008, COMMUNITY GENET, V11, P171, DOI 10.1159/000113880
MRC & Wellcome Trust, 2006, ACC COLL DAT MAT HLT
Ohm P, 2010, UCLA LAW REV, V57, P1701
Pentz RD, 2006, AM J MED GENET A, V140A, P733, DOI 10.1002/ajmg.a.31154
Popay J, 1998, QUAL HEALTH RES, V8, P341, DOI 10.1177/104973239800800305
Pope C, 2000, BMJ-BRIT MED J, V320, P114, DOI 10.1136/bmj.320.7227.114
Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
Sandelowski M, 2003, QUAL HEALTH RES, V13, P905, DOI 10.1177/1049732303253488
Strobl J, 2000, BRIT MED J, V321, P890, DOI 10.1136/bmj.321.7265.890
Thomas J, 2008, BMC MED RES METHODOL, V8, DOI 10.1186/1471-2288-8-45
Verity C, 2002, BRIT MED J, V324, P1210, DOI 10.1136/bmj.324.7347.1210
Veugelers PJ, 2001, AM J EPIDEMIOL, V154, P725, DOI 10.1093/aje/154.8.725
Wellcome Trust, 2016, ON WAY MIRR PUBL ATT
Wellcome Trust. Public health research data forum, 2015, EN DAT LINK MAX VAL
Young TK, 2000, AM J PUBLIC HEALTH, V90, P1466, DOI 10.2105/AJPH.90.9.1466

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JI BMC Med. Ethics
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AR 73
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PG 24
WC Ethics; Medical Ethics; Social Sciences, Biomedical
SC Social Sciences - Other Topics; Medical Ethics; Biomedical Social
   Sciences
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AU Antman, EM
   Benjamin, EJ
   Harrington, RA
   Houser, SR
   Peterson, ED
   Bauman, MA
   Brown, N
   Bufalino, V
   Califf, RM
   Creager, MA
   Daugherty, A
   Demets, DL
   Dennis, BP
   Ebadollahi, S
   Jessup, M
   Lauer, MS
   Lo, B
   MacRae, CA
   McConnell, MV
   McCray, AT
   Mello, MM
   Mueller, E
   Newburger, JW
   Okun, S
   Packer, M
   Philippakis, A
   Ping, PP
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   Roger, VL
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   Wayte, P
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AF Antman, Elliott M.
Benjamin, Emelia J.
Harrington, Robert A.
Houser, Steven R.
Peterson, Eric D.
Bauman, Mary Ann
Brown, Nancy
Bufalino, Vincent
Califf, Robert M.
Creager, Mark A.
Daugherty, Alan
Demets, David L.
Dennis, Bernard P.
Ebadollahi, Shahram
Jessup, Mariell
Lauer, Michael S.
Lo, Bernard
MacRae, Calum A.
McConnell, Michael V.
McCray, Alexa T.
Mello, Michelle M.
Mueller, Eric
Newburger, Jane W.
Okun, Sally
Packer, Milton
Philippakis, Anthony
Ping, Peipei
Prasoon, Prad
Roger, Veronique L.
Singer, Steve
Temple, Robert
Turner, Melanie B.
Vigilante, Kevin
Warner, John
Wayte, Patrick
CA Amer Heart Assoc Data Sharing
TI Acquisition, Analysis, and Sharing of Data in 2015 and Beyond: A Survey of the Landscape A Conference Report From the American Heart Association Data Summit 2015
SO JOURNAL OF THE AMERICAN HEART ASSOCIATION
LA English
DT Article
DE AHA Scientific Statements; clinical trials; data; epidemiology; ethics; mobile health; preclinical
ID CLINICAL-DATA STANDARDS; SCIENTIFIC STATEMENT; PRECISION MEDICINE; MOBILE HEALTH; BIG DATA; CARDIOVASCULAR-DISEASE; UNDIAGNOSED DISEASES; DIGITAL TECHNOLOGY; PHYSICAL-ACTIVITY; NATIONAL HEART

AB Background-A 1.5-day interactive forum was convened to discuss critical issues in the acquisition, analysis, and sharing of data in the field of cardiovascular and stroke science. The discussion will serve as the foundation for the American Heart Association's (AHA's) near-term and future strategies in the Big Data area. The concepts evolving from this forum may also inform other fields of medicine and science.

Methods and Results-A total of 47 participants representing stakeholders from 7 domains (patients, basic scientists, clinical investigators, population researchers, clinicians and healthcare system administrators, industry, and regulatory authorities) participated in the conference. Presentation topics included updates on data as viewed from conventional medical and nonmedical sources, building and using Big Data repositories, articulation of the goals of data sharing, and principles of responsible data sharing. Facilitated breakout sessions were conducted to examine what each of the 7 stakeholder domains wants from Big Data under ideal circumstances and the possible roles that the AHA might play in meeting their needs. Important areas that are high priorities for further study regarding Big Data include a description of the methodology of how to acquire and analyze findings, validation of the veracity of discoveries from such research, and integration into investigative and clinical care aspects of future cardiovascular and stroke medicine. Potential roles that the AHA might consider include facilitating a standards discussion (eg, tools, methodology, and appropriate data use), providing education (eg, healthcare providers, patients, investigators), and helping build an interoperable digital ecosystem in cardiovascular and stroke science.

Conclusion-There was a consensus across stakeholder domains that Big Data holds great promise for revolutionizing the way cardiovascular and stroke research is conducted and clinical care is delivered; however, there is a clear need for the creation of a vision of how to use it to achieve the desired goals. Potential roles for the AHA center around facilitating a discussion of standards, providing education, and helping establish a cardiovascular digital ecosystem. This ecosystem should be interoperable and needs to interface with the rapidly growing digital object environment of the modern-day healthcare system.

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CR Accreditation Council for Continuing Medical Education (ACCME ®), 2015, 2014 ANNUAL REPORT
Adler NE, 2015, NEW ENGL J MED, V372, P698, DOI 10.1056/NEJMp1413945
Alston C, 2012, COMMUNICATING PATIEN
Amarasingham R, 2014, HEALTH AFFAIR, V33, P1148, DOI 10.1377/hlthaff.2014.0352
American Heart Association (AHA), OP SCI POL TAT AHA F
Anderson G, 1998, CONTROL CLIN TRIALS, V19, P61
Anderson ML, 2015, NEW ENGL J MED, V372, P1031, DOI 10.1056/NEJMsa1409364
Angus DC, 2015, JAMA-J AM MED ASSOC, V314, P767, DOI 10.1001/jama.2015.7762
[Anonymous], 2013, ALL TRIALS REPORTED
[Anonymous], 2011, PREC MED BUILD KNOWL
[Anonymous], 2015, AM J MED GENET A A, V167a, pviii
Antman E, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g237
Antman E, 2012, WIRES SYST BIOL MED, V4, P367, DOI 10.1002/wsbm.1173
Antman EM, 2015, CIRCULATION, V131, P2238, DOI 10.1161/CIR.0000000000000224
Ashley EA, 2015, JAMA-J AM MED ASSOC, V313, P2119, DOI 10.1001/jama.2015.3595
Banchs JE, 2015, MED CLIN N AM, V99, P877, DOI 10.1016/j.mcna.2015.02.013
Begley CG, 2012, NATURE, V483, P531, DOI 10.1038/483531a
Bender MS, 2014, JMIR MHEALTH UHEALTH, V2, DOI 10.2196/mhealth.3710
Bild DE, 2002, AM J EPIDEMIOL, V156, P871, DOI 10.1093/aje/kwf113
Bollinger JM, 2012, GENET MED, V14, P451, DOI 10.1038/gim.2011.66
Bram JT, 2015, BIG DATA-US, V3, P59, DOI 10.1089/big.2014.0053
Brooks D., 2013, NY TIMES
Brooks GC, 2014, CIRCULATION, V130
Bufalino V, 2014, CIRC-CARDIOVASC QUAL, V7, P493, DOI 10.1161/HCQ.0000000000000003
Bufalino VJ, 2011, CIRCULATION, V123, P2167, DOI 10.1161/CIR.0b013e3182181529
Burke LE, 2015, CIRCULATION, V132, P1157, DOI 10.1161/CIR.0000000000000232
Califf RM, 2014, CLIN PHARMACOL THER, V95, P131, DOI 10.1038/clpt.2013.232
Case MA, 2015, JAMA-J AM MED ASSOC, V313, P625, DOI 10.1001/jama.2014.17841
Centers for Medicare & Medicaid Services, 2014, DAT PROGR REP 2014

Chesser A, 2016, INFORM HEALTH SOC CA, V41, P1, DOI 10.3109/17538157.2014.948171
Cho MK, 2015, ANN INTERN MED, V162, P690, DOI 10.7326/M15-0166
Chute CG, 2013, GENET MED, V15, P802, DOI 10.1038/gim.2013.121
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Cortez NG, 2014, NEW ENGL J MED, V371, P372, DOI 10.1056/NEJMhle1403384
DAWBER TR, 1951, AM J PUBLIC HEALTH, V41, P279
Dean J., 2004, OSDI 04 6 S OP SYST
Denny JC, 2013, NAT BIOTECHNOL, V31, P1102, DOI 10.1038/nbt.2749
Drazen JM, 2015, NEW ENGL J MED, V372, P201, DOI 10.1056/NEJMp1415160
Evans BJ, 2015, NEW ENGL J MED, V372, P2258, DOI 10.1056/NEJMsr1501194
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
FORCE11, GUID PRINC FIND ACC
Fordyce CB, 2015, J AM COLL CARDIOL, V65, P1567, DOI 10.1016/j.jacc.2015.03.016
Fox CS, 2015, CIRCULATION, V131, P1715, DOI 10.1161/CIR.0000000000000211
Fried Linda P., 1991, Annals of Epidemiology, V1, P263
FRIEDMAN GD, 1988, J CLIN EPIDEMIOL, V41, P1105, DOI 10.1016/0895-4356(88)90080-7
Gahl WA, 2012, GENET MED, V14, P51, DOI 10.1038/gim.0b013e318232a005
Gahl WA, 2012, DIS MODEL MECH, V5, P3, DOI 10.1242/dmm.009258
Grajales FCD, 2014, SOCIAL NETWORKING SI
Grande D, 2014, ANN INTERN MED, V161, P855, DOI 10.7326/M14-1118
Hawgood S, 2015, SCI TRANSL MED, V7, DOI 10.1126/scitranslmed.aaa9970
Hendel RC, 2014, CIRCULATION, V129, P2346, DOI 10.1161/01.cir.0000438353.32328.98
Hicks KA, 2015, CIRCULATION, V132, P302, DOI 10.1161/CIR.0000000000000156
Howard Barbara V, 2005, Int J Circumpolar Health, V64, P206
Howard VJ, 2005, NEUROEPIDEMIOLOGY, V25, P135, DOI 10.1159/000086678
IBM, IBM WATS HLTH
IOM (Institute of Medicine), 2015, SHARING CLIN TRIAL D
Jameson JL, 2015, NEW ENGL J MED, V372, P2229, DOI 10.1056/NEJMsb1503104
Joyner MJ, 2015, JAMA-J AM MED ASSOC, V314, P999, DOI 10.1001/jama.2015.7725
KANNEL WB, 1979, AM J EPIDEMIOL, V110, P281, DOI 10.1093/oxfordjournals.aje.a112813
Khoury MJ, 2015, JAMA-J AM MED ASSOC, V313, P2117, DOI 10.1001/jama.2015.3382
Klass D, 2007, ACAD MED, V82, P529, DOI 10.1097/ACM.0b013e31805557ba
Kohane IS, 2015, SCIENCE, V349, P37, DOI 10.1126/science.aab1328
Landis SC, 2012, NATURE, V490, P187, DOI 10.1038/nature11556
Lantos JD, 2015, ANN INTERN MED, V162, P731, DOI 10.7326/M15-0632
Lauer MS, 2012, JAMA-J AM MED ASSOC, V308, P1804, DOI 10.1001/jama.2012.14838
Lavange LM, 2010, ANN EPIDEMIOL, V20, P642, DOI 10.1016/j.annepidem.2010.05.006
LEE ET, 1990, AM J EPIDEMIOL, V132, P1141, DOI 10.1093/oxfordjournals.aje.a115757
Lindsey ML, 2015, CIRCULATION, V132, P852, DOI 10.1161/CIR.0000000000000226
Mandl KD, 2015, NAT BIOTECHNOL, V33, P360, DOI 10.1038/nbt.3180
McAfee A., 2012, HARVARD BUS REV, V60-66, P128
McAfee A, 2012, HARVARD BUS REV, V90, P60
McCray AT, 2014, NEUROINFORMATICS, V12, P291, DOI 10.1007/s12021-013-9211-4
McCray AT, 2000, ANN INTERN MED, V133, P609, DOI 10.7326/0003-4819-133-8-200010170-00013
McGovern L., 2014, HLTH POLICY BRIEF RE
Mega JL, 2014, JAMA-J AM MED ASSOC, V312, P1969, DOI 10.1001/jama.2014.15224
Mell P., 2011, NIST DEFINITION CLOU
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Mitka M, 2013, JAMA-J AM MED ASSOC, V310, P2495, DOI 10.1001/jama.2013.284528

Mozaffarian D, 2015, CIRCULATION, V131, pE29, DOI 10.1161/CIR.0000000000000152
Musunuru K, 2015, CIRC-CARDIOVASC GENE, V8, P216, DOI 10.1161/HCG.0000000000000020
[National Heart Lung and Blood Institute National Institutes of Health], DAT GEN PHEN DBGAP
National Institutes of Health, PRINC GUID RPEP PREL
National Institutes of Health, REPC MED IN
Neubeck L, 2015, NAT REV CARDIOL, V12, P350, DOI 10.1038/nrcardio.2015.34
Neuroscience Information Framework (NIF), NIF STAND ONT
[Office of the National Coordinator for Health Information Technology US Department of Health and Human Services], OFF NAT COORD HLTH I
Paltoo DN, 2014, NAT GENET, V46, P934, DOI 10.1038/ng.3062
PoliticoPro, C CALL REEX HIPAA
Prinz F, 2011, NAT REV DRUG DISCOV, V10, P712, DOI 10.1038/nrd3439-c1
Quan SF, 1997, SLEEP, V20, P1077
Rackspace Support Network, MOV YOUR INFR CLOUD
Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
Robinson PN, 2008, AM J HUM GENET, V83, P610, DOI 10.1016/j.ajhg.2008.09.017
Roger VL, 2015, AM J EPIDEMIOL, V181, P372, DOI 10.1093/aje/kwv009
Roger VL, 2015, AM J EPIDEMIOL, V181, P363, DOI 10.1093/aje/kwv011
Rothstein MA, 2010, AM J BIOETHICS, V10, P3, DOI 10.1080/15265161.2010.494215
Selby JV, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3006298
Sempos CT, 1999, AM J MED SCI, V317, P142, DOI 10.1097/00000441-199903000-00002
Sorlie PD, 2010, ANN EPIDEMIOL, V20, P629, DOI 10.1016/j.annepidem.2010.03.015
Splansky GL, 2007, AM J EPIDEMIOL, V165, P1328, DOI 10.1093/aje/kwm021
Stanley K, 2007, CIRCULATION, V115, P1164, DOI 10.1161/CIRCULATIONAHA.105.594945
Steinhubl SR, 2013, JAMA-J AM MED ASSOC, V310, P2395, DOI 10.1001/jama.2013.281078
Subramanian S, 2015, HARV BUS REV
Sugarman J, 2014, JAMA-J AM MED ASSOC, V311, P2381, DOI 10.1001/jama.2014.4164
The Robert Wood Johnson Foundation, DAT HLTH LEARN WHAT
The White House, 2015, PREC MED IN PROP PRI
Topol E, 2015, PATIENT WILL SEE YOU
Troiano RP, 2008, MED SCI SPORT EXER, V40, P181, DOI 10.1249/mss.0b013e31815a51b3
U. S. Food and Drug Administration, OPT FDAS REG OV NEXT
Vasan RS, 2015, AM J EPIDEMIOL, V181, P369, DOI 10.1093/aje/kwv012
Victor RG, 2004, AM J CARDIOL, V93, P1473, DOI 10.1016/j.amjcard.2004.02.058
Weber GM, 2014, JAMA-J AM MED ASSOC, V311, P2479, DOI 10.1001/jama.2014.4228
WILLIAMS OD, 1989, AM J EPIDEMIOL, V129, P687
Wilson James G, 2005, Ethn Dis, V15, pS6
Wyatt SB, 2003, ETHNIC DIS, V13, P438
NR 115
TC 24
Z9 25
U1 2
U2 41
PU WILEY
PI HOBOKEN
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WC Cardiac & Cardiovascular Systems
SC Cardiovascular System & Cardiology
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AU Kalpathy-Cramer, J
   Freymann, JB
   Kirby, JS
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AF Kalpathy-Cramer, Jayashree
   Freymann, John Blake
   Kirby, Justin Stephen
   Kinahan, Paul Eugene
   Prior, Fred William
TI Quantitative Imaging Network: Data Sharing and Competitive Algorithm
   Validation Leveraging The Cancer Imaging Archive
SO TRANSLATIONAL ONCOLOGY
LA English
DT Article
ID RESOURCE; THERAPY; SYSTEMS
AB The Quantitative Imaging Network (QIN), supported by the National Cancer
Institute, is designed to promote research and development of quantitative
imaging methods and candidate biomarkers for the measurement of tumor response
in clinical trial settings. An integral aspect of the QIN mission is to
facilitate collaborative activities that seek to develop best practices for the
analysis of cancer imaging data. The QIN working groups and teams are developing
new algorithms for image analysis and novel biomarkers for the assessment of
response to therapy. To validate these algorithms and biomarkers and translate
them into clinical practice, algorithms need to be compared and evaluated on
large and diverse data sets. Analysis competitions, or "challenges," are being
conducted within the QIN as a means to accomplish this goal. The QIN has
demonstrated, through its leveraging of The Cancer Imaging Archive (TCIA), that
data sharing of clinical images across multiple sites is feasible and that it
can enable and support these challenges. In addition to Digital Imaging and
Communications in Medicine (DICOM) imaging data, many TCIA collections provide
linked clinical, pathology, and "ground truth" data generated by readers that
could be used for further challenges. The TCIA-QIN partnership is a successful
model that provides resources for multisite sharing of clinical imaging data and
the implementation of challenges to support algorithm and biomarker validation.
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FU National Cancer Institute, National Institutes of Health (NIH) [HHSN261200800001E]; NIH grants [U01CA154602, R00LM009889, ST13-4130]; NIH grant [U01CA148131, 24XS036-004]
FX This project has been funded in whole or in part with federal funds from the National Cancer Institute, National Institutes of Health (NIH), under Contract No. HHSN261200800001E. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the US Government. J.K.-C. is funded in part by the NIH grants U01CA154602 and R00LM009889 and a contract ST13-4130. P.E.K. is funded in part by the NIH grant U01CA148131 and Contract 24XS036-004.
CR Armato SG, 2008, CLIN PHARMACOL THER, V84, P448, DOI 10.1038/clpt.2008.161
Atlassian, 2014, CONFL
Bell G, 2006, COMPUTER, V39, P110, DOI 10.1109/MC.2006.29
Channin DS, 2010, J DIGIT IMAGING, V23, P217, DOI 10.1007/s10278-009-9193-9
Clark K, 2013, J DIGIT IMAGING, V26, P1045, DOI 10.1007/s10278-013-9622-7
Clarke LP, 2009, TRANSL ONCOL, V2, P195, DOI 10.1593/tlo.09217
Fedorov A, 2014, MAGN RESON IMAGING, V32, P321, DOI 10.1016/j.mri.2014.01.004
Fielding R., 2000, ARCHITECTURAL STYLES
Freymann JB, 2012, J DIGIT IMAGING, V25, P14, DOI 10.1007/s10278-011-9422-x
General Services Administration, 2014, PARTN PUBL GOV SOLV
Gevaert O, 2012, RADIOLOGY, V264, P387, DOI 10.1148/radiol.12111607
Gutman DA, 2013, RADIOLOGY, V267, P560, DOI 10.1148/radiol.13120118
Huang W, 2014, TRANSL ONCOL, V7, P153, DOI 10.1593/tlo.13838
Hunter L, 2013, RADIOMICS NSCLC QUAN
Kalpathy-Cramer J, 2013, RAD SOC N AM RSNA 99
Kennedy DN, 2013, FRONT NEUROINFORM, DOI [10.3389/conf.fninf.2013.09.00024, DOI 10.3389/CONF.FNINF.2013.09.00024]
Lakhani KR, 2013, NAT BIOTECHNOL, V31, P108, DOI 10.1038/nbt.2495
Luo XZJ, 2009, NEUROINFORMATICS, V7, P55, DOI 10.1007/s12021-008-9036-8
Makki SK, 2008, 2008 3RD INTERNATIONAL CONFERENCE ON INTERNET AND WEB APPLICATIONS AND SERVICES (ICIW 2008), P445, DOI 10.1109/ICIW.2008.98
McLennan M, 2010, COMPUT SCI ENG, V12, P48, DOI 10.1109/MCSE.2010.41
McNitt-Gray MF, 2007, ACAD RADIOL, V14, P1464, DOI 10.1016/j.acra.2007.07.021
Menze B, 2013, P MICCAI CHALL MULT
Ozguner U, 2007, P IEEE, V95, P397, DOI 10.1109/JPROC.2006.888394
Parida SK, 2010, DRUG DISCOV TODAY, V15, P148, DOI 10.1016/j.drudis.2009.10.005
Prior FW, 2013, IEEE ENG MED BIO, P1282, DOI 10.1109/EMBC.2013.6609742
Radiological Society of North America, 2012, RSNA CLIN TRIAL PROC
Sharma A, 2013, PROJECT BINDAAS
Sivakumar S, 2013, INT J ENG TECHNOL, V5, P179
Stine D. D., 2009, FEDERALLY FUNDED INN
The Cancer Imaging Archive, 2014, NCI ISBI 2013 CHALL
The Cancer Imaging Archive, NSCLS RAD
WhiteHouse, 2012, BIG DAT FACT SHEET B
Zinn PO, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0025451
NR 33
TC 24

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PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
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J9 TRANSL ONCOL
JI Transl. Oncol.
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VL 7
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WC Oncology
SC Oncology
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UT WOS:000342684300018
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PT J
AU Perito, ER
   Glidden, D
   Roberts, JP
   Rosenthal, P
AF Perito, Emily Rothbaum
   Glidden, Dave
   Roberts, John Paul
   Rosenthal, Philip
TI Overweight and obesity in pediatric liver transplant recipients:
   Prevalence and predictors before and after transplant, United Network
   for Organ Sharing Data, 1987-2010
SO PEDIATRIC TRANSPLANTATION
LA English
DT Article
DE overweight; obesity; pediatrics; liver transplant; long-term
   complications
ID BODY-MASS INDEX; RISK-FACTORS; DIABETES-MELLITUS; CHILDREN; ADOLESCENTS;
   EPIDEMIOLOGY
AB Obesity is extremely common in adult liver transplant recipients and healthy
U.S. children. Little is known about the prevalence or risk factors for post-
transplant obesity in pediatric liver transplant recipients. UNOS data on all
U.S. liver transplants 1987-2010 in children 6 months-20 yr at transplant were
analyzed. Subjects were categorized as underweight, normal weight, overweight,
or obese by CDC guidelines. Predictors of weight status at and after transplant
were identified using multivariate logistic regression. Of 3043 children 6-24
months at transplant, 14% were overweight. Of 4658 subjects 2-20 yr at
transplant, 16% were overweight and 13% obese. Children overweight/obese at
transplant were more likely to be overweight/obese at one, two, and five yr
after transplant in all age groups after adjusting for age, ethnicity, primary
diagnosis, year of transplant, and transplant type. Weight status at transplant
was not associated with overweight/obesity by 10 yr after transplant. The
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prevalence of post-transplant obesity remained high in long-term follow-up, from 20% to 50% depending on age and weight status at transplant. Weight status at transplant is the strongest predictor of post-transplant overweight/obesity. To optimize long-term outcomes in pediatric liver transplant recipients, monitoring for obesity and its comorbidities is important.

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CR Barlow SE, 2007, PEDIATRICS, V120, pS164, DOI 10.1542/peds.2007-2329C
Centers for Disease Control and Prevention (CDC), GROWTH CHART TRAIN S
Dick AAS, 2010, LIVER TRANSPLANT, V16, P1296, DOI 10.1002/lt.22162
Everhart JE, 1998, LIVER TRANSPLANT SUR, V4, P285, DOI 10.1002/lt.500040402
Freedman DS, 2007, J PEDIATR-US, V150, P12, DOI 10.1016/j.jpeds.2006.08.042
Guo SS, 2002, AM J CLIN NUTR, V76, P653
Hathout E, 2009, PEDIATR TRANSPLANT, V13, P599, DOI 10.1111/j.1399-3046.2007.00603.x
Kuo HT, 2010, LIVER TRANSPLANT, V16, P1249, DOI 10.1002/lt.22139
MCDIARMID SV, 1992, TRANSPLANTATION, V53, P109, DOI 10.1097/00007890-199201000-00021
Ng VL, 2008, PEDIATRICS, V122, pE1128, DOI 10.1542/peds.2008-1363
Ogden CL, 2007, GASTROENTEROLOGY, V132, P2087, DOI 10.1053/j.gastro.2007.03.052
Ogden CL, 2010, JAMA-J AM MED ASSOC, V303, P242, DOI 10.1001/jama.2009.2012
Pagadala M, 2009, LIVER TRANSPLANT, V15, P1662, DOI 10.1002/lt.21952
Saito T, 2007, PEDIATR TRANSPLANT, V11, P764, DOI 10.1111/j.1399-3046.2007.00744.x
Troiano RP, 1998, PEDIATRICS, V101, P497

NR 15
TC 24
Z9 24
U1 0
U2 1
PU WILEY-BLACKWELL
PI MALDEN
PA COMMERCE PLACE, 350 MAIN ST, MALDEN 02148, MA USA
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J9 PEDIATR TRANSPLANT
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```
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SC Pediatrics; Transplantation
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AU Moser, RP
   Hesse, BW
   Shaikh, AR
   Courtney, P
   Morgan, G
   Augustson, E
   Kobrin, S
   Levin, KY
   Helba, C
   Garner, D
   Dunn, M
   Coa, K
AF Moser, Richard P.
   Hesse, Bradford W.
   Shaikh, Abdul R.
   Courtney, Paul
   Morgan, Glen
   Augustson, Erik
   Kobrin, Sarah
   Levin, Kerry Y.
   Helba, Cynthia
   Garner, David
   Dunn, Marsha
   Coa, Kisha
TI Grid-Enabled Measures Using Science 2.0 to Standardize Measures and
   Share Data
SO AMERICAN JOURNAL OF PREVENTIVE MEDICINE
LA English
DT Article
ID HEALTH-CARE; INFRASTRUCTURE; INFORMATION; SUPPORT; CYBERINFRASTRUCTURE;
   COLLABORATION; ASSOCIATION; ACCELERATE; SYSTEM
AB Scientists are taking advantage of the Internet and collaborative web
technology to accelerate discovery in a massively connected, participative
environment-a phenomenon referred to by some as Science 2.0. As a new way of
doing science, this phenomenon has the potential to push science forward in a
more efficient manner than was previously possible. The Grid-Enabled Measures
(GEM) database has been conceptualized as an instantiation of Science 2.0
principles by the National Cancer Institute (NCI) with two overarching goals: (1)
promote the use of standardized measures, which are tied to theoretically based
constructs; and (2) facilitate the ability to share harmonized data resulting
from the use of standardized measures. The first is accomplished by creating an
online venue where a virtual community of researchers can collaborate together
and come to consensus on measures by rating, commenting on, and viewing meta-
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data about the measures and associated constructs. The second is accomplished by connecting the constructs and measures to an ontological framework with data standards and common data elements such as the NCI Enterprise Vocabulary System (EVS) and the cancer Data Standards Repository (caDSR). This paper will describe the web 2.0 principles on which theGEMdatabase is based, describe its functionality, and discuss some of the important issues involved with creating the GEM database, such as the role of mutually agreed-on ontologies (i.e., knowledge categories and the relationships among these categories-for data sharing). (Am J Prev Med 2011;40(5S2):S134-S143) Published by Elsevier Inc. on behalf of American Journal of Preventive Medicine

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CR Abrams DB, 2006, HEALTH EDUC BEHAV, V33, P515, DOI 10.1177/1090198106287732
Agresti WW, 2003, COMMUN ACM, V46, P25, DOI 10.1145/859670.859691
Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
Blumenthal David, 2010, Conn Med, V74, P299
Braun R, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000668
BRECKLER S, 2008, PSYCHOL GRID AM PSYC
Buetow KH, 2009, HEALTH AFFAIR, V28, P923, DOI 10.1377/hlthaff.28.3.923-a
Buetow KH, 2009, DRUG DISCOV TODAY, V14, P605, DOI 10.1016/j.drudis.2009.03.011
Buetow KH, 2005, SCIENCE, V308, P821, DOI 10.1126/science.1112120
BUETOW KH, 2009, HLTH AFF MILLWOOD, V28, P924
BURKE J, 2006, WSW 06 SENSYS2006 BO
Cella D, 2010, J CLIN EPIDEMIOL, V63, P1179, DOI 10.1016/j.jclinepi.2010.04.011
COLLINS FS, 2010, NIH 21 CENT DIR PERS
*COMM SCI ENG PUBL, 2009, COMMITTEE ENSURING U
Curran PJ, 2009, PSYCHOL METHODS, V14, P81, DOI 10.1037/a0015914
Etheredge LM, 2007, HEALTH AFFAIR, V26, pW107, DOI 10.1377/hlthaff.26.2.w107
Eysenbach G, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1030
Ferguson T., 2007, EPATIENTS THEY CAN H
Forman MR, 2010, AM J PREV MED, V38, P646, DOI 10.1016/j.amepre.2010.03.002
FOX S, 2010, 20 SUMMARY RECENT RE
Gadaleta E, 2011, BRIEF BIOINFORM, V12, P52, DOI 10.1093/bib/bbq010
Gibbons M. C., 2007, EHEALTH SOLUTIONS HE
Giles J, 2005, NATURE, V438, P900, DOI 10.1038/438900a
*GLOB STAFF, 2010, NASA TEAMS INNOCENTI
Hannay T, 2010, COMPUTER, V43, P84, DOI 10.1109/MC.2010.331
Hesse BK, 2008, CANCER-AM CANCER SOC, V112, P2529, DOI 10.1002/cncr.23445
Hesse BW, 2008, AM J PREV MED, V35, pS235, DOI 10.1016/j.amepre.2008.05.011
Hesse BW, 2010, AM J PREV MED, V39, pS85, DOI 10.1016/j.amepre.2010.08.017
Hesse BW, 2010, COMPUTER, V43, P45, DOI 10.1109/MC.2010.326
Hesse BW, 2010, NEW ENGL J MED, V362, P859, DOI 10.1056/NEJMc0909595
HESSE BW, 2011, TRANSL BEHAV MED, P1
Hughes B, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1056
*I FUT, 2008, OP HLTH TOOLK INN GL

```
   Khoury MJ, 2007, GENET MED, V9, P665, DOI 10.1097/GIM.0b013e181569d0
   LANGENBERG DA, 1989, INFORM TECHNOLOGY CO
   Lopez JM, 2008, LECT NOTES ARTIF INT, V5288, P96, DOI 10.1007/978-3-540-
87781-3_11
   Nash JM, 2008, AM J PREV MED, V35, pS133, DOI 10.1016/j.amepre.2008.05.004
   National Committee on Vital and Health Statistics, 2001, INF HLTH STRAT BUILD
   Natl Acad Engn, 2009, ENSURING THE INTEGRITY, ACCESSIBILITY, AND STEWARDSHIP
OF RESEARCH DATA IN THE DIGITAL AGE, P1
   Pirolli P, 2010, COMPUTER, V43, P20, DOI 10.1109/MC.2010.315
   President's Council of Advisors on Science and Technology, 2010, DES DIG FUT
FED FUND
   President's Council of Advisors on Science and Technology, 2010, REAL FULL
POT HLTH I
   Psaty BM, 2009, CIRC-CARDIOVASC GENE, V2, P73, DOI
10.1161/CIRCGENETICS.108.829747
   Safran C, 2007, J AM MED INFORM ASSN, V14, P1, DOI 10.1197/jamia.M2273
   Shneiderman B, 2008, SCIENCE, V319, P1349, DOI 10.1126/science.1153539
   Stokols D, 2008, AM J PREV MED, V35, pS96, DOI 10.1016/j.amepre.2008.05.003
   Stover PJ, 2010, CURR OPIN LIPIDOL, V21, P136, DOI
10.1097/MOL.0b013e3283377395
   SUROWIESCKI J, 2004, WISDOM CROWDS WHY MA
   von Eschenbach AC, 2006, CANCER INFORM, V2, P22
   Waldrop MM, 2008, SCI AM, V298, P68, DOI 10.1038/scientificamerican0508-68
NR 50
TC 24
Z9 24
U1 0
U2 21
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
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AU Theseira, M
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TI Using Internet GIS technology for sharing health and health related data
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for the West Midlands Region
SO HEALTH & PLACE
LA English
DT Article
AB Recent government legislation highlights the need for co-operative working by government agencies to improve the overall health of people and to help reduce the existing health inequalities in England. To effectively tackle health inequalities, access to a range of timely and relevant data sets about a region is vital. The Multi-Agency Internet Geographic Information Service (MAIGIS) project is a 3-yr pilot project funded by the Public Health Development Fund to establish an interactive map-based web site for sharing health and health related data for the West Midlands Region (http://maigis.wmpho.org.uk). Data sets within the MAIGIS project follow three broad themes of health, socioeconomic and environmental information. Data are made available by different organisations and shared using a geography as the linking theme. This paper discusses the use of Internet GIS technology for sharing health and health related data based on the issues that arose during the formative period of the MAIGIS project. Issues such as data confidentiality, amalgamation and copyright are discussed and the technical development of the project is outlined. The links that MAIGIS has formed with other regional and national initiatives for the sharing of health and health related information are also presented. Finally, the future work programme for the MAIGIS project is summarised. (C) 2002 Elsevier Science Ltd. All rights reserved.
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RP Theseira, M (reprint author), Univ Birmingham, W Midlands Canc Intelligence Unit, Publ Hlth Bldg, Birmingham B15 2TT, W Midlands, England.
CR Acheson D., 1998, INDEPENDENT INQUIRY
*DEP HLTH, 1997, NEW NHS
*DEP HLTH, 1999, SAV LIV OUR HEALTH N
*DEP HLTH, 2000, HLTH EP STAT WEBS
*DEP HLTH, 2001, BUILD INF COR PROT U
ELLIOT P, 1996, GEOGRAPHICAL ENV EPI
*ESRI, 2000, US ARCIMS
Howard D. L., 2006, CARTOGR GEOGR INF SC, V23, P59, DOI [10.1559/152304096782562109, DOI 10.1559/152304096782562109]
Kingston R., 2000, Computers, Environment and Urban Systems, V24, P109, DOI 10.1016/S0198-9715(99)00049-6
MARTIN D, 1991, GEOGRAPHIC INFORMATI
*SOC EXCL UN, 2000, REP POL ACT TEAM 18
STANDING C, 1995, INTERACT COMPUT, V7, P219, DOI 10.1016/0953-5438(95)93602-2
Su YF, 2000, COMPUT GEOSCI, V26, P741, DOI 10.1016/S0098-3004(99)00130-2
THOMASSON E, 2000, SMALL AREA STAT LINE, V41, P2
WHITEHEAD M, 1992, INEQUALITIES HLTH PE
Ziliaskopoulos AK, 2000, TRANSPORT RES C-EMER, V8, P427, DOI 10.1016/S0968-090X(00)00027-9
2001, BIRMINGHAM CITY PRID
2001, NATL STAT
2001, ORDNANCE SURVEY
NR 19
TC 24
Z9 25
U1 0
U2 4
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 1353-8292

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JI Health Place
PD MAR
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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UT WOS:000174723700005
PM 11852262
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PT J
AU FIENBERG, SE
AF FIENBERG, SE
TI SHARING STATISTICAL-DATA IN THE BIOMEDICAL AND HEALTH-SCIENCES -
   ETHICAL, INSTITUTIONAL, LEGAL, AND PROFESSIONAL DIMENSIONS
SO ANNUAL REVIEW OF PUBLIC HEALTH
LA English
DT Article
DE ARCHIVES; DATA ACCESS; JOURNAL DATA POLICIES; OWNERSHIP OF DATA;
   RESEARCH DATA AS PUBLIC GOOD
ID CLINICAL-TRIALS; PUBLIC-HEALTH; OTITIS-MEDIA; EFFUSION; CHILDREN;
   WORKERS; ACCESS
RP FIENBERG, SE (reprint author), CARNEGIE MELLON UNIV, DEPT STAT, PITTSBURGH,
PA 15213 USA.
CR ALLISON J, 1991, DATA DISCLOSURE DATA, P6
   BARINAGA M, 1992, SCIENCE, V256, P1620, DOI 10.1126/science.256.5064.1620
   BARINAGA M, 1991, SCIENCE, V254, P23, DOI 10.1126/science.1925553
   BARON JN, 1988, AM SOCIOL REV, V53, P6
   BUZELLI DE, 1993, SCIENCE, V259, P584
   BUZELLI DE, 1993, SCIENCE, V259, P647
   CANTEKIN E I, 1991, Journal of the American Medical Association, V266, P3309,
DOI 10.1001/jama.266.23.3309
   CANTEKIN EI, 1990, JAMA-J AM MED ASSOC, V263, P1427, DOI
10.1001/jama.263.10.1427
   CARD JJ, 1989, FOOTNOTES AM SOCIOL, P8
   Cecil JS, 1985, SHARING RES DATA, P148
   *COMM RAD EP RES P, 1990, PROV ACC EP DAT
   CORDRAY DS, 1990, APR PUBL HLTH SERV W
   CULLITON BJ, 1990, SCIENCE, V250, P746, DOI 10.1126/science.2237421
   CULLITON BJ, 1988, SCIENCE, V242, P657, DOI 10.1126/science.3187510
   Duncan G., 1991, STAT SCI, V6, P219
   ERNHART CB, 1981, PEDIATRICS, V67, P911
   Fienberg S. E., 1985, SHARING RES DATA
   FIENBERG SE, 1994, IN PRESS J OFF STAT, V10
   GREENBERG H, 1992, CONTROL CLIN TRIALS, V13, P93, DOI 10.1016/0197-
2456(92)90014-Q
   HAMILTON DP, 1992, SCIENCE, V255, P1344, DOI 10.1126/science.1311866
   Hammond E C, 1979, Ann N Y Acad Sci, V330, P473, DOI 10.1111/j.1749-
6632.1979.tb18749.x
```

```
   HAUSER RM, 1987, AM SOCIOL REV, V52
   HAWTHORNE VM, 1992, INTERUNIVERSITY CONS, P1
   HOLDEN C, 1993, SCIENCE, V258, P1302
   HURWITZ ES, 1985, NEW ENGL J MED, V313, P849, DOI 10.1056/NEJM198510033131403
   LaFollette Marcel Chotkowski, 1992, STEALING PRINT FRAUD
   MANCUSO TF, 1977, HEALTH PHYS, V33, P369, DOI 10.1097/00004032-197711000-
00002
   MANDEL EM, 1987, NEW ENGL J MED, V316, P432, DOI 10.1056/NEJM198702193160803
   MARSHALL E, 1993, SCIENCE, V259, P592, DOI 10.1126/science.8430304
   MARSHALL E, 1991, SCIENCE, V251, P23, DOI 10.1126/science.1846046
   *NATL SCI F, 1989, RES I INV COND RES, V106
   NEEDLEMAN HL, 1992, PEDIATRICS, V90, P977
   NEEDLEMAN HL, 1979, NEW ENGL J MED, V300, P689, DOI
10.1056/NEJM197903293001301
   *NIH, 1990, GUID COND RES NIH, P8
   PALCA J, 1991, SCIENCE, V253, P842, DOI 10.1126/science.1843452
   Panel on Scientific Responsibility and the Conduct of Research National
Academy of Sciences National Academy of Engineering; & Institute of Medicine,
1992, RESP SCI ENS INT RES, VI
   PERKINS LL, 1992, CONTROL CLIN TRIALS, V13, P80, DOI 10.1016/0197-
2456(92)90031-T
   RENNIE D, 1991, JAMA-J AM MED ASSOC, V266, P3333, DOI
10.1001/jama.266.23.3333
   SELIKOFF IJ, 1980, JNCI-J NATL CANCER I, V65, P507
   Sieber J. E, 1991, SHARING SOCIAL SCI D
   Sieber Joan E, 1989, IRB, V11, P4, DOI 10.2307/3564184
   Weil Vivian, 1990, IRB, V12, P7, DOI 10.2307/3563522
   YOLLES BJ, 1986, NEW ENGL J MED, V315, P1669, DOI 10.1056/NEJM198612253152608
NR 43
TC 24
Z9 24
U1 0
U2 2
PU ANNUAL REVIEWS
PI PALO ALTO
PA 4139 EL CAMINO WAY, PO BOX 10139, PALO ALTO, CA 94303-0139 USA
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J9 ANNU REV PUBL HEALTH
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PT J
AU Smith, CT
   Hopkins, C
   Sydes, MR
   Woolfall, K
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Clarke, M
Murray, G
Williamson, P
AF Smith, C. Tudur
Hopkins, C.
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Woolfall, K.
Clarke, M.
Murray, G.
Williamson, P.
TI How should individual participant data (IPD) from publicly funded
clinical trials be shared?
SO BMC MEDICINE
LA English
DT Article
DE Data sharing; Individual participant data; IPD; Clinical trial; Publicly
funded; CTU; Good practice
ID METAANALYSIS; EFFICACY; CONDUCT
AB Background: Individual participant data (IPD) from completed clinical trials
should be responsibly shared to support efficient clinical research, generate
new knowledge and bring benefit to patients. The Medical Research Council (MRC)
Hubs for Trials Methodology Research (HTMR) has developed guidance to facilitate
the sharing of IPD from publicly funded clinical trials.

Methods: Development of the guidance was completed over four phases which
included a focussed review of policy documents, a web-based survey of the UK
Clinical Research Collaboration (CRC) Registered Clinical Trials Units (CTU)
Network, participation of an expert committee and an open consultation with the
UKCRC Registered CTU Network. The project was funded by the MRC HTMR
(MR/L004933/1-R39).

Results: Good practice principles include: (i) the use of a controlled access
approach, using a transparent and robust system to review requests and provide
secure data access; (ii) seeking consent for sharing IPD from trial participants
in all future clinical trials with adequate assurance that patient privacy and
confidentiality can be maintained; and (iii) establishing an approach to
resource the sharing of IPD which would include support from trial funders,
sponsor organisations and users of IPD. The guidance has been endorsed by Cancer
Research UK, MRC Methodology Research Programme Advisory Group, Wellcome Trust
and the Executive Group of the UKCRC Registered CTU Network. The National
Institute for Health Research (NIHR) has confirmed it is supportive of the
application of this guidance.

Conclusions: Implementation of these principles will improve transparency,
increase the coherent sharing of IPD from publicly funded trials, and help
publicly funded trials to adhere to trial funder and journal requirements for
data sharing.
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FU Medical Research Council (MRC) Hubs for Trials Methodology Research
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CR Alsheikh-Ali AA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0024357
[Anonymous], 2015, SCI DATA, V2
Berlin JA, 2014, CLIN TRIALS, V11, P7, DOI 10.1177/1740774513514497
Blanchard P, 2013, J CLIN ONCOL, V31, P2854, DOI 10.1200/JCO.2012.47.7802
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Chan AW, 2013, ANN INTERN MED, V158, P200, DOI 10.7326/0003-4819-158-3-
201302050-00583
Davies C, 2011, LANCET, V378, P771, DOI 10.1016/S0140-6736(11)60993-8
Doshi P, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001201
European Federation of Pharmaceutical Industries and Associations (EFPIA) and
The Pharmaceutical Research and Manufacturers of America (PhRMA), 2013, PRINC
RESP CLIN TRIA
European Medicines Agency, 2014, EMA2408102013
Health Research Authority, 2015, CONS PART INF
Hopkins C, 2016, J CLIN EPIDEMIOL, V70, P17, DOI
10.1016/j.jclinepi.2015.07.002
Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Jaspers GJ, 2014, SYST REV, V3, DOI 10.1186/2046-4053-3-97
Le Noury J, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h4320
Loder E, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2373
Medical Research Council (MRC), 2011, MRC POL GUID SHAR RE
NICE, 2012, EP DIAGN MAN EP AD C
Public Library of Science (PLOS), 2015, DAT AV
Research Councils UK (RCUK), 2015, COMM PRINC DAT POL
Riley RD, 2015, RES SYNTH METHODS, V6, P157, DOI 10.1002/jrsm.1129
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Schulz KF, 2010, BMC MED, V8, DOI 10.1186/1741-7015-8-18
Song F, 2010, HEALTH TECHNOL ASSES, V14, P1, DOI 10.3310/hta14080
Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
Tierney JF, 2015, J CLIN EPIDEMIOL, V68, P1325, DOI
10.1016/j.jclinepi.2015.05.024
Tudur Smith Catrin, 2007, Trials, V8, P34
WHO, 2015, WHO STAT PUBL DISCL
Ying A, 2015, LANCET, V385, P867, DOI 10.1016/S0140-6736(14)61171-5
NR 29
TC 23

```
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PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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AU Bull, S
   Roberts, N
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TI Views of Ethical Best Practices in Sharing Individual-Level Data From
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SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE biomedical research ethics; data sharing; data release; data access;
   research data; research governance; low-income countries; middle-income
   countries; clinical research; health policy; privacy; systematic review
ID CLINICAL-TRIAL DATA; WITHHOLDING ACCESS; PATIENT DATA; RAW DATA; DRUG;
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AB There is increasing support for sharing individual-level data generated by
medical and public health research. This scoping review of empirical research
and conceptual literature examined stakeholders' perspectives of ethical best
practices in data sharing, particularly in low- and middle-income settings.
Sixty-nine empirical and conceptual articles were reviewed, of which, only five
were empirical studies and eight were conceptual articles focusing on low- and
middle-income settings. We conclude that support for sharing individual-level
data is contingent on the development and implementation of international and
local policies and processes to support ethical best practices. Further
conceptual and empirical research is needed to ensure data sharing policies and
processes in low- and middle-income settings are appropriately informed by
stakeholders' perspectives.
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CR Anderson BJ, 2009, PEDIATR ANESTH, V19, P1005, DOI 10.1111/j.1460-9592.2009.03051.x
[Anonymous], 2014, NATURE, V505, P131
[Anonymous], 2009, NATURE, V461, P168
Antman E, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g237
Arksey H, 2005, INT J SOC RES METHOD, V8, P19, DOI DOI 10.1080/1364557032000119616
Armstrong R, 2011, J PUBLIC HEALTH-UK, V33, P147, DOI 10.1093/pubmed/fdr015
Brewer DD, 2010, LANCET, V375, P1872, DOI 10.1016/S0140-6736(10)60870-7
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Castellani J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1881
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201
Dawson A, 2011, PUBLIC HEALTH ETH-UK, V4, P1, DOI 10.1093/phe/phr011
de Wolf Virginia A, 2005, IRB, V27, P12, DOI 10.2307/3563537
de Wolf Virginia A, 2006, IRB, V28, P6
de Wolf Virginia A, 2006, IRB, V28, P10
Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
Doshi P, 2013, TRENDS PHARMACOL SCI, V34, P645, DOI 10.1016/j.tips.2013.10.006
Doshi P, 2013, JAMA INTERN MED, V173, DOI 10.1001/jamainternmed.2013.9989
Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
Estabrooks C A, 1995, Can J Nurs Res, V27, P77
Geller Nancy L, 2004, Clin Trials, V1, P517, DOI 10.1191/1740774504cn050oa
Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7888
GOLDACRE B, 2013, BMJ-BRIT MED J, V347, DOI DOI 10.1136/BMJ.F1880
Gotzsche P. C., 2011, COCHRANE DB SYST REV, V12
Gotzsche PC, 2012, CIRC-CARDIOVASC QUAL, V5, P236, DOI 10.1161/CIRCOUTCOMES.112.965277
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Greenhalgh T., 2009, BRIT MED J, V338, P903
Haines IE, 2011, MED J AUSTRALIA, V195, P575, DOI 10.5694/mja11.10599
Hampton T, 2011, JAMA-J AM MED ASSOC, V306, P593, DOI 10.1001/jama.2011.1102
Harris DJ, 2011, LANCET, V378, P1994, DOI 10.1016/S0140-6736(11)61869-2
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Hawkes N, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f321
Hawkes N, 2012, BRIT MED J, V344, DOI 10.1136/bmj.e3723
Hede K, 2013, JNCI-J NATL CANCER I, V105, P1159, DOI 10.1093/jnci/djt232
Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
Hughes S, 2014, PHARM STAT, V13, P179, DOI 10.1002/pst.1615
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
King R, 2011, MED TEACH, V33, P719, DOI 10.3109/0142159X.2011.558138
Kirwan JR, 1997, J RHEUMATOL, V24, P822
Kmietowicz Z, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f1636

Kuntz RE, 2013, ANN INTERN MED, V158, P914, DOI 10.7326/0003-4819-158-12-201306180-00011
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Lopez AD, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.078956
Medical Research Council, 2011, MRC POL RES DAT SHAR
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Moher D, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000097
*NIH, 2003, FIN NIH STAT SHAR RE
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P1873, DOI 10.1016/S0140-6736(10)60871-9
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Rabesandratana T, 2013, SCIENCE, V339, P1369, DOI 10.1126/science.339.6126.1369
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
Reidpath DD, 2001, BIOETHICS, V15, P125, DOI 10.1111/1467-8519.00220
Research Information Network, 2008, SHAR NOT SHAR RES DA
Rodwin MA, 2012, JAMA-J AM MED ASSOC, V308, P871, DOI 10.1001/jama.2012.9661
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI 10.1161/CIRCOUTCOMES.112.965798
Ross JS, 2012, AM J PUBLIC HEALTH, V102, P72, DOI 10.2105/AJPH.2011.300187
Sandercock PAG, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-101
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Sieber JE, 2006, J EMPIR RES HUM RES, V1, P47, DOI 10.1525/jer.2006.1.3.47
Smith CT, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0097886
SMITH GD, 1994, BRIT MED J, V308, P1519, DOI 10.1136/bmj.308.6943.1519
Sommer J, 2010, NAT MED, V16, P744, DOI 10.1038/nm0710-744
Spertus JA, 2012, CIRC-CARDIOVASC QUAL, V5, P143, DOI 10.1161/CIRCOUTCOMES.112.965814
Strech D, 2012, TRIALS, V13, DOI 10.1186/1745-6215-13-100
Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129
Vallance P, 2013, LANCET, V382, P1073, DOI 10.1016/S0140-6736(13)62001-2
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Wellcome Trust, 2009, POL DAT MAN SHAR
White PD, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f3379
Whitworth J, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.079202
Wieseler B, 2012, SYST REV, V1, DOI 10.1186/2046-4053-1-50
Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
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   Cheah, PY
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   Jao, I
   Marsh, V
   Merson, L
   More, NS
   Nhan, LNT
   Osrin, D
   Tangseefa, D
   Wassenaar, D
   Parker, M
AF Bull, Susan
   Cheah, Phaik Yeong
   Denny, Spencer
   Jao, Irene
   Marsh, Vicki
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TI Best Practices for Ethical Sharing of Individual-Level Health Research
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LA English
DT Article
DE biomedical research ethics; data sharing; data release; research data;
   research governance; low-income countries; middle-income countries;
   clinical research; health policy; privacy; trust
ID CLINICAL-TRIAL DATA; IMPROVE PUBLIC-HEALTH; PATIENT DATA; VIEWS;
   CONSENT; ACCESS; EXPERIENCES; RESPECT
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AB Sharing individual-level data from clinical and public health research is increasingly being seen as a core requirement for effective and efficient biomedical research. This article discusses the results of a systematic review and multisite qualitative study of key stakeholders' perspectives on best practices in ethical data sharing in low- and middle-income settings. Our research suggests that for data sharing to be effective and sustainable, multiple social and ethical requirements need to be met. An effective model of data sharing will be one in which considered judgments will need to be made about how best to achieve scientific progress, minimize risks of harm, promote fairness and reciprocity, and build and sustain trust.

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CR Alter GC, 2015, J EMPIR RES HUM RES, V10, P317, DOI 10.1177/1556264615591561
Anderson BJ, 2009, PEDIATR ANESTH, V19, P1005, DOI 10.1111/j.1460-9592.2009.03051.x
[Anonymous], 2009, NATURE, V461, P168
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Carr D, 2015, J EMPIR RES HUM RES, V10, P314, DOI 10.1177/1556264615593485
Carter P, 2015, J MED ETHICS, V41, P404, DOI 10.1136/medethics-2014-102374
Castellani J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1881
Caulfield T., 2007, KINGS LAW J, V18, P209
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Chan AW, 2004, JAMA-J AM MED ASSOC, V291, P2457, DOI 10.1001/jama.291.20.2457
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201
de Wolf Virginia A, 2005, IRB, V27, P12, DOI 10.2307/3563537
de Wolf Virginia A, 2006, IRB, V28, P6

Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
Doshi P, 2013, TRENDS PHARMACOL SCI, V34, P645, DOI 10.1016/j.tips.2013.10.006
Dove ES, 2014, J LAW BIOSCI, V1, P3, DOI 10.1093/jlb/lst002
Erlich Y, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001983
European Medicines Agency, 2014, EUR MED AG POL PUBL
Goldacre B, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1880
Gotzsche PC, 2012, CIRC-CARDIOVASC QUAL, V5, P236, DOI 10.1161/CIRCOUTCOMES.112.965277
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Greenhalgh T., 2009, BRIT MED J, V338, P903
Haines IE, 2011, MED J AUSTRALIA, V195, P575, DOI 10.5694/mja11.10599
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Herbst K, 2015, J EMPIR RES HUM RES, V10, P324, DOI 10.1177/1556264615594600
Hughes S, 2014, PHARM STAT, V13, P179, DOI 10.1002/pst.1615
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Lotter L, 2015, J EMPIR RES HUM RES, V10, P338, DOI 10.1177/1556264615592846
Mascalzoni D, 2008, PLOS MED, V5, P1302, DOI 10.1371/journal.pmed.0050192
Mathews DJH, 2014, GENES-BASEL, V5, P1, DOI 10.3390/genes5010001
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Murtagh M, 2012, NORSK EPIDEMIOL, V21, P203
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P1873, DOI 10.1016/S0140-6736(10)60871-9
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
Rodwin MA, 2012, JAMA-J AM MED ASSOC, V308, P871, DOI 10.1001/jama.2012.9661
Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI 10.1161/CIRCOUTCOMES.112.965798
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Sheehan M, 2011, PUBLIC HEALTH ETH-UK, V4, P226, DOI 10.1093/phe/phr020
Sieber JE, 2006, J EMPIR RES HUM RES, V1, P47, DOI 10.1525/jer.2006.1.3.47
Simon CM, 2011, GENET MED, V13, P821, DOI 10.1097/GIM.0b013e31821d2f88
SMITH GD, 1994, BRIT MED J, V308, P1519, DOI 10.1136/bmj.308.6943.1519
Sommer J, 2010, NAT MED, V16, P744, DOI 10.1038/nm0710-744
Strech D, 2012, TRIALS, V13, DOI 10.1186/1745-6215-13-100
Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129
Tindana P, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-76
Vallance P, 2013, LANCET, V382, P1073, DOI 10.1016/S0140-6736(13)62001-2
Vickers A. J., 2006, TRIALS, V7
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
White PD, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f3379
Whitworth J, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.079202
Wieseler B, 2012, SYST REV, V1, DOI 10.1186/2046-4053-1-50
Yozwiak NL, 2015, NATURE, V518, P477, DOI 10.1038/518477a

```
   Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
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AF Bailey, L. Charles
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TI Multi-Institutional Sharing of Electronic Health Record Data to Assess
   Childhood Obesity
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DT Article
ID PEDIATRIC OBESITY; RISK-FACTORS; CHILDREN; CARE; DISEASE;
   UNDERDIAGNOSIS; INFORMATION; PREVALENCE; OVERWEIGHT; SYSTEM
AB Objective: To evaluate the validity of multi-institutional electronic health
record (EHR) data sharing for surveillance and study of childhood obesity.
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Methods: We conducted a non-concurrent cohort study of 528,340 children with outpatient visits to six pediatric academic medical centers during 2007-08, with sufficient data in the EHR for body mass index (BMI) assessment. EHR data were compared with data from the 2007-08 National Health and Nutrition Examination Survey (NHANES).

Results: Among children 2-17 years, BMI was evaluable for 1,398,655 visits (56%). The EHR dataset contained over 6,000 BMI measurements per month of age up to 16 years, yielding precise estimates of BMI. In the EHR dataset, 18% of children were obese versus 18% in NHANES, while 35% were obese or overweight versus 34% in NHANES. BMI for an individual was highly reliable over time (intraclass correlation coefficient 0.90 for obese children and 0.97 for all children). Only 14% of visits with measured obesity (BMI >= 95%) had a diagnosis of obesity recorded, and only 20% of children with measured obesity had the diagnosis documented during the study period. Obese children had higher primary care (4.8 versus 4.0 visits, p<0.001) and specialty care (3.7 versus 2.7 visits, p<0.001) utilization than non-obese counterparts, and higher prevalence of diverse co-morbidities. The cohort size in the EHR dataset permitted detection of associations with rare diagnoses. Data sharing did not require investment of extensive institutional resources, yet yielded high data quality.

Conclusions: Multi-institutional EHR data sharing is a promising, feasible, and valid approach for population health surveillance. It provides a valuable complement to more resource-intensive national surveys, particularly for iterative surveillance and quality improvement. Low rates of obesity diagnosis present a significant obstacle to surveillance and quality improvement for care of children with obesity.

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CR Abrams P, 2011, CURR OPIN ENDOCRINOL, V18, P23, DOI 10.1097/MED.0b013e3283424b37
Allscripts Corporation, 2011, ALLSCR
[Anonymous], MYSQL DAT MAN SYST
Barlow SE, 2007, PEDIATRICS, V120, pS164, DOI 10.1542/peds.2007-2329C
BARTKO JJ, 1976, PSYCHOL BULL, V83, P762, DOI 10.1037/0033-2909.83.5.762
Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
Borycki EM, 2011, STUD HEALTH TECHNOL, V166, P197, DOI 10.3233/978-1-60750-740-6-197
Centers for Disease Control and Prevention, 2011, SAS PROGR CDC GROWTH
Centers for Disease Prevention and Control, 2011, CUT OFFS DEF OUTL 20
Centers for Medicare and Medicaid Services, 2011, EL PROF MEAN US TABL
Centers for Medicare & Medicaid Services (CMS) HHS, 2010, Fed Regist, V75, P44313
Cerner Corporation, 2011, CERN MILL

Collins L, 2010, J PEDIAT HEMATOL ONC, V32, pE304, DOI 10.1097/MPH.0b013e3181ece2bb
Cook S, 2011, PEDIATR CLIN N AM, V58, P1363, DOI 10.1016/j.pcl.2011.09.003
Diamond CC, 2009, HEALTH AFFAIR, V28, P454, DOI 10.1377/hlthaff.28.2.454
Dolin RH, 2011, J AM MED INFORM ASSN, V18, P99, DOI 10.1136/jamia.2010.007864
Epic Systems Corporation, 2011, EPICARE EL MED REC
Etheredge LM, 2007, HEALTH AFFAIR, V26, pW107, DOI 10.1377/hlthaff.26.2.w107
Falkner B, 2006, J PEDIATR-US, V148, P195, DOI 10.1016/j.jpeds.2005.10.030
Flegal KM, 2010, JAMA-J AM MED ASSOC, V303, P235, DOI 10.1001/jama.2009.2014
Franks S, 2008, INT J OBESITY, V32, P1035, DOI 10.1038/ijo.2008.61
Goolsby WA, 2011, CLIN DATA BASIC STAP
Holve E, 2012, MED CARE, V50, pS11, DOI 10.1097/MLR.0b013e318258530f
Hripcsak G, 2013, J AM MED INFORM ASSN, V20, P117, DOI 10.1136/amiajnl-2012-001145
Hripcsak G, 2011, J BIOMED DISCOV COLL, V6, DOI 10.5210/disco.v6i0.3581
Huang RC, 2011, DIABETES CARE, V34, P1019, DOI 10.2337/dc10-1809
Juonala M, 2011, NEW ENGL J MED, V365, P1876, DOI 10.1056/NEJMoa1010112
Kahn MG, 2012, MED CARE, V50, pS21, DOI 10.1097/MLR.0b013e318257dd67
Kho AN, 2011, SCI TRANSLATIONAL ME, V3
Koebnick C, 2012, J PEDIATR GASTR NUTR, V55, P328, DOI 10.1097/MPG.0b013e31824d256f
Lemay CA, 2003, J AM BOARD FAM PRACT, V16, P14, DOI 10.3122/jabfm.16.1.14
Lieu TA, 2011, CLIN MED RES, V9, P137, DOI 10.3121/cmr.2011.1025
Lim Choi Keung Sarah N, 2012, AMIA Jt Summits Transl Sci Proc, V2012, P9
Lin MC, 2012, J BIOMED INFORM, V45, P658, DOI 10.1016/j.jbi.2012.01.008
Maxson ER, 2010, HEALTH AFFAIR, V29, P1671, DOI 10.1377/hlthaff.2010.0577
Nadkarni PM, 2011, J AM MED INFORM ASSN, V18, P544, DOI 10.1136/amiajnl-2011-000464
National Center for Health Statistics Centers for Disease Control and Prevention, 2007, NAT HLTH NUTR EX SUR
National Center for Health Statistics CfDCaP, 2012, INT CLASS DIS 9 REV
National Research Council, 2004, CHILDR HLTH NAT WEAL
Natl High Blood Pressure Educ Prog, 2004, PEDIATRICS, V114, P555
Olsen LA, 2007, LEARNING HEALTHCARE
Patel AI, 2010, ACAD PEDIATR, V10, P405, DOI 10.1016/j.acap.2010.09.004
R Development Core Team, 2011, R LANG ENV STAT COMP
Rea S, 2012, J BIOMEDICAL INFORM
Ruser CB, 2005, J GEN INTERN MED, V20, P1139, DOI 10.1111/j.1525-1497.2005.0263.x
SAS Institute Inc, 2008, SAS SYST MICR WIND 9
Slutsky JR, 2007, HEALTH AFFAIR, V26, pW122, DOI 10.1377/hlthaff.26.2.w122
Tauman R, 2011, EXPERT REV RESP MED, V5, P425, DOI [10.1586/ERS.11.7, 10.1586/ers.11.7]
The Perl Foundation, 2010, PERL
Volovelsky O, 2011, INT J PEDIATR OBES, V6, P59, DOI 10.3109/17477166.2011.583661
Weber GM, 2009, J AM MED INFORM ASSN, V16, P624, DOI 10.1197/jamia.M3191
Weiner J, 2009, J HOPKINS ACG SYSTEM
Wen XZ, 2012, PEDIATRICS, V129, P823, DOI 10.1542/peds.2011-1833
Williams C, 2012, HEALTH AFFAIR, V31, P527, DOI 10.1377/hlthaff.2011.1314
NR 54
TC 23
Z9 23
U1 1
U2 11
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA

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SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD JUN 18
PY 2013
VL 8
IS 6
AR e66192
DI 10.1371/journal.pone.0066192
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
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OA DOAJ Gold, Green Published
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ER

PT J
AU Menssen, A
   Edinger, G
   Grun, JR
   Haase, U
   Baumgrass, R
   Grutzkau, A
   Radbruch, A
   Burmester, GR
   Haupl, T
AF Menssen, Adriane
   Edinger, Goetz
   Gruen, Joachim R.
   Haase, Ulrike
   Baumgrass, Ria
   Gruetzkau, Andreas
   Radbruch, Andreas
   Burmester, Gerd-R
   Haeupl, Thomas
TI SiPaGene: A new repository for instant online retrieval, sharing and
   meta-analyses of GeneChip (R) expression data
SO BMC GENOMICS
LA English
DT Article
ID OLIGONUCLEOTIDE ARRAY DATA; PROBE LEVEL DATA; GENE-EXPRESSION;
   MICROARRAY DATA; NCBI GEO; ARRAYEXPRESS; PROFILES; TOOLS; NORMALIZATION;
   SUMMARIES
AB Background: Microarray expression profiling is becoming a routine technology
for medical research and generates enormous amounts of data. However, reanalysis
of public data and comparison with own results is laborious. Although many
different tools exist, there is a need for more convenience and online analysis
with restriction of access and user specific sharing options. Furthermore, most
of the currently existing tools do not use the whole range of statistical power
provided by the MAS5.0/GCOS algorithms.
   Description: With a current focus on immunology, infection, inflammation,
tissue regeneration and cancer we developed a database platform that can load
preprocessed Affymetrix GeneChip expression data for immediate access. Group or
subgroup comparisons can be calculated online, retrieved for candidate genes,
transcriptional activity in various biological conditions and compared with
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different experiments. The system is based on Oracle 9i with algorithms in java and graphical user interfaces implemented as java servlets. Signals, detection calls, signal log ratios, change calls and corresponding p-values were calculated with MAS5.0/GCOS algorithms. MIAME information and gene annotations are provided via links to GEO and EntrezGene. Users access via https protocol their own, shared or public data. Sharing is comparison- and user-specific with different levels of rights. Arrays for group comparisons can be selected individually. Twenty-two different group comparison parameters can be applied in user-defined combinations on single or multiple group comparisons. Identified genes can be reviewed online or downloaded. Optimized selection criteria were developed and reliability was demonstrated with the "Latin Square" data set. Currently more than 1,000 arrays, 10,000 pairwise comparisons and 500 group comparisons are presented with public or restricted access by different research networks or individual users.

Conclusion: SiPaGene is a repository and a high quality tool for primary analysis of GeneChips. It exploits the MAS5.0/GCOS pairwise comparison algorithm, enables restricted access and user specific sharing. It does not aim for a complete representation of all public arrays but for high quality analysis with stepwise integration of reference signatures for detailed meta-analyses. Development of additional tools like functional annotation networks based on expression information will be future steps towards a systematic biological analysis of expression profiles.

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FU National Genome Research Network in Germany; German Federal Ministry of Education and Research [01GS0413]; GenoStem [503161]; Auto-Cure [018661]

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CR *AFF, 2002, STAT ALG DESCR DOC
*AFF, 2003, LAT SQUAR DAT FIL DE
Ameur A, 2006, BIOINFORMATICS, V22, P1024, DOI 10.1093/bioinformatics/btl036
Barrett T, 2005, NUCLEIC ACIDS RES, V33, pD562
Barrett T, 2007, NUCLEIC ACIDS RES, V35, pD760, DOI 10.1093/nar/gkl887
Bolstad BM, 2003, BIOINFORMATICS, V19, P185, DOI 10.1093/bioinformatics/19.2.185
Brazma A, 2006, METHOD ENZYMOL, V411, P370, DOI 10.1016/S0076-6879(06)11020-4
Brown MPS, 2000, P NATL ACAD SCI USA, V97, P262, DOI 10.1073/pnas.97.1.262
Cope LM, 2004, BIOINFORMATICS, V20, P323, DOI 10.1093/bioinformatics/btg410
Day A, 2007, GENOME BIOL, V8, DOI 10.1186/gb-2007-8-6-r112
Edgar R, 2002, NUCLEIC ACIDS RES, V30, P207, DOI 10.1093/nar/30.1.207
Haupl T, 2008, ARTHRITIS RHEUM, V58, P2981, DOI 10.1002/art.23907

```
   Haverty PM, 2002, NUCLEIC ACIDS RES, V30, P214, DOI 10.1093/nar/30.1.214
   *ING, 2007, ING PATHW AN 5 0
   Irizarry RA, 2003, BIOSTATISTICS, V4, P249, DOI 10.1093/biostatistics/4.2.249
   Irizarry RA, 2003, NUCLEIC ACIDS RES, V31, DOI 10.1093/nar/gng015
   Jenssen TK, 2001, NAT GENET, V28, P21, DOI 10.1038/ng0501-21
   Katz S, 2006, BMC BIOINFORMATICS, V7, DOI 10.1186/1471-2105-7-464
   Li C, 2001, P NATL ACAD SCI USA, V98, P31, DOI 10.1073/pnas.011404098
   LI C, 2003, ANAL GENE EXPRESSION, P120
   Maurer M, 2005, BMC BIOINFORMATICS, V6, DOI 10.1186/1471-2105-6-101
   MCGEE M, 2006, COBRA PREPRINT SERIE
   Nikitin A, 2003, BIOINFORMATICS, V19, P2155, DOI
10.1093/bioinformatics/btg290
   Parkinson H, 2005, NUCLEIC ACIDS RES, V33, pD553
   Parkinson H, 2007, NUCLEIC ACIDS RES, V35, pD747, DOI 10.1093/nar/gkl995
   Rhodes DR, 2007, NEOPLASIA, V9, P166, DOI 10.1593/neo.07112
   Rhodes DR, 2004, NEOPLASIA, V6, P1, DOI 10.1016/S1476-5586(04)80047-2
   Riley ML, 2007, NUCLEIC ACIDS RES, V35, pD354, DOI 10.1093/nar/gkl1005
   Rock J, 2007, EUR J IMMUNOL, V37, P3564, DOI 10.1002/eji.200737711
   SAAL LH, 2002, GENOME BIOL, V3
   Sarkans U, 2005, BIOINFORMATICS, V21, P1495, DOI
10.1093/bioinformatics/bti157
   Shedden K, 2005, BMC BIOINFORMATICS, V6, DOI 10.1186/1471-2105-6-26
   Sturn A, 2002, BIOINFORMATICS, V18, P207, DOI 10.1093/bioinformatics/18.1.207
   Tibshirani R, 2002, P NATL ACAD SCI USA, V99, P6567, DOI
10.1073/pnas.082099299
   Troein C, 2006, METHOD ENZYMOL, V411, P99, DOI 10.1016/S0076-6879(06)11007-1
   Tusher VG, 2001, P NATL ACAD SCI USA, V98, P5116, DOI 10.1073/pnas.091062498
   Yoon S, 2006, BIOINFORMATICS, V22, P2898, DOI 10.1093/informatics/btl500
NR 37
TC 23
Z9 24
U1 0
U2 3
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1471-2164
J9 BMC GENOMICS
JI BMC Genomics
PD MAR 5
PY 2009
VL 10
AR 98
DI 10.1186/1471-2164-10-98
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WC Biotechnology & Applied Microbiology; Genetics & Heredity
SC Biotechnology & Applied Microbiology; Genetics & Heredity
GA 430IJ
UT WOS:000264982500001
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PT B
AU Chen, LB
   Zhang, DQ
   Pan, G
```

Ma, XJ
Yang, DQ
Kushlev, K
Zhang, WS
Li, SJ
AF Chen, Longbiao
Zhang, Daqing
Pan, Gang
Ma, Xiaojuan
Yang, Dingqi
Kushlev, Kostadin
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GP ACM
TI Bike Sharing Station Placement Leveraging Heterogeneous Urban Open Data
SO PROCEEDINGS OF THE 2015 ACM INTERNATIONAL JOINT CONFERENCE ON PERVASIVE AND UBIQUITOUS COMPUTING (UBICOMP 2015)
LA English
DT Proceedings Paper
CT ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp)
CY SEP 07-11, 2015
CL Osaka, JAPAN
SP Assoc Comp Machinery, ACM SIGCHI, ACM SIGMOBILE, Panasonic, Bell Labs, Microsoft, Google, Yahoo Japan, KDDI, FXPAL, Rakuten Inst Technol, ISTC PC, NTT DOCOMO, Telefonica Investigac & Desarrollo
DE Open data; urban computing; bike sharing system
AB Bike sharing systems have been deployed in many cities to promote green transportation and a healthy lifestyle. One of the key factors for maximizing the utility of such systems is placing bike stations at locations that can best meet users' trip demand. Traditionally, urban planners rely on dedicated surveys to understand the local bike trip demand, which is costly in time and labor, especially when they need to compare many possible places. In this paper, we formulate the bike station placement issue as a bike trip demand prediction problem. We propose a semi-supervised feature selection method to extract customized features from the highly variant, heterogeneous urban open data to predict bike trip demand. Evaluation using real-world open data from Washington, D.C. and Hangzhou shows that our method can be applied to different cities to effectively recommend places with higher potential bike trip demand for placing future bike stations.
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OI Kushlev, Kostadin/0000-0003-1025-3258; Ma, Xiaojuan/0000-0002-9847-7784
CR Burden AM., 2009, BIKE SHARE OPPORTUNI
Garcia-Palomares JC, 2012, APPL GEOGR, V35, P235, DOI 10.1016/j.apgeog.2012.07.002
Chen L., P UBICOMP 14, P847

```
   DeMaio P, 2009, J PUBLIC TRANSPORT, V12, P41, DOI DOI 10.5038/2375-
0901.12.4.3
   Foursquare Inc, 2015, FOURSQ API
   Froehlich J., P IJCAI 09, V9, P1420
   Hangzhou Online, 2015, HANGZH PUBL BIC SYST
   Jarvelin K, 2002, ACM T INFORM SYST, V20, P422, DOI 10.1145/582415.582418
   Jensen I, 2006, PHYS REV E, V74, DOI 10.1103/PhysRevE.74.020101
   Karamshuk D., P KDD 13, P793
   LDA Consulting, 2013, 2013 CAP BIK MEMB SU
   Malmi E., P ICWSM 13
   Pucher J, 2010, PREV MED, V50, pS106, DOI 10.1016/j.ypmed.2009.07.028
   Shaheen SA, 2011, TRANSPORT RES REC, P33, DOI 10.3141/2247-05
   Shaheen SA, 2010, TRANSP RES RECORD, P159, DOI 10.3141/2143-20
   SPECHT DF, 1991, IEEE T NEURAL NETWOR, V2, P568, DOI 10.1109/72.97934
   Ubaldi B., 2013, OECD WORKING PAPERS, V22, P1, DOI DOI 10.1787/5K46BJ4F03S7-
EN>[
   Yang DQ, 2015, IEEE T SYST MAN CY-S, V45, P129, DOI 10.1109/TSMC.2014.2327053
   Yuan J., P KDD 12, P186
   ZAR JH, 1972, J AM STAT ASSOC, V67, P578, DOI 10.2307/2284441
   Zhang DQ, 2011, COMPUTER, V44, P21, DOI 10.1109/MC.2011.65
   Zheng Y., P UBICOMP 14, P715
   Zheng Y., P KDD 13, P1436
NR 23
TC 22
Z9 22
U1 0
U2 8
PU ASSOC COMPUTING MACHINERY
PI NEW YORK
PA 1515 BROADWAY, NEW YORK, NY 10036-9998 USA
BN 978-1-4503-3574-4
PY 2015
BP 571
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DI 10.1145/2750858.2804291
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WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic
SC Computer Science; Engineering
GA BF6WQ
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PT B
AU Terzo, O
   Ruiu, P
   Bucci, E
   Xhafa, F
AF Terzo, Olivier
   Ruiu, Pietro
   Bucci, Enrico
   Xhafa, Fatos
BE Barolli, L
   Xhafa, F
   Chen, HC
   Gomez, ASF
   Hussain, F
TI Data as a Service (DaaS) for Sharing and Processing of Large Data
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Collections in the Cloud
SO 2013 SEVENTH INTERNATIONAL CONFERENCE ON COMPLEX, INTELLIGENT, AND
SOFTWARE INTENSIVE SYSTEMS (CISIS)
LA English
DT Proceedings Paper
CT 7th International Conference on Complex, Intelligent, and Software
Intensive Systems (CISIS)
CY JUL 03-05, 2013
CL Asia Univ, Taichung, TAIWAN
SP CIS, Fukuoka Inst Technol, Univ Politecnica Catalunya, Korean Bible Univ
HO Asia Univ
DE Cloud Computing; Data as a Service; Large Data Collection; Sharing;
Health Data Collections; Genomics

AB Data as a Service (DaaS) is among the latest kind of services being investigated in the Cloud computing community. The main aim of DaaS is to overcome limitations of state-of-the-art approaches in data technologies, according to which data is stored and accessed from repositories whose location is known and is relevant for sharing and processing. Besides limitations for the data sharing, current approaches also do not achieve to fully separate/decouple software services from data and thus impose limitations in inter-operability. In this paper we propose a DaaS approach for intelligent sharing and processing of large data collections with the aim of abstracting the data location (by making it relevant to the needs of sharing and accessing) and to fully decouple the data and its processing. The aim of our approach is to build a Cloud computing platform, offering DaaS to support large communities of users that need to share, access, and process the data for collectively building knowledge from data. We exemplify the approach from large data collections from health and biology domains.

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OI Bucci, Enrico/0000-0002-3317-8003; XHAFA, FATOS/0000-0001-6569-5497

CR Altshuler DM, 2012, NATURE, V491, P56, DOI 10.1038/nature11632
[Anonymous], 2012, GARTN 2012 HYP CYCL
[Anonymous], 2010, A WAT AG EX TOOLS AP
BUNN J., 2003, GRID COMPUTING MAKIN
Cisco and/or its affiliates, 2011, CISC GLOB CLOUD IND
Daneshyar Samira, 2012, INT J WEB SERVICE CO, V3
Demchenko Y., 2012, 2012 IEEE 4th International Conference on Cloud Computing Technology and Science (CloudCom). Proceedings, P614, DOI 10.1109/CloudCom.2012.6427494
Edmonds A, 2012, IEEE INTERNET COMPUT, V16, P15, DOI 10.1109/MIC.2012.65
Fernandez-Suarez XM, 2013, NUCLEIC ACIDS RES, V41, pD1, DOI 10.1093/nar/gks1297
Fritz MHY, 2011, GENOME RES, V21, P734, DOI 10.1101/gr.114819.110
Gattiker Anne E., 2013, IBM RES REPORT UNDER
GLOBAL RESEARCH INFRASTRUCTURE SUB GROUP ON DATA, 2011, E INFR ACT IN PRESS
Magoules Frederic, 2012, MULTIDIMENSIONAL DAT, P63
PARADE - Partnership for Accessing Data in Europe, 2009, STRAT EUR DAT INFR
Pectcu Dana, 2012, EUROPEAN RES ACTIVIT
SNIA, ADV STOR INF TECHN I
Strijkers Rudolph, 2010, AMOS USING CLOUD ON, P331
NR 17

```
TC 22
Z9 22
U1 0
U2 4
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-0-7695-4992-7
PY 2013
BP 475
EP 480
DI 10.1109/CISIS.2013.87
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WC Computer Science, Artificial Intelligence; Computer Science, Software
   Engineering; Engineering, Electrical & Electronic
SC Computer Science; Engineering
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ER

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AU Stone, MA
   Redsell, SA
   Ling, JT
   Hay, AD
AF Stone, MA
   Redsell, SA
   Ling, JT
   Hay, AD
TI Sharing patient data: competing demands of privacy, trust and research
   in primary care
SO BRITISH JOURNAL OF GENERAL PRACTICE
LA English
DT Article
DE confidentiality; ethics; general practice; medical records; research
ID INFORMED-CONSENT; CONFIDENTIALITY; INFORMATION; REGISTRY; RECORDS;
   DEBATE; THREAT
AB Background Patient privacy may conflict with the advancement of knowledge
through data sharing. The data contained in primary care records are uniquely
comprehensive.
   Aim To explore the knowledge and attitudes of patients and members of the
primary healthcare team regarding the sharing of data held in primary care
records, with particular reference to data sharing for research and the impact
that this may have on trust between patients and health professionals.
   Design of study Qualitative study using quota sampled, semi-structured
interviews.
   Setting Five general practices in Leicestershire, UK.
   Method Grounded theory and framework methodology were used. Interviews were
transcribed and analysed thematically.
   Results Twenty patients and 15 healthcare professionals and managers were
interviewed. Patients had limited knowledge of the type of information held in
their general practice records and the ways in which these data are shared, but
appeared ready to form preliminary views on issues such as data sharing for
audit and disease registration. In this climate of limited awareness, there was
no suggestion that concern about data sharing for research adversely affects
patient trust or leads patients to withhold relevant information from health
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professionals in primary care. Interviews carried out with staff suggested a lack of clear practice policies regarding data sharing.

Conclusions General practices may need to develop policies on data sharing, bring these to the attention of their patient population and improve patient awareness about the nature of the data contained in their records. Researchers should ensure that patients are adequately informed about the nature of data contained in patient records when seeking consent for data extraction.

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CR Baker R, 2000, BRIT J GEN PRACT, V50, P655
Boyd P, 2003, J MED ETHICS, V29, P34, DOI 10.1136/jme.29.1.34
Brown RF, 2004, SOC SCI MED, V58, P379, DOI 10.1016/S0277-9536(03)00204-1
Chalmers J, 2003, BMJ-BRIT MED J, V326, P725, DOI 10.1136/bmj.326.7392.725
*DEP HLTH, 2003, CONF NHS COD PRACT
Glaser B, 1992, BASICS GROUNDED THEO
Ingelfinger JR, 2004, NEW ENGL J MED, V350, P1452, DOI 10.1056/NEJMe048027
Kent A, 2003, J MED ETHICS, V29, P16, DOI 10.1136/jme.29.1.16
*MED RES COUNC, 2000, PERS INF MED RES
Melton LJ, 1997, NEW ENGL J MED, V337, P1466, DOI 10.1056/NEJM199711133372012
*NHS INF AUTH CONJ, 2002, SHAR CAR PEOPL VIEWS
O'Brien J, 2003, J MED ETHICS, V29, P36, DOI 10.1136/jme.29.1.36
Paterson ICM, 2001, BRIT MED J, V322, P1130, DOI 10.1136/bmj.322.7294.1130
Ritchie J., 1994, ANAL QUALITATIVE DAT
Rogers WA, 2002, BRIT J GEN PRACT, V52, P1007
*SCHARR, 2002, PAT EL REC INF CONS
Schers H, 2003, SCAND J PRIM HEALTH, V21, P21, DOI 10.1080/02813430310000519
Strobl J, 2000, BRIT MED J, V321, P890, DOI 10.1136/bmj.321.7265.890
Tu JV, 2004, NEW ENGL J MED, V350, P1414, DOI 10.1056/NEJMsa031697
Verity C, 2002, BRIT MED J, V324, P1210, DOI 10.1136/bmj.324.7347.1210

NR 20
TC 22
Z9 22
U1 0
U2 10
PU ROYAL COLL GENERAL PRACTITIONERS
PI LONDON
PA 14 PRINCES GATE, HYDE PARK, LONDON SW7 1PU, ENGLAND
SN 0960-1643
J9 BRIT J GEN PRACT
JI Br. J. Gen. Pract.
PD OCT
PY 2005
VL 55
IS 519
BP 783
EP 789
PG 7
WC Primary Health Care; Medicine, General & Internal
SC General & Internal Medicine
GA 984IV
UT WOS:000233297400010
PM 16212854

```
DA 2019-08-06
ER

PT J
AU Bhattacharjee, Y
AF Bhattacharjee, Yudhijit
TI BIOMEDICINE Pharma Firms Push for Sharing Of Cancer Trial Data
SO SCIENCE
LA English
DT News Item
NR 0
TC 21
Z9 21
U1 0
U2 3
PU AMER ASSOC ADVANCEMENT SCIENCE
PI WASHINGTON
PA 1200 NEW YORK AVE, NW, WASHINGTON, DC 20005 USA
SN 0036-8075
J9 SCIENCE
JI Science
PD OCT 5
PY 2012
VL 338
IS 6103
BP 29
EP 29
DI 10.1126/science.338.6103.29
PG 1
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA 015PC
UT WOS:000309457400014
PM 23042862
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ER

PT J
AU Tucker, K
   Branson, J
   Dilleen, M
   Hollis, S
   Loughlin, P
   Nixon, MJ
   Williams, Z
AF Tucker, Katherine
   Branson, Janice
   Dilleen, Maria
   Hollis, Sally
   Loughlin, Paul
   Nixon, Mark J.
   Williams, Zoe
TI Protecting patient privacy when sharing patient-level data from clinical
   trials
SO BMC MEDICAL RESEARCH METHODOLOGY
LA English
DT Article
DE Clinical trial; Data sharing; Transparency; De-identification;
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Anonymisation; Pharmaceutical research
ID ANONYMIZATION

AB Background: Greater transparency and, in particular, sharing of patient-level data for further scientific research is an increasingly important topic for the pharmaceutical industry and other organisations who sponsor and conduct clinical trials as well as generally in the interests of patients participating in studies. A concern remains, however, over how to appropriately prepare and share clinical trial data with third party researchers, whilst maintaining patient confidentiality. Clinical trial datasets contain very detailed information on each participant. Risk to patient privacy can be mitigated by data reduction techniques. However, retention of data utility is important in order to allow meaningful scientific research. In addition, for clinical trial data, an excessive application of such techniques may pose a public health risk if misleading results are produced. After considering existing guidance, this article makes recommendations with the aim of promoting an approach that balances data utility and privacy risk and is applicable across clinical trial data holders.

Discussion: Our key recommendations are as follows:

1. Data anonymisation/de-identification: Data holders are responsible for generating de-identified datasets which are intended to offer increased protection for patient privacy through masking or generalisation of direct and some indirect identifiers.

2. Controlled access to data, including use of a data sharing agreement: A legally binding data sharing agreement should be in place, including agreements not to download or further share data and not to attempt to seek to identify patients. Appropriate levels of security should be used for transferring data or providing access; one solution is use of a secure 'locked box' system which provides additional safeguards.

Summary: This article provides recommendations on best practices to de-identify/anonymise clinical trial data for sharing with third-party researchers, as well as controlled access to data and data sharing agreements. The recommendations are applicable to all clinical trial data holders. Further work will be needed to identify and evaluate competing possibilities as regulations, attitudes to risk and technologies evolve.

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CR Aggarwal CC, 2008, ADV DATABASE SYST, V34, P11
[Anonymous], 2014, WORKING PARTY PROTEC
El Emam K, 2015, INT DATA PRIV LAW, V5, P73, DOI 10.1093/idpl/ipu033
European Commission, AGR COMM EUR DAT PRO
European Federation of Pharmaceutical Industries and Associations (EFPIA) and The Pharmaceutical Research and Manufacturers of America (PhRMA), 2013, PRINC RESP CLIN TRIA
European Medicines Agency, 2014, EUR MED AG POL PUBL
European Medicines Agency, 2016, EXT GUID IMPL EUR ME

```
   Eze B, 2015, PROCEDIA COMPUT SCI, V63, P348, DOI 10.1016/j.procs.2015.08.353
   Gibson B., 2014, MULTISPONSOR DATA TR
   Hrynaszkiewicz I, 2010, BRIT MED J, V340, DOI 10.1136/bmj.c181
   Hughes S, 2014, PHARM STAT, V13, P179, DOI 10.1002/pst.1615
   Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
   International Pharmaceutical Privacy Consortium, 2014, IPPC WHIT PAP AN CLI
   Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
   National Heart Lung and Blood Institute, GUID NHLBI DAT SET P
   Pfizer, DAT ACC REQ
   Taichman DB, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001950
   Tarran B, 2014, SIGNIFICANCE, V11, P10
   TransCelerate Biopharma Inc, CLIN STUD REP APPR P
   Tudur Smith C, 2015, GOOD PRACTICE PRINCI
   UK Data Service, 2015, ACC SENS DAT RES 5 S
   US Office for Civil Rights (OCR), 2012, GUID REG METH DEID P
   Yale University Open Data Access (YODA) Project, NEW APPR DAT ACC TRA
NR 23
TC 20
Z9 22
U1 2
U2 5
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1471-2288
J9 BMC MED RES METHODOL
JI BMC Med. Res. Methodol.
PY 2016
VL 16
SU 1
AR 77
DI 10.1186/s12874-016-0169-4
PG 10
WC Health Care Sciences & Services
SC Health Care Sciences & Services
GA EZ9CB
UT WOS:000405025700005
PM 27410040
OA DOAJ Gold, Green Published
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PT J
AU de Chardon, CM
   Caruso, G
AF de Chardon, Cyrille Medard
   Caruso, Geoffrey
TI Estimating bike-share trips using station level data
SO TRANSPORTATION RESEARCH PART B-METHODOLOGICAL
LA English
DT Article
DE Bicycle-sharing systems; Bike-share; Open data; Trip estimation;
   Rebalancing
ID BICYCLE SCHEME; IMPACT; PROGRAM; MELBOURNE; BIKESHARE; BARRIERS;
   MONTREAL; WEATHER; EUROPE
AB Bicycle sharing systems (BSS) have increased in number rapidly since 2007.
The potential benefits of BSS, mainly sustainability, health and equity, have
encouraged their adoption through support and promotion by mayors in Europe and
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North America alike. In most cases municipal governments desire their BSS to be successful and, with few exceptions, state them as being so. New technological improvements have dramatically simplified the use and enforcement of bicycle return, resulting in the widespread adoption of BSS. Unfortunately little evaluation of the effectiveness of differently distributed and managed BSS has taken place. Comparing BSS systems quantitatively is challenging due to the limited data made available. The metrics of success presented by municipalities are often too general or incomparable to others making relative evaluations of BSS success arduous. This paper presents multiple methodologies allowing the estimation of the number of daily trips, the most significant measure of BSS usage, based on data that is commonly available, the number of bicycles available at a station over time. Results provide model coefficients as well as trip count estimates for select cities. Of four spatial and temporal aggregate models the day level aggregation is found to be most effective for estimation. In addition to trip estimation this work provides a rigorous formalization of station level data and the ability to distinguish spatio-temporal rebalancing quantities as well as new characteristics of BSS station use. (C) 2015 Elsevier Ltd. All rights reserved.

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FX This research was partially funded by Luxembourg's Fonds National de la Recherche (Grant #4054695). Thanks to all the BSS operators who made their trip data available: Boston's Hubway, Chicago's Divvy, London's TfL, Minneapolis's Nice Ride Minnesota, NYC's Citibike, SF's Bay Area Bike Share, Vienna's Gewista Werbegesellschaft and WDC's Capital Bikeshare. The authors also wish to thank the two anonymous reviewers, whose comments refined this paper.

CR Austwick MZ, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0074685
Basch CH, 2014, J COMMUN HEALTH, V39, P956, DOI 10.1007/s10900-014-9836-8
Beecham R, 2014, COMPUT ENVIRON URBAN, V47, P5, DOI 10.1016/j.compenvurbsys.2013.10.007
Beland D, 2014, INT J SOCIOL SOC POL, V34, P545, DOI 10.1108/IJSSP-07-2013-0072
Bialick Aaron, 2013, BAY AREA BIKE SHARE
Bordagaray M., 2014, INT J SUSTAINABLE TR
Borgnat P, 2011, ADV COMPLEX SYST, V14, P415, DOI 10.1142/S0219525911002950
Chow JYJ, 2014, TRANSPORT RES B-METH, V62, P13, DOI 10.1016/j.trb.2014.01.008
Corcoran J, 2014, J TRANSP GEOGR, V41, P292, DOI 10.1016/j.jtrangeo.2014.09.003
Cripps Karla, 2013, BIKE SHARE BOOM 7 CI
DeMaio P, 2009, J PUBLIC TRANSPORT, V12, P41, DOI DOI 10.5038/2375-0901.12.4.3
DEMAIO P, 2004, J PUBLIC TRANSPORT, V7, P1, DOI DOI 10.5038/2375-0901.7.2.1
Faghih-Imani A., 2014, J TRANSPORT GEOGRAPH
Fishman E, 2016, TRANSPORT REV, V36, P1, DOI 10.1080/01441647.2015.1114271
Fishman E, 2015, TRANSPORT RES A-POL, V71, P17, DOI 10.1016/j.tra.2014.10.021
Fishman E, 2014, J TRANSP GEOGR, V41, P325, DOI 10.1016/j.jtrangeo.2014.08.005
Fishman E, 2014, TRANSPORT RES D-TR E, V31, P13, DOI 10.1016/j.trd.2014.05.013
Fishman E, 2013, TRANSPORT REV, V33, P148, DOI 10.1080/01441647.2013.775612

Fishman E, 2012, TRANSPORT RES F-TRAF, V15, P686, DOI 10.1016/j.trf.2012.08.002
Forma IA, 2015, TRANSPORT RES B-METH, V71, P230, DOI 10.1016/j.trb.2014.10.003
Fuller D, 2012, PREV MED, V54, P74, DOI 10.1016/j.ypmed.2011.09.021
Fuller D, 2011, AM J PREV MED, V41, P80, DOI 10.1016/j.amepre.2011.03.002
Gebhart K, 2014, TRANSPORTATION, V41, P1205, DOI 10.1007/s11116-014-9540-7
Gelman A., 2007, DATA ANAL USING REGR
Goodyear Sarah, 2013, WORLDS TOP 7 BIKE SH
Jappinen S, 2013, APPL GEOGR, V43, P13, DOI 10.1016/j.apgeog.2013.05.010
JCDecaux, VEL DEP CAP 500000 L
JCDecaux, 2014, TWEET REG STAT LEV D
Jensen P, 2010, TRANSPORT RES D-TR E, V15, P522, DOI 10.1016/j.trd.2010.07.002
Jurdak R, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0079396
Kaltenbrunner A, 2010, PERVASIVE MOB COMPUT, V6, P455, DOI 10.1016/j.pmcj.2010.07.002
Kaspi M, 2014, TRANSPORT RES B-METH, V62, P35, DOI 10.1016/j.trb.2014.01.006
Kloimullner Christian, 2014, Evolutionary Computation in Combinatorial Optimisation. 14th European Conference (EvoCOP 2014). Revised Selected Papers: LNCS 8600, P73, DOI 10.1007/978-3-662-44320-0_7
Kohnen Julien, 2014, ECOLOGIQUE CONCEPT V
Labadi K., 2014, IEEE T AUTOM SCI ENG, P1
Laporte G., 2014, EUROPEAN J OPERATION
Lathia N, 2012, TRANSPORT RES C-EMER, V22, P88, DOI 10.1016/j.trc.2011.12.004
Martin E. W., 2014, J TRANSPORT GEOGRAPH
Midgley P., 2009, JOURNEYS, V2, P23
Molina-Garcia J., 2013, HLTH PROMOTION INT
Murphy E, 2015, INT J SUSTAIN TRANSP, V9, P116, DOI 10.1080/15568318.2012.748855
Nakamura H, 2014, TRANSPORT POLICY, V35, P31, DOI 10.1016/j.tranpol.2014.05.009
O'Brien O, 2014, J TRANSP GEOGR, V34, P262, DOI 10.1016/j.jtrangeo.2013.06.007
Office for National Statistics, 2013, UK POP EST
Ogilvie F, 2012, PREV MED, V55, P40, DOI 10.1016/j.ypmed.2012.05.002
Paris.fr, 2013, VELIB ANATOMIE SUCCE
Parkes SD, 2013, J TRANSP GEOGR, V31, P94, DOI 10.1016/j.jtrangeo.2013.06.003
Parkin J, 2008, TRANSPORTATION, V35, P93, DOI 10.1007/s11116-007-9137-5
Pfrommer J, 2014, IEEE T INTELL TRANSP, V15, P1567, DOI 10.1109/TITS.2014.2303986
Ravalet E., 2012, RECHERCHE TRANSPORTS, V28, P15, DOI DOI 10.1007/S13547-011
Shaheen SA, 2010, TRANSP RES RECORD, P159, DOI 10.3141/2143-20
Tironi M., 2014, J CULTURAL EC, P1
United Nations Statistics Division, 2011, CIT POP SEX CIT CIT
US Census Bureau, 2011, TABL 1 ANN EST POP M
Ville de Luxembourg, 2014, 6 ANNIVERSAIRE VELOH
Vogel M., 2014, J TRANSPORT GEOGRAPH
WHITE H, 1980, ECONOMETRICA, V48, P817, DOI 10.2307/1912934
Wood J., 2011, CARTOGRAPHICA INT J, V46, P239, DOI DOI 10.3138/CARTO.46.4.239
Woodcock J, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g425
Zhang L., 2014, J CLEANER PRODUCTION
Zhao JB, 2014, TRANSPORT POLICY, V35, P253, DOI 10.1016/j.tranpol.2014.06.008
NR 61
TC 20
Z9 20
U1 3
U2 83

PU PERGAMON-ELSEVIER SCIENCE LTD
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PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
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J9 TRANSPORT RES B-METH
JI Transp. Res. Pt. B-Methodol.
PD AUG
PY 2015
VL 78
BP 260
EP 279
DI 10.1016/j.trb.2015.05.003
PG 20
WC Economics; Engineering, Civil; Operations Research & Management Science;
   Transportation; Transportation Science & Technology
SC Business & Economics; Engineering; Operations Research & Management
   Science; Transportation
GA CN0GK
UT WOS:000358091900015
DA 2019-08-06
ER

PT J
AU Critchley, C
   Nicol, D
   Otlowski, M
AF Critchley, Christine
   Nicol, Dianne
   Otlowski, Margaret
TI The Impact of Commercialisation and Genetic Data Sharing Arrangements on
   Public Trust and the Intention to Participate in Biobank Research
SO PUBLIC HEALTH GENOMICS
LA English
DT Article
DE Biobanking; Data sharing; Commercialisation; Genetics research; Public
   trust in science; Public health
ID ISSUES; CONSENT
AB Objectives: The necessity for biobanks to share their resources with third parties poses potential risks to public trust and the intention to participate in genetic research. We explore the effects of data sharing and the type of third-party access (public vs. private) on public trust and, in turn, the intention to participate in biobank research. Methods: An experimental design was used to assess a national sample of 1,701 Australians via a computer-assisted telephone interview. Results: The results revealed that trust and the intention to participate significantly decreased in relation to private compared to public biobanks, and when access to third-party researchers was allowed compared to when it was not. Somewhat surprisingly, no differences were found in relation to the third party being international compared to Australian, but trust and the intention to participate were significantly eroded when private third parties were allowed access. Those with a university education were particularly distrustful of private biobanks and biobanks that allowed access, while those who were more aware of genetic databases appeared more confident with biobanks sharing with private-sector third parties. Conclusion: The pattern of results suggests that public awareness of the need for biobanks to share their resources widely needs to be increased to maintain public trust and support. (C) 2015 S. Karger AG, Basel
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RI Nicol, Dianne/J-7253-2014
OI Nicol, Dianne/0000-0002-6553-2839
CR American Association for Public Opinion Research, 2011, STAND DEF FIN DISP C
   Australian Bureau of Statistics, 2014, POP AG SEX REG AUSTR
   Bryant RJ, 2008, J CLIN PATHOL, V61, P322, DOI 10.1136/jcp.2007.053173
   Cadigan R Jean, 2013, Life Sci Soc Policy, V9, P1
   Caulfield T, 2008, PLOS BIOL, V6, P430, DOI 10.1371/journal.pbio.0060073
   Caulfield T, 2014, J LAW BIOSCI, V1, P94, DOI 10.1093/jlb/lst004
   Caulfield T, 2014, NAT REV GENET, V15, P220, DOI 10.1038/nrg3704
   Caulfield T, 2012, BIOPRESERV BIOBANK, V10, P433, DOI 10.1089/bio.2012.0029
   Critchley CR, 2008, PUBLIC UNDERST SCI, V17, P309, DOI
10.1177/0963662506070162
   Critchley CR, 2012, EUR J PUBLIC HEALTH, V22, P139, DOI 10.1093/eurpub/ckq136
   Critchley CR, 2011, PUBLIC UNDERST SCI, V20, P347, DOI
10.1177/0963662509346910
   Fleming J, 2007, HUMAN BIOTECHNOLOGY, P184
   Hewitt RE, 2011, CURR OPIN ONCOL, V23, P112, DOI 10.1097/CCO.0b013e32834161b8
   Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
   Kettis-Lindblad A, 2006, EUR J PUBLIC HEALTH, V16, P433, DOI
10.1093/eurpub/cki198
   Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
   Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
   Levitt M, 2005, CRIT PUBLIC HEALTH, V15, P311, DOI DOI
10.1080/09581590500523186
   LITTLE RJA, 1993, J AM STAT ASSOC, V88, P1001, DOI 10.2307/2290792
   Master Z, 2013, BMC MED GENOMICS, V6, DOI 10.1186/1755-8794-6-8
   McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
   McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
   Meijer I, 2012, SCI PUBL POLICY, V39, P491, DOI 10.1093/scipol/scs033
   Miller FA, 2014, HLTH EXPECT
   Nilstun Tore, 2006, Med Health Care Philos, V9, P81, DOI 10.1007/s11019-005-
7984-4
   Page MPA, 1998, PSYCHOL REV, V105, P761, DOI 10.1037/0033-295X.105.4.761-781
   Rubin DB, 1989, MULTIPLE IMPUTATION
   Schafer J. L., 1997, ANAL INCOMPLETE MULT
   Tabachnick B. G., 2012, USING MULTIVARIATE S
   Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
   Tutton R, 2004, TRENDS BIOTECHNOL, V22, P284, DOI 10.1016/S0167-
7799(04)00112-X
   Watson RWG, 2010, NAT REV CANCER, V10, P646, DOI 10.1038/nrc2913
   Yuan KH, 2000, SOCIOL METHODOL, V30, P165, DOI 10.1111/0081-1750.00078
NR 33
TC 20
Z9 21
U1 2
U2 12
PU KARGER
PI BASEL
PA ALLSCHWILERSTRASSE 10, CH-4009 BASEL, SWITZERLAND
SN 1662-4246
EI 1662-8063
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J9 PUBLIC HEALTH GENOM
JI Pub. Health Genomics
PY 2015
VL 18
IS 3
BP 160
EP 172
DI 10.1159/000375441
PG 13
WC Genetics & Heredity; Public, Environmental & Occupational Health
SC Genetics & Heredity; Public, Environmental & Occupational Health
GA CG8NN
UT WOS:000353565000004
PM 25790760
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ER

PT J
AU Reinhardt, JD
   Wahrendorf, M
   Siegrist, J
AF Reinhardt, Jan D.
   Wahrendorf, Morten
   Siegrist, Johannes
TI Socioeconomic position, psychosocial work environment and disability in an ageing workforce: a longitudinal analysis of SHARE data from 11 European countries
SO OCCUPATIONAL AND ENVIRONMENTAL MEDICINE
LA English
DT Article
ID EFFORT-REWARD IMBALANCE; CORONARY-HEART-DISEASE; SOCIAL SUPPORT; WHITEHALL-II; HEALTH; INEQUALITIES; SF-36; ICF

AB Objectives Prevention of disability in the ageing workforce is essential for sustaining economic growth in Europe. In order to provide information on entry points for preventive measures, it is important to better understand sociodemographic, socioeconomic and work-related determinants of disability in older employees. We aimed to test the hypothesis that low socioeconomic position and exposure to a stressful psychosocial work environment at baseline contribute to later disability. We further assumed that the association of socioeconomic position with disability is partly mediated by exposure to adverse working conditions.

Methods We studied longitudinal data from the first two waves of the Survey on Health, Ageing and Retirement in Europe comprising 11 European countries. Sociodemographic, socioeconomic and work-related factors (low control, effort-reward imbalance) and baseline disability of 2665 male and 2209 female employees aged between 50 and 64 years were used to predict disability 2 years later. Following the International Classification of Functioning (ICF), disability was subdivided into the components 'impairment' and 'restriction in activities and participation'. Two multilevel Poisson regressions were fitted to the data.

Results After adjusting for baseline disability and relevant confounding variables, low socioeconomic position and chronic stress at work exerted significant effects on disability scores 2 years later. We found some support for the hypothesis that the association of socioeconomic position with disability is partly mediated by work stress.

Conclusions Investing in reduction of work stress and reducing social inequalities in health functioning are relevant entry points of policies that aim at maintaining work ability in early old age.

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CR Avendano M, 2011, INDIVIDUAL AND THE WELFARE STATE: LIFE HISTORIES IN EUROPE, P203, DOI 10.1007/978-3-642-17472-8_18
Blekesaune M, 2005, RES AGING, V27, P3, DOI 10.1177/0164027504271438
Borsch-Supan A., 2005, SURVEY HLTH AGING RE
Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
Cieza A, 2005, J REHABIL MED, V37, P212, DOI 10.1080/16501970510040263
Dale C, 2012, J EPIDEMIOL COMMUN H, V66, P170, DOI 10.1136/jech-2011-200078
Finkel S. E., 1995, CAUSAL ANAL PANEL DA
Haan P, 2009, J HEALTH ECON, V28, P1116, DOI 10.1016/j.jhealeco.2009.09.001
Huisman M, 2003, SOC SCI MED, V57, P861, DOI 10.1016/S0277-9536(02)00454-9
Karasek R, 1998, J Occup Health Psychol, V3, P322, DOI 10.1037/1076-8998.3.4.322
Karasek R. A., 1990, HLTH WORK
Kivimaki M, 2006, SCAND J WORK ENV HEA, V32, P431, DOI 10.5271/sjweh.1049
Kolenikov S, 2009, STATA J, V9, P329, DOI 10.1177/1536867X0900900301
Koukouli S, 2002, BMC HEALTH SERV RES, V2, DOI 10.1186/1472-6963-2-20
Kuper H, 2002, OCCUP ENVIRON MED, V59, P777, DOI 10.1136/oem.59.11.777
Li JA, 2006, SOC SCI MED, V62, P1066, DOI 10.1016/j.socscimed.2005.07.011
Lynch J, 2000, SOCIAL EPIDEMIOLOGY, P13
Marmot M, 2006, SOCIAL DETERMINANTS, P97
Minkler M, 2006, NEW ENGL J MED, V355, P695, DOI 10.1056/NEJMsa044316
Nunnally J. C., 1994, PSYCHOMETRIC THEORY
OECD, 2010, SICKN DIS WORK BREAK
Rabe-Hesketh S., 2005, MULTILEVEL LONGITUDI

```
   Ramsay SE, 2008, ANN EPIDEMIOL, V18, P896, DOI
10.1016/j.annepidem.2008.09.006
   Rautio N, 2005, SOC SCI MED, V60, P2405, DOI 10.1016/j.socscimed.2004.11.029
   Reinhardt J, 2012, PLOS ONE, V7
   Schoeni RF, 2005, AM J PUBLIC HEALTH, V95, P2065, DOI
10.2105/AJPH.2004.048744
   Schroder M, 2008, HLTH AGEING RETIREME, P325
   Siegrist J, 2004, SOC SCI MED, V58, P1483, DOI 10.1016/S0277-9536(03)00351-4
   Siegrist J, 1996, J Occup Health Psychol, V1, P27, DOI 10.1037/1076-
8998.1.1.27
   Siegrist J, 2009, LANCET, V374, P1872, DOI 10.1016/S0140-6736(09)61666-4
   Stansfeld SA, 1998, PSYCHOSOM MED, V60, P247, DOI 10.1097/00006842-199805000-
00004
   Stansfeld S, 2006, SCAND J WORK ENV HEA, V32, P443, DOI 10.5271/sjweh.1050
   United Nations, 2006, CONV RIGHTS PERS DIS
   van Oorschot W, 2001, DISABILITY POLICIES
   Vaupel JW, 2010, NATURE, V464, P536, DOI 10.1038/nature08984
   WARE JE, 1992, MED CARE, V30, P473, DOI 10.1097/00005650-199206000-00002
   Weber G., 2005, HLTH AGEING RETIREME, P357
   WHO, 2011, WORLD REPORT ON DISABILITY, P1
   World Health Organization, 2001, INT CLASS FUNCT DIS
NR 39
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U1 0
U2 49
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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SC Public, Environmental & Occupational Health
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PT J
AU Jao, I
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TI Involving Research Stakeholders in Developing Policy on Sharing Public Health Research Data in Kenya: Views on Fair Process for Informed Consent, Access Oversight, and Community Engagement

SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS

LA English

DT Article

DE Africa; Kenya; data sharing; community consultation; informed consent; governance; trust; ethics

ID INDIVIDUAL-LEVEL DATA; EXPERIENCES; TRUST; REPRESENTATIVES; PERSPECTIVE; GOVERNANCE; BENEFITS

AB Increased global sharing of public health research data has potential to advance scientific progress but may present challenges to the interests of research stakeholders, particularly in low-to-middle income countries. Policies for data sharing should be responsive to public views, but there is little evidence of the systematic study of these from low-income countries. This qualitative study explored views on fair data-sharing processes among 60 stakeholders in Kenya with varying research experience, using a deliberative approach. Stakeholders' attitudes were informed by perceptions of benefit and concerns for research data sharing, including risks of stigmatization, loss of privacy, and undermining scientific careers and validity, reported in detail elsewhere. In this article, we discuss institutional trust-building processes seen as central to perceptions of fairness in sharing research data in this setting, including forms of community involvement, individual prior awareness and agreement to data sharing, independence and accountability of governance mechanisms, and operating under a national framework.

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   Fellowship (WT085418).
CR [Anonymous], 2015, SCIENCE
   [Anonymous], 2014, NATURE
   [Anonymous], 2014, PLOS J
   Biotechnology and Biological Sciences Research Council, 2010, DAT SHAR POL
   Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
   Bull S, 2013, J EMPIR RES HUM RES, V8, P1, DOI 10.1525/jer.2013.8.4.1
   Burgess Michael M, 2004, J Bioeth Inq, V1, P4, DOI 10.1007/BF02448901
   Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
   Chuma J, 2007, TROP MED INT HEALTH, V12, P673, DOI 10.1111/j.1365-
3156.2007.01825.x
   Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201
   Cowgill KD, 2006, JAMA-J AM MED ASSOC, V296, P671, DOI 10.1001/jama.296.6.671
   Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
   Economic and Social Research Council, 2010, RES DAT POL
   Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
   Fullerton SM, 2010, SCI TRANSL MED, V2, DOI 10.1126/scitranslmed.3000361
   Gilson L, 2003, SOC SCI MED, V56, P1453, DOI 10.1016/S0277-9536(02)00142-9
   Green J, 2007, QUALITATIVE METHODS
   Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
   Hawkins AK, 2010, NEW GENET SOC, V29, P311, DOI 10.1080/14636778.2010.507487
   Kamuya DM, 2013, DEV WORLD BIOETH, V13, P10, DOI 10.1111/dewb.12014
   Kamuya DM, 2013, DEV WORLD BIOETH, V13, P1, DOI 10.1111/dewb.12009
   Marsh VM, 2011, PUBLIC HEALTH ETH-UK, V4, P26, DOI 10.1093/phe/phr007
   Marsh V, 2008, SOC SCI MED, V67, P721, DOI 10.1016/j.socscimed.2008.02.007
   Marsh V, 2013, BMC MED ETHICS, V14, DOI 10.1186/1472-6939-14-41
   Medical Research Council, 2014, MRC DAT SHAR
   Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
   Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
   National Institutes of Health, 2014, NIH DAT SHAR POL
   Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
   Njue M, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0113112
   Parker M, 2002, HEALTHCARE ETHICS HU, P29
   Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
   Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
   Parkin D, 1991, SACRED VOID SPATIAL
   Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
   Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
   Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
   Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-
5391.2011.01161.x
   Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
   Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
   Sheehan M, 2011, PUBLIC HEALTH ETH-UK, V4, P226, DOI 10.1093/phe/phr020
   Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI
10.2471/BLT.10.079129
   Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI
10.1038/461168a
   Wellcome Trust, 2010, POL DAT MAN SHAR
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AF Denny, Spencer G.
   Silaigwana, Blessing
   Wassenaar, Douglas
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TI Developing Ethical Practices for Public Health Research Data Sharing in
   South Africa: The Views and Experiences From a Diverse Sample of
   Research Stakeholders
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE data sharing; data curation; research ethics; public funded research;
   South Africa; public health
ID TRIAL; CONSENT
AB The abundance of South African clinical and public health research data has
the potential to unlock important and valuable future advances in biomedical
science. Amid increasing calls for more effective sharing of individual-level
data, commitment to promote access to research data is evident within South
Africa's public research sector, but national guidance and regulation are absent.
This qualitative study examined the perceptions, experiences and concerns of 32
research stakeholders about data-sharing practices. There was consensus about
the utility of data sharing in publicly funded health research. However,
disparate views emerged about the possible harms and benefits of sharing data
and how these should be weighed. The relative dearth of policies governing data-
sharing practices needs to be addressed and a framework of support developed
that incentivizes data-sharing practices for researchers that are both ethical
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CR Bishop Pam, 2010, ENCY CASE STUDY RES, P588, DOI [10.4135/9781412957397, DOI 10.4135/9781412957397.N219]
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Braun V., 2007, QUALITATIVE RES PSYC, V3, P77, DOI [DOI 10.1191/1478088706QP0630A, 10.1191/1478088706qp063oa]
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Chalmers DRC, 2014, APPL TRANSL GENOM, V3, P116, DOI 10.1016/j.atg.2014.09.011
Department of Health, 2004, ETH HLTH RES PRINC S
Department of Health, 2015, ETH HLTH RES PRINC S
Guyer M, 1998, GENOME RES, V8, P413
Lotter L, 2015, J EMPIR RES HUM RES, V10, P338, DOI 10.1177/1556264615592846
Manasa J, 2014, DATABASE-OXFORD, DOI 10.1093/database/bat082
Manju R., 2012, B WORLD HEALTH ORGAN, V90, P932, DOI DOI 10.2471/BLT.12.105908
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
Medical Research Council (U. K.), 2014, MRC DAT SHAR
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
QSR International Pty Ltd, 2012, NVIVO QUAL DAT AN SO
Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
Ritchie J, 2002, QUALITATIVE RES COMP, P305, DOI DOI 10.4135/9781412986274
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Smith CT, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0097886
Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
Wallace H, 2013, NATURE, V501, P167, DOI 10.1038/501167c
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Wellcome Trust, 2009, POL DAT MAN SHAR
Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
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   Medrano-Gracia, P
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AF Suinesiaputra, Avan
   Medrano-Gracia, Pau
   Cowan, Brett R.
   Young, Alistair A.
TI Big Heart Data: Advancing Health Informatics Through Data Sharing in
   Cardiovascular Imaging
SO IEEE JOURNAL OF BIOMEDICAL AND HEALTH INFORMATICS
LA English
DT Article
DE Anatomical models; cardiac atlas; cardiac MRI; data sharing
ID LEFT-VENTRICULAR DILATATION; MAGNETIC-RESONANCE; MYOCARDIAL-INFARCTION;
   ANATOMICAL MODELS; MEDICAL IMAGE; PATIENT; DISEASE; ATLAS; SHAPE; RISK
AB The burden of heart disease is rapidly worsening due to the increasing
prevalence of obesity and diabetes. Data sharing and open database resources for
heart health informatics are important for advancing our understanding of
cardiovascular function, disease progression and therapeutics. Data sharing
enables valuable information, often obtained at considerable expense and effort,
to be reused beyond the specific objectives of the original study. Many
government funding agencies and journal publishers are requiring data reuse, and
are providing mechanisms for data curation and archival. Tools and
infrastructure are available to archive anonymous data from a wide range of
studies, from descriptive epidemiological data to gigabytes of imaging data.
Meta-analyses can be performed to combine raw data from disparate studies to
obtain unique comparisons or to enhance statistical power. Open benchmark
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datasets are invaluable for validating data analysis algorithms and objectively comparing results. This review provides a rationale for increased data sharing and surveys recent progress in the cardiovascular domain. We also highlight the potential of recent large cardiovascular epidemiological studies enabling collaborative efforts to facilitate data sharing, algorithms benchmarking, disease modeling and statistical atlases.
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FU NHLBI NIH HHS [R01 HL121754]
CR [Anonymous], 2013, 5687 MIN HLTH
Bild DE, 2002, AM J EPIDEMIOL, V156, P871, DOI 10.1093/aje/kwf113
Bild DE, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0094916
Bluemke DA, 2008, J AM COLL CARDIOL, V52, P2148, DOI 10.1016/j.jacc.2008.09.014
Bond RR, 2011, INT J MED INFORM, V80, P681, DOI 10.1016/j.ijmedinf.2011.06.008
Borugian MJ, 2010, CAN MED ASSOC J, V182, P1197, DOI 10.1503/cmaj.091540
Britten RD, 2013, MED BIOL ENG COMPUT, V51, P1191, DOI 10.1007/s11517-013-1097-7
Bruder O, 2013, J CARDIOVASC MAGN R, V15, DOI 10.1186/1532-429X-15-9
Burchfield JS, 2013, CIRCULATION, V128, P388, DOI 10.1161/CIRCULATIONAHA.113.001878
Buxton AE, 2006, CIRCULATION, V114, P2534, DOI 10.1161/CIRCULATIONAHA.106.180199
Carr J. J., 2012, ETHNIC DIS, V22
Chuang ML, 2014, J MAGN RESON IMAGING, V39, P895, DOI 10.1002/jmri.24239
Clark CR, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0063254
Cohn JN, 2000, J AM COLL CARDIOL, V35, P569, DOI 10.1016/S0735-1097(99)00630-0
Duchateau N, 2011, MED IMAGE ANAL, V15, P316, DOI 10.1016/j.media.2010.12.006
Flanders AE, 2009, RADIOGRAPHICS, V29, P1247, DOI 10.1148/rg.295095151
Fonseca CG, 2011, BIOINFORMATICS, V27, P2288, DOI 10.1093/bioinformatics/btr360
Ge YR, 2013, J AM MED INFORM ASSN, V20, P157, DOI 10.1136/amiajnl-2012-001146
Gianni D, 2010, PHILOS T R SOC A, V368, P3039, DOI 10.1098/rsta.2010.0025
Gkoulalas-Divanis A, 2014, J BIOMED INFORM, V50, P4, DOI 10.1016/j.jbi.2014.06.002
Glatard T, 2013, IEEE T MED IMAGING, V32, P110, DOI 10.1109/TMI.2012.2220154
Goldberger AL, 2000, CIRCULATION, V101, pE215, DOI 10.1161/01.CIR.101.23.e215
Harman J, 2013, J CLIN HYPERTENS, V15, P367, DOI 10.1111/jch.12088
Hinojar R, 2014, FUTUR CARDIOL, V10, P273, DOI [10.2217/FCA.13.102, 10.2217/fca.13.102]
Hoogendoorn C, 2013, IEEE T MED IMAGING, V32, P28, DOI 10.1109/TMI.2012.2230015
Kadish AH, 2009, J CARDIOVASC ELECTR, V20, P982, DOI 10.1111/j.1540-8167.2009.01503.x
Kannel W B, 1987, J Cardiovasc Pharmacol, V10 Suppl 6, pS135, DOI 10.1097/00005344-198706106-00018
KANNEL WB, 1961, ANN INTERN MED, V55, P33, DOI 10.7326/0003-4819-55-1-33
Karim R, 2013, J CARDIOVASC MAGN R, V15, DOI 10.1186/1532-429X-15-105

Kerfoot E, 2013, MED BIOL ENG COMPUT, V51, P1181, DOI 10.1007/s11517-012-1023-4
Kohane IS, 2009, GENOME MED, V1, DOI 10.1186/gm4
Konstam MA, 2002, J CARD FAIL, V8, pS506, DOI 10.1054/jcaf.2002.130303
Konstam MA, 2011, JACC-CARDIOVASC IMAG, V4, P98, DOI 10.1016/j.jcmg.2010.10.008
Krueger MW, 2013, MED BIOL ENG COMPUT, V51, P1251, DOI 10.1007/s11517-012-0970-0
Lamata P, 2014, J R SOC INTERFACE, V11, DOI 10.1098/rsif.2013.1023
Lamata P, 2011, MED IMAGE ANAL, V15, P801, DOI 10.1016/j.media.2011.06.010
LAUER MS, 1992, AM J CARDIOL, V70, P1180, DOI 10.1016/0002-9149(92)90052-Z
Lekadir K, 2014, IEEE T MED IMAGING, V33, P882, DOI 10.1109/TMI.2013.2297333
Lewandowski AJ, 2013, CIRCULATION, V127, P197, DOI 10.1161/CIRCULATIONAHA.112.126920
Li MQ, 2014, INT J MED INFORM, V83, P750, DOI 10.1016/j.ijmedinf.2014.07.002
Lombaert H, 2012, IEEE T MED IMAGING, V31, P1436, DOI 10.1109/TMI.2012.2192743
Mannaerts HFJ, 2004, EUR HEART J, V25, P680, DOI 10.1016/j.ehj.2004.02.030
McLeod K, 2013, LECT NOTES COMPUT SC, V8150, P501, DOI 10.1007/978-3-642-40763-5_62
Medrano-Gracia P, 2014, J CARDIOVASC MAGN R, V16, DOI 10.1186/s12968-014-0056-2
Medrano-Gracia P, 2013, J CARDIOVASC MAGN R, V15, DOI 10.1186/1532-429X-15-80
MITCHELL GF, 1992, J AM COLL CARDIOL, V19, P1136, DOI 10.1016/0735-1097(92)90314-D
Mori S, 2013, ANNU REV BIOMED ENG, V15, P71, DOI 10.1146/annurev-bioeng-071812-152335
Murdoch TB, 2013, JAMA-J AM MED ASSOC, V309, P1351, DOI 10.1001/jama.2013.393
Murray CJL, 2012, LANCET, V380, P2197, DOI 10.1016/S0140-6736(12)61689-4
Ohno-Machado L, 2012, J AM MED INFORM ASSN, V19, P196, DOI 10.1136/amiajnl-2011-000538
Ouzounian M, 2007, CAN J CARDIOL, V23, p28A, DOI 10.1016/S0828-282X(07)71003-6
Payne Thomas J, 2005, Ethn Dis, V15, pS6
Petersen SE, 2013, J CARDIOVASC MAGN R, V15, DOI 10.1186/1532-429X-15-46
Schaap M, 2009, MED IMAGE ANAL, V13, P701, DOI 10.1016/j.media.2009.06.003
Schelbert EB, 2012, JAMA-J AM MED ASSOC, V308, P890, DOI 10.1001/2012.jama.11089
Sermesant M, 2012, MED IMAGE ANAL, V16, P201, DOI 10.1016/j.media.2011.07.003
Smith N, 2011, INTERFACE FOCUS, V1, P349, DOI 10.1098/rsfs.2010.0048
Sneddon TP, 2012, GIGASCIENCE, V1, DOI 10.1186/2047-217X-1-11
Steinert-Threlkeld S, 2012, J BIOMED INFORM, V45, P522, DOI 10.1016/j.jbi.2012.02.013
Stratz C, 2012, CARDIOL REV, V20, P111, DOI 10.1097/CRD.0b013e31824394e1
Suinesiaputra A., 2012, STAT ATLASES COMPUTA
Suinesiaputra A, 2014, MED IMAGE ANAL, V18, P50, DOI 10.1016/j.media.2013.09.001
Suinesiaputra A, 2009, IEEE T MED IMAGING, V28, P595, DOI 10.1109/TMI.2008.2008966
Sunnybrook Health Sciences Centre, CARD MR LEFT VENTR S
Sutton MGS, 2000, CIRCULATION, V101, P2981, DOI 10.1161/01.CIR.101.25.2981
Taylor Herman A Jr, 2005, Ethn Dis, V15, pS6
Tobon-Gomez C, 2013, MED IMAGE ANAL, V17, P632, DOI 10.1016/j.media.2013.03.008
Vachiery JL, 2012, EUR RESPIR REV, V21, P40, DOI 10.1183/09059180.00009011
Vasan RS, 1997, NEW ENGL J MED, V336, P1350, DOI 10.1056/NEJM199705083361903
Weese J, 2013, MED BIOL ENG COMPUT, V51, P1209, DOI 10.1007/s11517-012-1027-0
Welter P, 2010, INT J COMPUT ASS RAD, V5, P393, DOI 10.1007/s11548-010-0416-9

```
   Wong ND, 2014, NAT REV CARDIOL, V11, P276, DOI 10.1038/nrcardio.2014.26
   Wong SP, 2004, AM J CARDIOL, V94, P1270, DOI 10.1016/j.amjcard.2004.07.110
   Young AA, 2009, EXP PHYSIOL, V94, P578, DOI 10.1113/expphysiol.2008.044081
NR 74
TC 19
Z9 19
U1 0
U2 27
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
PI PISCATAWAY
PA 445 HOES LANE, PISCATAWAY, NJ 08855-4141 USA
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J9 IEEE J BIOMED HEALTH
JI IEEE J. Biomed. Health Inform.
PD JUL
PY 2015
VL 19
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BP 1283
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DI 10.1109/JBHI.2014.2370952
PG 8
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Mathematical & Computational Biology;
   Medical Informatics
SC Computer Science; Mathematical & Computational Biology; Medical
   Informatics
GA CN7NE
UT WOS:000358620500011
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DA 2019-08-06
ER

PT J
AU James, R
   Tsosie, R
   Sahota, P
   Parker, M
   Dillard, D
   Sylvester, I
   Lewis, J
   Klejka, J
   Muzquiz, L
   Olsen, P
   Whitener, R
   Burke, W
AF James, Rosalina
   Tsosie, Rebecca
   Sahota, Puneet
   Parker, Myra
   Dillard, Denise
   Sylvester, Ileen
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   Klejka, Joseph
   Muzquiz, LeeAnna
   Olsen, Polly
   Whitener, Ron
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CA Kiana Grp
TI Exploring pathways to trust: a tribal perspective on data sharing
SO GENETICS IN MEDICINE
LA English
DT Review
DE data sharing; ethics; genetics; indigenous; tribal
ID BIOTECHNOLOGY; SCIENCE; PEOPLE
AB The data-sharing policies of the National Institutes of Health aim to maximize public benefit derived from genetic studies by increasing research efficiency and use of a pooled data resource for future studies. Although broad access to data may lead to benefits for populations underrepresented in genetic studies, such as indigenous groups, tribes have ownership interest in their data. The Northwest-Alaska Pharmacogenetic Research Network, a partnership involving tribal organizations and universities conducting basic and translational pharmacogenetic research, convened a meeting to discuss the collection, management, and secondary use of research data, and of the processes surrounding access to data stored in federal repositories. This article reports the tribal perspectives that emerged from the dialogue and discusses the implications of tribal government sovereign status on research agreements and data-sharing negotiations. There is strong tribal support for efficient research processes that expedite the benefits from collaborative research, but there is also a need for data-sharing procedures that take into account tribal sovereignty and appropriate oversight of research-such as tribally based research review processes and review of draft manuscripts. We also note specific ways in which accountability could be encouraged by the National Institutes of Health as part of the research process.
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FX The authors thank all of the participants of the Pathways to Trust meeting. This work was supported by the Northwest-Alaska Pharmacogenomics Research Network (NIGMS U01GM092676) and the Center for Genomics and Healthcare Equality (NHGRI P50HG3374).
CR [Anonymous], 2003, DATA SHARING POLICY
[Anonymous], 2010, AM I MED GENET, V152A
[Anonymous], 2007, POLICY SHARING DATA
[Anonymous], 2014, RES BENEFITS NATIVE
[Anonymous], 2000, REPORT
[Anonymous], 2014, PRC TRIBAL RES REGUL
Brugge D, 2006, SCI ENG ETHICS, V12, P491, DOI 10.1007/s11948-006-0047-2
Coffey Wallace, 2001, STAN L POLY REV, V12, P191

Dalton R, 2004, NATURE, V430, P500, DOI 10.1038/430500a
Goldberg CE, 2013, AM INDIAN LAW NATIVE
Goodkind JR, 2012, QUAL HEALTH RES, V22, P1019, DOI 10.1177/1049732312450324
Harding A, 2012, ENVIRON HEALTH PERSP, V120, P6, DOI 10.1289/ehp.1103904
Hiratsuka V, 2012, PROG COMM HLTH PARTN, V6, P131, DOI 10.1353/cpr.2012.0025
Hoxie FF, 1984, FINAL PROMISE CAMPAI
Jacobs B, 2010, J LAW MED ETHICS, V38, P684, DOI 10.1111/j.1748-720X.2010.00521.x
Joseph W, 2003, NEW ENG LAW REV, V37, P641
Klein TE, 2009, NEW ENGL J MED, V360, P753, DOI 10.1056/NEJMoa0809329
Nuu-chah-nulth Tribal Council Research Ethics Committee, 2008, PROTOCOLS PRINCIPLES
Otis D. S., 1973, DAWES ACT ALLOTMENT
Peppercorn J, 2012, CANCER-AM CANCER SOC, V118, P5060, DOI 10.1002/cncr.27515
Reardon J, 2012, CURR ANTHROPOL, V53, pS233, DOI 10.1086/662629
Rodriguez LL, 2013, SCIENCE, V339, P275, DOI 10.1126/science.1234593
Singeo L, 2007, AM J LAW MED, V33, P119, DOI 10.1177/009885880703300104
Sotero M, 2006, J HLTH DISPAR RES PR, V1, P93
Tallbear K, 7 INT C ETHN
Taniguchi NK, 2012, INT INDIGENOUS POL, V3
Thomas ME, 1986, POLAR REC, V23, P27
Tsosie R, 2002, ARIZ ST LJ, V34, P299
Tsosie R, 2007, J LAW MED ETHICS, V35, P396, DOI 10.1111/j.1748-720X.2007.00163.x
Walker L, 2011, SCI TRANSL MED, V3, DOI 10.1126/scitranslmed.3002788
Wallerstein N, 2010, AM J PUBLIC HEALTH, V100, pS40, DOI 10.2105/AJPH.2009.184036
NR 31
TC 19
Z9 19
U1 0
U2 15
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1098-3600
EI 1530-0366
J9 GENET MED
JI Genet. Med.
PD NOV
PY 2014
VL 16
IS 11
BP 820
EP 826
DI 10.1038/gim.2014.47
PG 7
WC Genetics & Heredity
SC Genetics & Heredity
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PT S
AU Giannandrea, A

Raqueno, N
Messinger, DW
Faulring, J
Kerekes, JP
van Aardt, J
Canham, K
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Ontiveros, E
Gerace, A
Kaufman, J
Vongsy, KM
Griffith, H
Bartlett, BD
Ientilucci, E
Meola, J
Scarff, L
Daniel, B
AF Giannandrea, AnneMarie
Raqueno, Nina
Messinger, David W.
Faulring, Jason
Kerekes, John P.
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Canham, Kelly
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BE Shen, SS
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TI The SHARE 2012 Data Campaign
SO ALGORITHMS AND TECHNOLOGIES FOR MULTISPECTRAL, HYPERSPECTRAL, AND ULTRASPECTRAL IMAGERY XIX
SE Proceedings of SPIE
LA English
DT Proceedings Paper
CT Conference on Algorithms and Technologies for Multispectral, Hyperspectral, and Ultraspectral Imagery XIX
CY APR 29-MAY 02, 2013
CL Baltimore, MD
SP SPIE
DE Data Collection; Hyperspectral; Ground Truth; HSI Dataset; HSI Signatures; LiDAR; Target Detection
ID HYPERSPECTRAL COLLECTION EXPERIMENT; MEGACOLLECT 2004; ROCHESTER
AB A multi-modal (hyperspectral, multispectral, and LIDAR) imaging data collection campaign was conducted just south of Rochester New York in Avon, NY on September 20, 2012 by the Rochester Institute of Technology (RIT) in conjunction with SpecTIR, LLC, the Air Force Research Lab (AFRL), the Naval Research Lab (NRL), United Technologies Aerospace Systems (UTAS) and MITRE. The campaign was a follow on from the SpecTIR Hyperspectral Airborne Rochester Experiment (SHARE) from 2010. Data was collected in support of the eleven

simultaneous experiments described here. The airborne imagery was collected over four different sites with hyperspectral, multispectral, and LIDAR sensors. The sites for data collection included Avon, NY, Conesus Lake, Hemlock Lake and forest, and a nearby quarry. Experiments included topics such as target unmixing, subpixel detection, material identification, impacts of illumination on materials, forest health, and in-water target detection. An extensive ground truthing effort was conducted in addition to collection of the airborne imagery. The ultimate goal of the data collection campaign is to provide the remote sensing community with a shareable resource to support future research. This paper details the experiments conducted and the data that was collected during this campaign.

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CR Analytical Spectral Devices Inc., 2013, FIELDSPEC PRO US GUI
Canham K., 2013, P SPIE ALGORITHMS TE, V8743
Casterline M., 2010, P SPIE SPIE DEFENSE
Herweg J. A., 2012, ALGORITHMS TECHNOLOG, V8390, P554
Ientilucci E., 2013, P SPIE ALGORITHMS TE, V8743
Kerekes J. P., 2013, P SPIE ALGORITHMS TE, V8743
Kucera International Inc, 2013, LID SERV
Raqueno NG, 2005, P SOC PHOTO-OPT INS, V5806, P554, DOI 10.1117/12.605838
Raqueno RV, 2005, P SOC PHOTO-OPT INS, V5806, P566, DOI 10.1117/12.605856
Snyder D., 2008, DEV WEB BASED APPL E
SpecTIR LLC, 2012, PROJECT REPORT
SpectraVista Corporation, 2013, SVC HR 1024
van Aardt JAN, 2011, PHOTOGRAMM ENG REM S, V77, P943, DOI 10.14358/PERS.77.9.943
Van der Zande D, 2006, AGR FOREST METEOROL, V141, P147, DOI 10.1016/j.agrformet.2006.09.007

NR 14
TC 19
Z9 19
U1 0
U2 2
PU SPIE-INT SOC OPTICAL ENGINEERING
PI BELLINGHAM
PA 1000 20TH ST, PO BOX 10, BELLINGHAM, WA 98227-0010 USA
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WC Optics; Spectroscopy
SC Optics; Spectroscopy
GA BHH00
UT WOS:000325394800011
DA 2019-08-06
ER

PT J
AU Haeusermann, T
   Greshake, B
   Blasimme, A
   Irdam, D
   Richards, M
   Vayena, E
AF Haeusermann, Tobias
   Greshake, Bastian
   Blasimme, Alessandro
   Irdam, Darja
   Richards, Martin
   Vayena, Effy
TI Open sharing of genomic data: Who does it and why?
SO PLOS ONE
LA English
DT Article
ID CONSUMER PERCEPTIONS; HEALTH; BENEFITS; RISKS
AB We explored the characteristics and motivations of people who, having
obtained their genetic or genomic data from Direct-To-Consumer genetic testing
(DTC-GT) companies, voluntarily decide to share them on the publicly accessible
web platform open SNP. The study is the first attempt to describe open data
sharing activities undertaken by individuals without institutional oversight. In
the paper we provide a detailed overview of the distribution of the demographic
characteristics and motivations of people engaged in genetic or genomic open
data sharing. The geographical distribution of the respondents showed the USA as
dominant. There was no significant gender divide, the age distribution was broad,
educational background varied and respondents with and without children were
equally represented. Health, even though prominent, was not the respondents'
primary or only motivation to be tested. As to their motivations to openly share
their data, 86.05% indicated wanting to learn about themselves as relevant,
followed by contributing to the advancement of medical research (80.30%),
improving the predictability of genetic testing (76.02%) and considering it fun
to explore genotype and phenotype data (75.51%). Whereas most respondents were
well aware of the privacy risks of their involvement in open genetic data
sharing and considered the possibility of direct, personal repercussions
troubling, they estimated the risk of this happening to be negligible. Our
findings highlight the diversity of DTC-GT consumers who decide to openly share
their data. Instead of focusing exclusively on health-related aspects of genetic
testing and data sharing, our study emphasizes the importance of taking into
account benefits and risks that stretch beyond the health spectrum. Our results
thus lend further support to the call for a broader and multi-faceted
conceptualization of genomic utility.
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FU University of Zurich's Priority Research Program; Swiss National Science Foundation
FX This study was funded by the University of Zurich's Priority Research Program and the Swiss National Science Foundation.
CR Abbott A, 2012, NATURE, V486, P167, DOI 10.1038/486167a
Annas GJ, 2014, NEW ENGL J MED, V370, P985, DOI 10.1056/NEJMp1316367
[Anonymous], 2015, NAT BIOTECHNOL, V33, P435, DOI 10.1038/nbt0515-435a
Auffray C, 2016, GENOME MED, V8, DOI 10.1186/s13073-016-0265-4
Ball MP, 2014, GENOME MED, V6, DOI 10.1186/gm527
Bloss CS, 2011, NEW ENGL J MED, V364, P524, DOI 10.1056/NEJMoa1011893
Carere DA, 2016, GENETICS MED
Cheung C, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0166389
Christofides E, 2016, NEW GENET SOC, V35, P101, DOI 10.1080/14636778.2016.1162092
Chung MWH, 2016, J MED ETHICS, V42, P649, DOI 10.1136/medethics-2015-103057
Corpas M, 2016, FRONT LINE GENOMICS
Corpas M, 2015, BMC GENOMICS, V16, DOI 10.1186/s12864-015-1973-7
Critchley C, 2015, PUBLIC HEALTH GENOM, V18, P160, DOI 10.1159/000375441
Evans JP, 2009, GENET MED, V11, P568, DOI 10.1097/GIM.0b013e3181afbaed
Fernandez-Luque L, 2015, HEALTHC INFORM RES, V21, P67, DOI 10.4258/hir.2015.21.2.67
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Gray SW, 2016, J CLIN ONCOL
Greshake B, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0089204
Hartung AM, 2016, THESIS
Heshka JT, 2008, GENET MED, V10, P19, DOI 10.1097/GIM.0b013e31815f524f
Humbert M, 2015, P PRIVACY ENHANCING, V2, P99
Laestadius L, 2016, GENETICS MED
Lapin V, 2016, HUM GENET, V135, P655, DOI 10.1007/s00439-016-1677-3
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Lewin JH, 2016, J CLIN ONCOL, V34, DOI 10.1200/JCO.2016.34.15_suppl.11502
McGrath SP, 2016, PUBLIC HEALTH GENOM, V19, P116, DOI [10.1159/000444477, 10.1159/000441177]
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
Nelson B, 2016, CANCER CYTOPATHOL, V124, P159, DOI 10.1002/cncy.21706
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Roberts J Scott, 2013, Curr Genet Med Rep, V1, P182
Roberts JS, 2017, PUBLIC HEALTH GENOMI
Roberts JS, 2017, PUBLIC HLTH GENOMICS
Rothstein MA, 2016, J LAW MED ETHICS, V44, P161, DOI 10.1177/1073110516644207
Rotimi Charles N, 2003, Dev World Bioeth, V3, P151, DOI 10.1046/j.1471-8731.2003.00071.x
Royal CD, 2010, AM J HUM GENET, V86, P661, DOI 10.1016/j.ajhg.2010.03.011
Savage N, 2016, NATURE, P537
Shendure J, 2004, NAT REV GENET, V5, P335, DOI 10.1038/nrg1325

```
   Shih TH, 2008, FIELD METHOD, V20, P249, DOI 10.1177/1525822X08317085
   Slavkovic A, 2015, CHANCE, V28, P37
   Spector-Bagdady K, 2016, ANN EPIDEMIOL, V26, P515, DOI
10.1016/j.annepidem.2016.05.007
   Sprenger P., 1999, WIRED
   Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
   Tubaro P, 2014, HYPOTHESIS END PRIVA
   van der Wouden CH, 2016, ANN INTERN MED, V164, P513, DOI 10.7326/M15-0995
   Vayena E, 2012, PUBLIC HEALTH GENOM, V15, P352, DOI 10.1159/000343792
   Vayena E, 2015, J MED ETHICS, V41, P310, DOI 10.1136/medethics-2014-102026
   Vayena E, 2014, PUBLIC HEALTH GENOM, V17, P158, DOI 10.1159/000360257
   Vayena E, 2012, AM J PUBLIC HEALTH, V102, P2225, DOI 10.2105/AJPH.2012.300813
   Wallis JC, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067332
   Wicks P, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g368
   Wilbanks JT, 2016, NATURE
   Zaaijer S, 2016, DEMOCRATIZING DNA FI
NR 52
TC 18
Z9 19
U1 0
U2 11
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
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J9 PLOS ONE
JI PLoS One
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AR e0177158
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
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PM 28486511
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ER

PT J
AU Green, AK
   Reeder-Hayes, KE
   Corty, RW
   Basch, E
   Milowsky, AI
   Dusetzina, SB
   Bennett, AV
   Wood, DA
AF Green, Angela K.
   Reeder-Hayes, Katherine E.
   Corty, Robert W.
   Basch, Ethan
   Milowsky, Amathew I.
   Dusetzina, Stacie B.
```

Bennett, Antonia V.
Wood, Dwilliam A.
TI The Project Data Sphere Initiative: Accelerating Cancer Research by Sharing Data
SO ONCOLOGIST
LA English
DT Editorial Material
DE Project Data Sphere; Data sharing; Prostate cancer; Comparative effectiveness research
ID RESISTANT PROSTATE-CANCER; MITOXANTRONE PLUS PREDNISONE; POPULATION-BASED VALIDATION; CLINICAL-TRIAL DATA; LEUKEMIA GROUP-B; QUALITY-OF-LIFE; PHASE-III TRIAL; PROGNOSTIC MODEL; MEN; SURVIVAL

AB Background. In this paper, we provide background and context regarding the potential for a new data-sharing platform, the Project Data Sphere (PDS) initiative, funded by financial and in-kind contributions from the CEO Roundtable on Cancer, to transform cancer research and improve patient outcomes. Given the relatively modest decline in cancer death rates over the past several years, a new research paradigm is needed to accelerate therapeutic approaches for oncologic diseases. Phase III clinical trials generate large volumes of potentially usable information, often on hundreds of patients, including patients treated with standard of care therapies (i.e., controls). Both nationally and internationally, a variety of stakeholders have pursued data-sharing efforts to make individual patient-level clinical trial data available to the scientific research community.

Potential Benefits and Risks of Data Sharing. For researchers, shared data have the potential to foster a more collaborative environment, to answer research questions in a shorter time frame than traditional randomized control trials, to reduce duplication of effort, and to improve efficiency. For industry participants, use of trial data to answer additional clinical questions could increase research and development efficiency and guide future projects through validation of surrogate end points, development of prognostic or predictive models, selection of patients for phase II trials, stratification in phase III studies, and identification of patient subgroups for development of novel therapies. Data transparency also helps promote a public image of collaboration and altruism among industry participants. For patient participants, data sharing maximizes their contribution to public health and increases access to information that may be used to develop better treatments. Concerns about data-sharing efforts include protection of patient privacy and confidentiality. To alleviate these concerns, data sets are deidentified to maintain anonymity. To address industry concerns about protection of intellectual property and competitiveness, we illustrate several models for data sharing with varying levels of access to the data and varying relationships between trial sponsors and data access sponsors.

The Project Data Sphere Initiative. PDS is an independent initiative of the CEO Roundtable on Cancer Life Sciences Consortium, built to voluntarily share, integrate, and analyze comparator arms of historical cancer clinical trial data sets to advance future cancer research. The aim is to provide a neutral, broad-access platform for industry and academia to share raw, deidentified data from late-phase oncology clinical trials using comparator-arm data sets. These data are likely to be hypothesis generating or hypothesis confirming but, notably, do not take the place of performing a well-designed trial to address a specific hypothesis. Prospective providers of data to PDS complete and sign a data sharing agreement that includes a description of the data they propose to upload, and then they follow easy instructions on the website for uploading their deidentified data. The SAS Institute has also collaborated with the initiative to provide intrinsic analytic tools accessible within the website itself.

As of October 2014, the PDS website has available data from 14 cancer clinical trials covering 9,000 subjects, with hopes to further expand the

database to include more than 25,000 subject accruals within the next year. PDS differentiates itself from other data-sharing initiatives by its degree of openness, requiring submission of only a brief application with background information of the individual requesting access and agreement to terms of use. Data from several different sponsors may be pooled to develop a comprehensive cohort for analysis. In order to protect patient privacy, data providers in the U.S. are responsible for deidentifying data according to standards set forth by the Privacy Rule of the U.S. Health Insurance Portability and Accountability Act of 1996.

Using Data Sharing to Improve Outcomes in Cancer: The "Prostate Cancer Challenge." Control-arm data of several studies among patients with metastatic castration-resistant prostate cancer (mCRPC) are currently available through PDS. These data sets have multiple potential uses. The "Prostate Cancer Challenge" will ask the cancer research community to use clinical trial data deposited in the PDS website to address key research questions regarding mCRPC.

General themes that could be explored by the cancer community are described in this article: prognostic models evaluating the influence of pretreatment factors on survival and patient-reported outcomes; comparative effectiveness research evaluating the efficacy of standard of care therapies, as illustrated in our companion article comparing mitoxantrone plus prednisone with prednisone alone; effects of practice variation in dose, frequency, and duration of therapy; level of patient adherence to elements of trial protocols to inform the design of future clinical trials; and age of subjects, regional differences in health care, and other confounding factors that might affect outcomes.

Potential Limitations and Methodological Challenges. The number of data sets available and the lack of experimental arm data limit the potential scope of research using the current PDS. The number of trials is expected to grow exponentially over the next year and may include multiple cancer settings, such as breast, colorectal, lung, hematologic malignancy, and bone marrow transplantation. Other potential limitations include the retrospective nature of the data analyses performed using PDS and its generalizability, given that clinical trials are often conducted among younger, healthier, and less racially diverse patient populations. Methodological challenges exist when combining individual patient data from multiple clinical trials; however, advancements in statistical methods for secondary database analysis offer many tools for reanalyzing data arising from disparate trials, such as propensity score matching. Despite these concerns, few if any comparable data sets include this level of detail across multiple clinical trials and populations.

Conclusion. Access to large, late-phase, cancer-trial data sets has the potential to transform cancer research by optimizing research efficiency and accelerating progress toward meaningful improvements in cancer care. This type of platform provides opportunities for unique research projects that can examine relatively neglected areas and that can construct models necessitating large amounts of detailed data. The full potential of PDS will be realized only when multiple tumor types and larger numbers of data sets are available through the website.

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CR [Anonymous], 2000, Fed Regist, V65, P82462
   [Anonymous], 2013, BLOOD, V121, P4439
   [Anonymous], 1999, QUICKSTATS AGE ADJUS
   Bahl A, 2013, ANN ONCOL, V24, P2402, DOI 10.1093/annonc/mdt194
   Bauchner H, 2013, JAMA-J AM MED ASSOC, V309, P607, DOI 10.1001/jama.2013.58
   Berry W, 2002, J UROLOGY, V168, P2439, DOI 10.1097/01.ju.0000035648.32750.00
   Berthold DR, 2008, CLIN CANCER RES, V14, P2763, DOI 10.1158/1078-0432.CCR-07-
0944
   Commins SP, 2010, CURR ALLERGY ASTHM R, V10, P29, DOI 10.1007/s11882-009-
0079-1
   De Bono JS, 2011, NEW ENGL J MED, V364, P1995, DOI 10.1056/NEJMoa1014618
   Drazen JM, 2012, NEW ENGL J MED, V367, P863, DOI 10.1056/NEJMe1209433
   Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
   El Emam K, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0028071
   Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7304
   Green AK, 2015, ONCOLOGIST, V20, P516, DOI 10.1634/theoncologist.2014-0432
   Halabi S, 2003, J CLIN ONCOL, V21, P1232, DOI 10.1200/JCO.2003.06.100
   Halabi S, 2013, JNCI-J NATL CANCER I, V105, P1729, DOI 10.1093/jnci/djt280
   Hede K, 2013, JNCI-J NATL CANCER I, V105, P1159, DOI 10.1093/jnci/djt232
   Kantoff PW, 1999, J CLIN ONCOL, V17, P2506, DOI 10.1200/JCO.1999.17.8.2506
   Mathieu S, 2009, JAMA-J AM MED ASSOC, V302, P977, DOI 10.1001/jama.2009.1242
   Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
   Michaelson MD, 2014, J CLIN ONCOL, V32, P76, DOI 10.1200/JCO.2012.48.5268
   Murthy VH, 2004, JAMA-J AM MED ASSOC, V291, P2720, DOI
10.1001/jama.291.22.2720
   Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
   O'Neil BH, 2007, J CLIN ONCOL, V25, P3644, DOI 10.1200/JCO.2007.11.7812
   Olivotto IA, 2005, J CLIN ONCOL, V23, P2716, DOI 10.1200/JCO.2005.06.178
   Osoba D, 1999, J CLIN ONCOL, V17, P1654, DOI 10.1200/JCO.1999.17.6.1654
   Pfister DG, 2013, J CLIN ONCOL, V31, P3487, DOI 10.1200/JCO.2013.50.3466
   Riley RD, 2010, BMJ-BRIT MED J, V340, DOI 10.1136/bmj.c221
   Rosner GL, 1996, J CLIN ONCOL, V14, P3000, DOI 10.1200/JCO.1996.14.11.3000
   Ross JS, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000144
   Roy A, STIFLING NEW CURES T
   Scher HI, 2011, J CLIN ONCOL, V29, P2191, DOI 10.1200/JCO.2010.32.8815
   SHIPP MA, 1993, NEW ENGL J MED, V329, P987
   Siegel R, 2013, CA-CANCER J CLIN, V63, P11, DOI 10.3322/caac.21166
   Simmonds MC, 2005, CLIN TRIALS, V2, P209, DOI 10.1191/1740774505cn087oa
   Stewart GB, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0046042
   Tannock IF, 2013, LANCET ONCOL, V14, P760, DOI 10.1016/S1470-2045(13)70184-0
   Tannock IF, 1996, J CLIN ONCOL, V14, P1756, DOI 10.1200/JCO.1996.14.6.1756
   Wishart GC, 2011, EJSO-EUR J SURG ONC, V37, P411, DOI
10.1016/j.ejso.2011.02.001
NR 39
TC 18
Z9 19
U1 0
U2 14
PU WILEY
PI HOBOKEN
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J9 ONCOLOGIST
JI Oncologist
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AF Vogel, Joshua
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TI MDPHnet: Secure, Distributed Sharing of Electronic Health Record Data for Public Health Surveillance, Evaluation, and Planning
SO AMERICAN JOURNAL OF PUBLIC HEALTH
LA English
DT Article
ID AUTOMATED DETECTION; SYSTEM; MASSACHUSETTS; DESIGN
AB Electronic health record systems contain clinically detailed data from large populations of patients that could significantly enrich public health surveillance. Clinical practices' security, privacy, and proprietary concerns, however, have limited their willingness to share these data with public health agencies.
   We describe a novel distributed network for public health surveillance called MDPHnet. The system allows the Massachusetts Department of Public Health (MDPH) to initiate custom queries against participating practices' electronic health records while the data remain behind each practice's firewall.
   Practices can review proposed queries before execution and approve query results before releasing them to the health department. MDPH is using the system for routine surveillance for priority conditions and to evaluate the impact of public health interventions.
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   Coordinator for Health Information Technology (contract 90HT0038/01) and
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CR Allen-Dicker J, 2012, J PUBLIC HEALTH MAN, V18, P209, DOI
10.1097/PHH.0b013e31821f2d73
   [Anonymous], 1980, DHHS PUBLICATION PHS, V80-1260
   Behrman RE, 2011, NEW ENGL J MED, V364, P498, DOI 10.1056/NEJMp1014427
   Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
   Brown JS, 2009, DESIGN SPECIFICATION
   Brown JS, 2010, MED CARE SUPPL, V48, pS45
   Buck MD, 2012, J AM MED INFORM ASSN, V19, pE46, DOI 10.1136/amiajnl-2011-
000322
   Calderwood MS, 2010, PUBLIC HEALTH REP, V125, P843, DOI
10.1177/003335491012500611
   Curtis LH, 2012, PHARMACOEPIDEM DR S, V21, P23, DOI 10.1002/pds.2336
   Davis RL, 2005, EPIDEMIOLOGY, V16, P336, DOI
10.1097/01.ede.0000155506.05636.a4
   Klann JG, 2014, J AM MED INFORM ASSN, V21, P650, DOI 10.1136/amiajnl-2014-
002707
   Klompas M., 2008, Morbidity and Mortality Weekly Report, V57, P373
   Klompas M, 2013, DIABETES CARE, V36, P914, DOI 10.2337/dc12-0964
   Klompas Michael, 2012, Am J Public Health, V102 Suppl 3, pS325, DOI
10.2105/AJPH.2012.300811
   Klompas M, 2011, MAYO CLIN PROC, V86, P1146, DOI 10.4065/mcp.2011.0305
   Klompas M, 2008, PLOS ONE, V3, DOI 10.1371/journal.pone.0002626
   Lazarus R, 2009, J AM MED INFORM ASSN, V16, P18, DOI 10.1197/jamia.M2848
   Lenert Leslie, 2012, Am J Public Health, V102, pe1, DOI
10.2105/AJPH.2011.300542
   Maro JC, 2009, ANN INTERN MED, V151, P341, DOI 10.7326/0003-4819-151-5-
200909010-00139
   McMurry AJ, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0055811
   Overhage JM, 2008, AM J PUBLIC HEALTH, V98, P344, DOI
10.2105/AJPH.2006.092700
   Turner Kathryn, 2011, Morbidity and Mortality Weekly Report, V60, P1421
   Yih WK, 2014, PUBLIC HEALTH REP, V129, P55, DOI 10.1177/003335491412900109
NR 23
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Z9 18
U1 2
U2 18
PU AMER PUBLIC HEALTH ASSOC INC
PI WASHINGTON
PA 800 I STREET, NW, WASHINGTON, DC 20001-3710 USA
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J9 AM J PUBLIC HEALTH
JI Am. J. Public Health
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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PT J
AU Gotzsche, PC
AF Gotzsche, Peter C.
TI Strengthening and Opening Up Health Research by Sharing Our Raw Data
SO CIRCULATION-CARDIOVASCULAR QUALITY AND OUTCOMES
LA English
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DE ethics
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   Cohen D, 2009, BMJ-BRIT MED J, V339, DOI 10.1136/bmj.b5387
   Dwan K, 2008, PLOS ONE, V3, DOI 10.1371/journal.pone.0003081
   Gotzsche PC, 2010, COCHRANE DB SYST REV, V7
   Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
   Gotzsche PC, 2011, BMJ-BRIT MED J, V342, DOI 10.1136/bmj.d2686
   Jefferson T, 2012, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD008965.pub3
   Jefferson T, 2011, BMJ-BRIT MED J, V342, DOI 10.1136/bmj.c7258
   Lenzer J, 2004, BRIT MED J, V329, P1253, DOI 10.1136/bmj.329.7477.1253
   Topol EJ, 2004, NEW ENGL J MED, V351, P1707, DOI 10.1056/NEJMp048286
NR 10
TC 18
Z9 18
U1 0
U2 0
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
SN 1941-7705
EI 1941-7713
J9 CIRC-CARDIOVASC QUAL
JI Circ.-Cardiovasc. Qual. Outcomes
PD MAR
PY 2012
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IS 2
BP 236
EP 237
DI 10.1161/CIRCOUTCOMES.112.965277
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WC Cardiac & Cardiovascular Systems
SC Cardiovascular System & Cardiology
GA 916RG
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TI Bayesian Random Segmentation Models to Identify Shared Copy Number
   Aberrations for Array CGH Data
SO JOURNAL OF THE AMERICAN STATISTICAL ASSOCIATION
LA English
DT Article
DE Bayesian methods; Comparative genomic hybridization; Copy number;
   Functional data analysis; Mixed models; Mixture models
ID COMPARATIVE GENOMIC HYBRIDIZATION; HIGH-RESOLUTION ANALYSIS; FUNCTIONAL
   MIXED MODELS; CELL LUNG-CANCER; MICROARRAY ANALYSIS; MASS-SPECTROMETRY;
   GENE-EXPRESSION; REGRESSION; FRAMEWORK; VARIANCE
AB Array-based comparative genomic hybridization (aCGH) is a high-resolution, high-throughput technique for studying the genetic basis of cancer. The resulting data consist of log fluorescence ratios as a function of the genomic DNA location and provide a cytogenetic representation of the relative DNA copy number variation. Analysis of such data typically involves estimating the underlying copy number state at each location and segmenting regions of DNA with similar copy number states. Most current methods proceed by modeling a single sample/array at a time, and thus fail to borrow strength across multiple samples to infer shared regions of copy number aberrations. We propose a hierarchical Bayesian random segmentation approach for modeling aCGH data that uses information across arrays from a common population to yield segments of shared copy number changes. These changes characterize the underlying population and allow us to compare different population aCGH profiles to assess which regions of the genome have differential alterations. Our method, which we term Bayesian detection of shared aberrations in aCGH (BDSAScgh), is based on a unified Bayesian hierarchical model that allows us to obtain probabilities of alteration states as well as probabilities of differential alterations that correspond to local false discovery rates for both single and multiple groups. We evaluate the operating characteristics of our method via simulations and an application using a lung cancer aCGH data set. This article has supplementary material online.
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CR Aguirre AJ, 2004, P NATL ACAD SCI USA, V101, P9067, DOI 10.1073/pnas.0402932101
BARRY D, 1993, J AM STAT ASSOC, V88, P309, DOI 10.1080/01621459.1993.10594323
Brooks SP, 2000, J COMPUT GRAPH STAT, V9, P266, DOI 10.2307/1390654
CARLIN BP, 1992, J R STAT SOC C-APPL, V41, P389
Chib S, 1998, J ECONOMETRICS, V86, P221, DOI 10.1016/S0304-4076(97)00115-2
Coe BP, 2006, BRIT J CANCER, V94, P1927, DOI 10.1038/sj.bjc.6603167
Denison DGT, 1998, STAT COMPUT, V8, P337, DOI 10.1023/A:1008824606259
Diskin SJ, 2006, GENOME RES, V16, P1149, DOI 10.1101/gr.5076506
Eilers PHC, 2005, BIOINFORMATICS, V21, P1146, DOI 10.1093/bioinformatics/bti148
Erdman C, 2008, BIOINFORMATICS, V24, P2143, DOI 10.1093/bioinformatics/btn404
Fawcett T, 2006, PATTERN RECOGN LETT, V27, P861, DOI 10.1016/j.patrec.2005.10.010
Fraley C, 2002, J AM STAT ASSOC, V97, P611, DOI 10.1198/016214502760047131
Fridlyand J, 2004, J MULTIVARIATE ANAL, V90, P132, DOI 10.1016/j.jmva.2004.02.008
Garnis C, 2006, INT J CANCER, V118, P1556, DOI 10.1002/ijc.21491
Gelman A, 1992, STAT SCI, V7, P457, DOI DOI 10.1214/SS/1177011136
GILKS WR, 1996, MARKOC CHAIN MONTE C
Green PJ, 1995, BIOMETRIKA, V82, P711, DOI 10.1093/biomet/82.4.711
Guha S, 2008, J AM STAT ASSOC, V103, P485, DOI 10.1198/016214507000000923
Guo WS, 2002, BIOMETRICS, V58, P121, DOI 10.1111/j.0006-341X.2002.00121.x
Herr A, 2005, GENOMICS, V85, P392, DOI 10.1016/j.ygeno.2004.07.015
Hodgson G, 2001, NAT GENET, V29, P459, DOI 10.1038/ng771
Hoeting JA, 1999, STAT SCI, V14, P382
Hsu L, 2005, BIOSTATISTICS, V6, P211, DOI 10.1093/biostatistics/kxi004
Huang T, 2005, BIOINFORMATICS, V21, P3811, DOI 10.1093/bioinformatics/bti646
Hupe P, 2004, BIOINFORMATICS, V20, P3413, DOI 10.1093/bioinformatics/bth418
Hutter M, 2007, BAYESIAN ANAL, V2, P635, DOI 10.1214/07-BA225
INCLAN C, 1993, J BUS ECON STAT, V11, P289, DOI 10.2307/1391953
Ji Y, 2007, J ROY STAT SOC C-APP, V56, P139, DOI 10.1111/j.1467-9876.2007.00570.x
KALLIONIEMI A, 1992, SCIENCE, V258, P818, DOI 10.1126/science.1359641
Khojasteh M, 2005, BMC BIOINFORMATICS, V6, DOI 10.1186/1471-2105-6-274
Lucito R, 2000, GENOME RES, V10, P1726, DOI 10.1101/gr.138300
Morris JS, 2008, BIOMETRICS, V64, P479, DOI 10.1111/j.1541-0420.2007.00895.x
Morris JS, 2008, BIOINFORMATICS, V24, P529, DOI 10.1093/bioinformatics/btm590
Morris JS, 2005, BIOINFORMATICS, V21, P1764, DOI 10.1093/bioinformatics/bti254
Morris JS, 2006, J R STAT SOC B, V68, P179, DOI 10.1111/j.1467-9868.2006.00539.x
Muller P, 2004, J AM STAT ASSOC, V99, P990, DOI 10.1198/016214504000001646
Newton MA, 2004, BIOSTATISTICS, V5, P155, DOI 10.1093/biostatistics/5.2.155
Olshen AB, 2004, BIOSTATISTICS, V5, P557, DOI 10.1093/biostatistics/kxh008
Parmigiani G, 2002, J ROY STAT SOC B, V64, P717, DOI 10.1111/1467-9868.00358
PICARD F, 2005, BMC BIOINFORMATICS, V6, P1
Pinkel D, 1998, NAT GENET, V20, P207, DOI 10.1038/2524
Pinkel D, 2005, NAT GENET, V37, pS11, DOI 10.1038/ng1569
Pollack JR, 1999, NAT GENET, V23, P41

   Pollack JR, 2002, P NATL ACAD SCI USA, V99, P12963, DOI
10.1073/pnas.162471999
   Raftery AE, 1997, J AM STAT ASSOC, V92, P179, DOI 10.2307/2291462
   Ramsay JO, 2005, FUNCTIONAL DATA ANAL
   Rossi MR, 2005, GENE CHROMOSOME CANC, V44, P85, DOI 10.1002/gcc.20218
   SEN A, 1975, ANN STAT, V3, P98, DOI 10.1214/aos/1176343001
   Shah SP, 2007, BIOINFORMATICS, V23, pI450, DOI 10.1093/bioinformatics/btm221
   Snijders AM, 2001, NAT GENET, V29, P263, DOI 10.1038/ng754
   STEPHENS DA, 1994, APPL STAT-J ROY ST C, V43, P159, DOI DOI 10.2307/2986119
   Storey JD, 2003, ANN STAT, V31, P2013, DOI 10.1214/aos/1074290335
   Tibshirani R, 2008, BIOSTATISTICS, V9, P18, DOI 10.1093/biostatistics/kxm013
   Weakliem DL, 1999, SOCIOL METHOD RES, V27, P359, DOI
10.1177/0049124199027003002
   Willenbrock H, 2005, BIOINFORMATICS, V21, P4084, DOI
10.1093/bioinformatics/bti677
   Zhao XJ, 2004, CANCER RES, V64, P3060, DOI 10.1158/0008-5472.CAN-03-3308
NR 56
TC 18
Z9 18
U1 0
U2 2
PU AMER STATISTICAL ASSOC
PI ALEXANDRIA
PA 732 N WASHINGTON ST, ALEXANDRIA, VA 22314-1943 USA
SN 0162-1459
J9 J AM STAT ASSOC
JI J. Am. Stat. Assoc.
PD DEC
PY 2010
VL 105
IS 492
BP 1358
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DI 10.1198/jasa.2010.ap09250
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WC Statistics & Probability
SC Mathematics
GA 710VU
UT WOS:000286545900007
PM 21512611
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PT J
AU Van Horn, JD
   Ball, CA
AF Van Horn, John Darrell
   Ball, Catherine A.
TI Domain-specific data sharing in neuroscience: What do we have to learn
   from each other?
SO NEUROINFORMATICS
LA English
DT Editorial Material
DE neuroscience; brain imaging; molecular biology; genomics; meta-data;
   data sharing
ID GENE-EXPRESSION; MICROARRAY DATA; BRAIN; ONTOLOGY; BIOLOGY;
   NEUROBIOLOGY; INFORMATION; STANDARDS; COGNITION; RESOURCE

AB Molecular biology and genomics have made notable strides in the sharing of primary data and resources. In other domains of neuroscience research, however, there has been resistance to adopting formalized strategies for data exchange, archiving, and availability. In this article, we discuss how neuroscience domains might follow the lead of molecular biology on what has been successful and what has failed in active data sharing. This considers not only the technical challenges but also the sociological concerns in making it possible. Though, not a pain-free process, with increased data availability, scientists from multiple fields can enjoy greater opportunity for novel discoveries about the brain in health and disease.

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FU NIMH NIH HHS [RC1 MH088194-01, RC1 MH088194, RC1 MH088194-02]

CR Ascoli GA, 2003, NEUROINFORMATICS, V1, P1, DOI 10.1385/NI:1:1:001
Ashburner M, 2000, NAT GENET, V25, P25, DOI 10.1038/75556
Ball CA, 2006, NAT BIOTECHNOL, V24, P1374, DOI 10.1038/nbt1106-1374
Basser PJ, 2002, NMR BIOMED, V15, P456, DOI 10.1002/nbm.783
Berman HM, 2002, ACTA CRYSTALLOGR D, V58, P899, DOI 10.1107/S0907444902003451
Bloom F, 2006, SCIENCE, V314, P17, DOI 10.1126/science.1135216
Boguski MS, 2004, NAT NEUROSCI, V7, P429, DOI 10.1038/nn1232
Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
Buckner RL, 2000, J COGNITIVE NEUROSCI, V12, P24, DOI 10.1162/089892900564046
Butte A, 2002, NAT REV DRUG DISCOV, V1, P951, DOI 10.1038/nrd961
Chokshi DA, 2006, B WORLD HEALTH ORGAN, V84, P382, DOI 10.2471/BLT.06.029843
D 'Esposito M, 2000, SEMIN NEUROL, V20, P487, DOI 10.1055/s-2000-13182
De Schutter E, 2006, NEUROINFORMATICS, V4, P129, DOI 10.1385/NI:4:2:129
Gazzaniga MS, 2006, SCIENCE, V311, P176
Greicius MD, 2003, P NATL ACAD SCI USA, V100, P253, DOI 10.1073/pnas.0135058100
Harris MA, 2004, NUCLEIC ACIDS RES, V32, pD258, DOI 10.1093/nar/gkh036
Hodaie M, 2006, BRAIN RES, V1115, P1, DOI 10.1016/j.brainres.2006.07.085
Hood L, 2003, MECH AGEING DEV, V124, P9, DOI 10.1016/S0047-6374(02)00164-1
Keator DB, 2006, NEUROINFORMATICS, V4, P199, DOI 10.1385/NI:4:2:199
Kennedy DN, 2003, NEUROINFORMATICS, V1, P211, DOI 10.1385/NI:1:3:211
Konradi C, 2005, BRAIN RES REV, V50, P142, DOI 10.1016/j.brainresrev.2005.05.004
Koslow SH, 2000, NAT NEUROSCI, V3, P863, DOI 10.1038/78760
Laurens KR, 2005, SCHIZOPHR RES, V75, P159, DOI 10.1016/j.schres.2004.12.010
Lukic AS, 2002, ARTIF INTELL MED, V25, P69, DOI 10.1016/S0933-3657(02)00009-X
Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
Marshall E, 2002, SCIENCE, V295, P1206, DOI 10.1126/science.295.5558.1206
Miles MF, 2001, NAT REV NEUROSCI, V2, P441, DOI 10.1038/35077582
Mitka M, 2007, JAMA-J AM MED ASSOC, V297, P1867, DOI 10.1001/jama.297.17.1867
Noor MAF, 2006, PLOS BIOL, V4, P1113, DOI 10.1371/journal.pbio.0040228
Oldham MC, 2006, GENES BRAIN BEHAV, V5, P54, DOI 10.1111/j.1601-183X.2006.00195.x
PARKINSON H, 2007, NUCLEIC ACIDS RES, V35, pD760
Raichle ME, 2003, J NEUROSCI, V23, P3959
Roberts L, 2002, SCIENCE, V298, P1312, DOI 10.1126/science.298.5597.1312
Seringhaus M, 2008, FEBS LETT, V582, P1170, DOI 10.1016/j.febslet.2008.02.073
Shields R, 2006, TRENDS GENET, V22, P65, DOI 10.1016/j.tig.2005.12.006

```
   Soldatova LN, 2005, NAT BIOTECHNOL, V23, P1095, DOI 10.1038/nbt0905-1095
   SPELLMAN PT, 2002, GENOME BIOL, V3, P46
   Thomas PD, 2007, CURR OPIN CHEM BIOL, V11, P4, DOI 10.1016/j.cbpa.2006.11.039
   Van Horn JD, 2004, NAT NEUROSCI, V7, P473, DOI 10.1038/nn1231
   WALTON MM, 2008, J NEUROPHYS IN PRESS
   Whetzel PL, 2006, BIOINFORMATICS, V22, P866, DOI
10.1093/bioinformatics/btl005
NR 41
TC 18
Z9 18
U1 0
U2 6
PU HUMANA PRESS INC
PI TOTOWA
PA 999 RIVERVIEW DRIVE SUITE 208, TOTOWA, NJ 07512 USA
SN 1539-2791
J9 NEUROINFORMATICS
JI Neuroinformatics
PD JUN
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VL 6
IS 2
BP 117
EP 121
DI 10.1007/s12021-008-9019-9
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WC Computer Science, Interdisciplinary Applications; Neurosciences
SC Computer Science; Neurosciences & Neurology
GA 328BH
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PT J
AU Mojon-Azzi, SM
   Mojon, DS
AF Mojon-Azzi, Stefania M.
   Mojon, Daniel S.
TI Waiting times for cataract surgery in ten European countries: An
   analysis using data from the SHARE survey
SO BRITISH JOURNAL OF OPHTHALMOLOGY
LA English
DT Article
ID WILLINGNESS-TO-PAY; PATIENT SATISFACTION; LISTS; DETERMINANTS; CARE
AB Aims: To assess waiting times for cataract surgery and their acceptance in
European countries, and to find explanatory, country-specific health indicators.
   Methods: Using data from the survey of health, ageing and retirement in
Europe (SHARE), waiting times for cataract surgery of 245 respondents in ten
countries were analysed with the help of linear regression. The influence of
four country specific health indicators on waiting times was studied by multiple
linear regression. The influence of waiting time and country on the wish to have
surgery performed earlier was determined through logistic regression. Additional
information was obtained for each country from opinion leaders in the field of
cataract surgery.
   Results: Waiting times differed significantly (p < 0.001) between the ten
analysed European countries. The length of wait was significantly influenced by
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the total expenditure on health ($p < 0.01$) but not by the other country specific health indicators. The wish to have surgery performed earlier was determined by the length of wait ($p < 0.001$) but not by the country where surgery was performed.

Conclusion: The length of wait is influenced by the total expenditure on health, but not by the rate of public expenditure on health, by the physician density or by the acute bed density. The wish to have surgery performed earlier depends on the length of wait for surgery and is not influenced by the country.

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CR Anderson G, 1997, HEALTH AFFAIR, V16, P181, DOI 10.1377/hlthaff.16.5.181
Ballan L, 2001, CAN MED ASSOC J, V164, P1177
Bishai DM, 2000, J HEALTH ECON, V19, P219, DOI 10.1016/S0167-6296(99)00024-7
Borsch-Supan A., 2005, SURVEY HLTH AGING RE
Conner-Spady BL, 2005, CAN J OPHTHALMOL, V40, P439, DOI 10.1016/S0008-4182(05)80003-1
Conner-Spady BL, 2004, BRIT J OPHTHALMOL, V88, P1305, DOI 10.1136/bjo.2003.037721
De Coster C, 2005, CAN J AGING, V24, P47, DOI 10.1353/cja.2005.0043
DeCoster C, 1999, MED CARE, V37, pJS187, DOI 10.1097/00005650-199906001-00016
Dunn E, 1997, SOC SCI MED, V44, P1603, DOI 10.1016/S0277-9536(96)00251-1
GLANTZ SA, 2001, PRIMER APPL REGRESSI
Hadjistavropoulos H D, 1998, Jt Comm J Qual Improv, V24, P407
Hanning M, 1998, INT J TECHNOL ASSESS, V14, P180, DOI 10.1017/S026646230001062X
Hoel M, 2003, J HEALTH ECON, V22, P599, DOI 10.1016/S0167-6296(03)00007-9
Johannesson M, 1998, J HEALTH ECON, V17, P627, DOI 10.1016/S0167-6296(97)00044-1
Martin RM, 2003, BMJ-BRIT MED J, V326, P188, DOI 10.1136/bmj.326.7382.188
Nijkamp MD, 2000, J CATARACT REFR SURG, V26, P1379, DOI 10.1016/S0886-3350(00)00501-0
Shrank W, 2005, ARCH OPHTHALMOL-CHIC, V123, P1733, DOI 10.1001/archopht.123.12.1733
Taylor HR, 2000, BRIT J OPHTHALMOL, V84, P1, DOI 10.1136/bjo.84.1.1
Windmeijer F, 2005, HEALTH ECON, V14, P971, DOI 10.1002/hec.1043

NR 19
TC 18
Z9 18
U1 0
U2 3
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 0007-1161
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J9 BRIT J OPHTHALMOL
JI Br. J. Ophthalmol.
PD MAR
PY 2007
VL 91
IS 3
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WC Ophthalmology
SC Ophthalmology
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ER

PT J
AU Zhang, P
   White, J
   Schmidt, DC
   Lenz, G
   Rosenbloom, ST
AF Zhang, Peng
   White, Jules
   Schmidt, Douglas C.
   Lenz, Gunther
   Rosenbloom, S. Trent
TI FHIRChain: Applying Blockchain to Securely and Scalably Share Clinical Data
SO COMPUTATIONAL AND STRUCTURAL BIOTECHNOLOGY JOURNAL
LA English
DT Article
DE Blockchain; Smart contracts; Decentralized app; Interoperability; Digital health identity; Clinical data sharing; Cancer care
ID TUMOR BOARD; TRIAL DATA; CARE; TELEMEDICINE; CHALLENGES; LESSONS; IMPACT; GAPS
AB Secure and scalable data sharing is essential for collaborative clinical decision making. Conventional clinical data efforts are often siloed, however, which creates barriers to efficient information exchange and impedes effective treatment decision made for patients. This paper provides four contributions to the study of applying blockchain technology to clinical data sharing in the context of technical requirements defined in the "Shared Nationwide Interoperability Roadmap" from the Office of the National Coordinator for Health Information Technology (ONC). First, we analyze the ONC requirements and their implications for blockchain-based systems. Second, we present FHIRChain, which is a blockchain-based architecture designed to meet ONC requirements by encapsulating the HL7 Fast Healthcare Interoperability Resources (FHIR) standard for shared clinical data. Third, we demonstrate a FHIRChain-based decentralized app using digital health identities to authenticate participants in a case study of collaborative decisionmaking for remote cancer care. Fourth, we highlight key lessons learned from our case study. (c) 2018 The Authors. Published by Elsevier B.V. on behalf of Research Network of Computational and Structural Biotechnology. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/4.0/).
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FU Varian Medical Systems
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CR Al Omar A, 2018, INT C SEC PRIV AN CO, P534
Alvarez RM, 2009, PS-POLIT SCI POLIT, V42, P497, DOI 10.1017/S1049096509090787
Amazon Web Services, 2018, AWS BLOCKCH TEMPL
Anthes G, 2015, COMMUN ACM, V58, P18, DOI 10.1145/2754951
Azaria A, 2018, OP BIG DAT OBD INT C, P25
Bender D, 2013, 2013 IEEE 26TH INTERNATIONAL SYMPOSIUM ON COMPUTER-BASED MEDICAL SYSTEMS (CBMS), P326, DOI 10.1109/CBMS.2013.6627810
Berman M, 2005, HEALTH ECON, V14, P559, DOI 10.1002/hec.952
Bondi AB, 2018, P 2 INT WORKSH SOFTW, P195
Buterin Vitalik, 2013, ETHEREUM WHITE PAPER
Castaneda Christian, 2015, J Clin Bioinforma, V5, P4, DOI 10.1186/s13336-015-0019-3
Centers for Disease Control and Prevention (CDC), 2003, MMWR Suppl, V52, P1
Crockford D., 2006, APPL JSON MEDIA TYPE
Das Reenita, 2017, FORBES
DeSalvo K. B., 2015, CONNECTING HLTH CARE
Dolin RH, 2006, J AM MED INFORM ASSN, V13, P30, DOI 10.1197/jamia.M1888
Downey AS, 2013, WORKSH SUMM
Dubovitskaya Alevtina, 2017, ARXIV170906528
Ekblaw A, 2018, P IEEE OP BIG DAT C
Even S, 2018, ADV CRYPTOLOGY, P383
Geifman N, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0525-y
Greenspan G., 2015, MULTICHAIN PRIVATE B
Greenspan G., 2018, UNDERSTANDING ZERO K
Gropper A., 2016, POWERING PHYS PATIEN
GROSS GE, 1987, CA-CANCER J CLIN, V37, P88, DOI 10.3322/canjclin.37.2.88
Hardt D., 2012, OAUTH 2 0 AUTHORIZAT
Hartvigsen G, 2007, STUD HEALTH TECHNOL, V129, P82
HealthIT.gov, DIR PROJ
Hripcsak G, 2014, J AM MED INFORM ASSN, V21, P204, DOI 10.1136/amiajnl-2013-002117
I. G. B. S. P. S. Team, 2016, BLOCKCH CHAIN TRUST
Johnston D, 2014, GEN THEORY DECENTRAL
Kaushal R, 2003, ARCH INTERN MED, V163, P1409, DOI 10.1001/archinte.163.12.1409
Kawamoto K, 2013, J AM MED INFORM ASSN, V20, P199, DOI 10.1136/amiajnl-2012-000887
Kim Futrell M., 2013, STRUCTURED DATA
Krawczyk H., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P310
Krawiec R, 2018, P NIST WORKSH BLOCKC, P1
Kuo TT, 2017, J AM MED INFORM ASSN, V24, P1211, DOI 10.1093/jamia/ocx068
LaRose R, 2011, GOV INFORM Q, V28, P91, DOI 10.1016/j.giq.2009.12.013
Leff A, 2001, FIFTH IEEE INTERNATIONAL ENTERPRISE DISTRIBUTED OBJECT COMPUTING CONFERENCE, PROCEEDINGS, P118, DOI 10.1109/EDOC.2001.950428
Levit L, 2010, J ONCOL PRACT, V6, P7, DOI 10.1200/JOP.091067
Maheu M, 2002, HLTH TELEHEALTH TELE
Marshall CL, 2014, TELEMED E-HEALTH, V20, P705, DOI 10.1089/tmj.2013.0320
Menezes AJ, 1996, HDB APPL CRYPTOGRAPH
Mettler M., 2016, 2016 IEEE 18 INT C E, P1, DOI [10.1109/HealthCom.2016.7749510, DOI 10.1109/HEALTHCOM.2016.7749510]
Nakamoto S., 2008, BITCOIN PEER TO PEER
Ossher H, 2001, COMMUN ACM, V44, P43, DOI 10.1145/383845.383856

Peter JB, 2016, CO CREATION TRUST HE
Peterson K, 2016, BLOCKCHAIN BASED APP
Rackoff C, 2018, ANN INT CRYPT C, P433
Richesson RL, 2007, J AM MED INFORM ASSN, V14, P687, DOI 10.1197/jamia.M2470
Ricke J, 2000, EUR J CANCER, V36, P826, DOI 10.1016/S0959-8049(00)00057-5
Schiff GD, 2009, ARCH INTERN MED, V169, P1881, DOI 10.1001/archinternmed.2009.333
Shea R., 2018, SIMPLE CONTRACTS ARE
Singh H, 2013, JAMA INTERN MED, V173, P418, DOI 10.1001/jamainternmed.2013.2777
Taichman DB, 2016, ANN INTERN MED, V164, P505, DOI 10.7326/M15-2928
Terry M, 2009, TELEMED J E-HEALTH, V15, P132, DOI 10.1089/tmj.2009.9990
Warren E, 2016, NEW ENGL J MED, V375, P401, DOI 10.1056/NEJMp1607282
Ylonen T., 2006, SECURE SHELL SSH PRO
Yue X, 2016, J MED SYST, V40, DOI 10.1007/s10916-016-0574-6
Zhang P., 2017, 24 PATT LANG PROGR C
Zhang P, 2017, L N INST COMP SCI SO, V202, P1, DOI 10.1007/978-3-319-60753-5_1
NR 60
TC 17
Z9 17
U1 5
U2 14
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
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J9 COMPUT STRUCT BIOTEC
JI Comp. Struct. Biotechnol. J..
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WC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology
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PT J
AU Dye, C
Bartolomeos, K
Moorthy, V
Kieny, MP
AF Dye, Christopher
Bartolomeos, Kidist
Moorthy, Vasee
Kieny, Marie Paule
TI Data sharing in public health emergencies: a call to researchers
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Editorial Material

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OI Kieny, Marie-Paule/0000-0002-5943-6488; Dye,
   Christopher/0000-0002-2957-1793; Moorthy, Vasee/0000-0002-6535-2854
FU World Health Organization [001]
CR Modjarrad K, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001935
   Soares de Araujo J. S., 2016, B WHO UNPUB
   Whitty CJM, 2015, LANCET, V386, P1797, DOI 10.1016/S0140-6736(15)00758-8
   World Health Organization, DEV GLOB NORMS SHAR
NR 4
TC 17
Z9 17
U1 0
U2 4
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
EI 1564-0604
J9 B WORLD HEALTH ORGAN
JI Bull. World Health Organ.
PD MAR
PY 2016
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DI 10.2471/BLT.16.170860
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA DH4RX
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ER

PT S
AU Mehmood, R
   Graham, G
AF Mehmood, Rashid
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BE CruzCunha, MM
   Varajao, J
   Rijo, R
   Martinho, R
   Schubert, P
   Boonstra, A
   Correia, R
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   Berler, R
TI Big data logistics: a health-care transport capacity sharing model
SO CONFERENCE ON ENTERPRISE INFORMATION SYSTEMS/INTERNATIONAL CONFERENCE ON
   PROJECT MANAGEMENT/CONFERENCE ON HEALTH AND SOCIAL CARE INFORMATION
   SYSTEMS AND TECHNOLOGIES, CENTERIS/PROJMAN / HCIST 2015
SE Procedia Computer Science
LA English
DT Proceedings Paper
CT Conference on ENTERprise Information Systems (CENTERIS) / International
   Conference on Project MANagement (ProjMAN) / International Conference on
   Health and Social Care Information Systems and Technologies (HCist)
CY OCT 07-09, 2015
CL Vilamoura, PORTUGAL
DE future city; Big data; transport operation management; healthcare
   information systems; integrated systems; shared resources
AB The growth of cities in the 21st century has put more pressure on resources
and conditions of urban life. There are several reasons why the health-care
industry is the focus of this investigation. For instance, in the UK various
studies point to the lack of failure of basic quality control procedures and
misalignment between customer needs and provider services and duplication of
logistics practices. The development of smart cities and big data present
unprecedented challenges and opportunities for operations managers; they need to
develop new tools and techniques for network planning and control. Our paper
aims to make a contribution to big data and city operations theory by exploring
how big data can lead to improvements in transport capacity sharing. We explore
using Markov models the integration of big data with future city (health-care)
transport sharing. A mathematical model was designed to illustrate how sharing
transport load (and capacity) in a smart city can improve efficiencies in
meeting demand for city services. The results from our analysis of 13 different
sharing/demand scenarios are presented. A key finding is that the probability
for system failure and performance variance tends to be highest in a scenario of
high demand/zero sharing. (C) 2015 The Authors. Published by Elsevier B.V.
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CR AlAzawi Z., 2015, P ACM WORKSH WIR MOB, P1
   Audit Scotland, 2011, TRANSP HLTH SOC CAR
   Bamford J., 2009, OPERATIONAL RES SOC, V22, P140
   Blanco E.E., 2013, 404 TUE
   Caplice C., 2013, 4 TRENDS COULD REDEF
   Cocozza P, 2014, GUARDIAN
   Deakin M., 2012, SMART CITIES GOVERNI
   Dirks S., 2010, SMARTER CITIES SMART
   Manville C., 2014, IPAITREST201302 POL
   Manyika J., 2011, BIG DATA NEXT FRONTI
   Mehmood R., 2004, THESIS
   MEHMOOD R, 2005, UCAMCLTR650 U CAMBR
   Mehmood R., 2015, HDB RES REDESIGNING, P531, DOI DOI 10.4018/978-1-4666-8371-
6.CH022
   Mehmood R, 2011, J MANUF TECHNOL MANA, V22, P804, DOI
10.1108/17410381111149657
   Orsi J., 2009, 4 DEGREES SHARING
   Wamba SF, 2015, INT J PROD ECON, V165, P234, DOI 10.1016/j.ijpe.2014.12.031
NR 16
TC 17
```

```
Z9 17
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U2 21
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA SARA BURGERHARTSTRAAT 25, PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
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WC Computer Science, Information Systems; Computer Science, Theory &
   Methods
SC Computer Science
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UT WOS:000373839900140
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PT J
AU Yu, F
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AF Yu, Fei
   Ji, Zhanglong
TI Scalable privacy-preserving data sharing methodology for genome-wide
   association studies: an application to iDASH healthcare privacy
   protection challenge
SO BMC MEDICAL INFORMATICS AND DECISION MAKING
LA English
DT Article
AB In response to the growing interest in genome-wide association study (GWAS)
data privacy, the Integrating Data for Analysis, Anonymization and SHaring
(iDASH) center organized the iDASH Healthcare Privacy Protection Challenge, with
the aim of investigating the effectiveness of applying privacy-preserving
methodologies to human genetic data. This paper is based on a submission to the
iDASH Healthcare Privacy Protection Challenge. We apply privacy-preserving
methods that are adapted from Uhler et al. 2013 and Yu et al. 2014 to the
challenge's data and analyze the data utility after the data are perturbed by
the privacy-preserving methods. Major contributions of this paper include new
interpretation of the chi(2) statistic in a GWAS setting and new results about
the Hamming distance score, a key component for one of the privacy-preserving
methods.
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   NLM [R00LM011392, R21LM012060]; CTSA [UL1TR000100]; NCBC-linked grant
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CR Bhaskar R., 2010, P 16 ACM SIGKDD INT, P503, DOI DOI 10.1145/1835804.1835869
   Cynthia Dwork, 2006, THEORY CRYPTOGRAPHY, P1
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Jiang Xiaoqian, 2014, BMC
   Johnson Aaron, 2013, KDD, V2013, P1079
   McSherry F, 2007, ANN IEEE SYMP FOUND, P94, DOI 10.1109/FOCS.2007.66
   Uhlerop Caroline, 2013, J Priv Confid, V5, P137
   Yu F, 2014, J BIOMED INFORM, V50, P133, DOI 10.1016/j.jbi.2014.01.008
NR 8
TC 17
Z9 17
U1 0
U2 8
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1472-6947
J9 BMC MED INFORM DECIS
JI BMC Med. Inform. Decis. Mak.
PD DEC 8
PY 2014
VL 14
SU 1
AR S3
DI 10.1186/1472-6947-14-S1-S3
PG 8
WC Medical Informatics
SC Medical Informatics
GA AW3MB
UT WOS:000346189700003
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PT J
AU Mohammed, N
   Jiang, XQ
   Chen, R
   Fung, BCM
   Ohno-Machado, L
AF Mohammed, Noman
   Jiang, Xiaoqian
   Chen, Rui
   Fung, Benjamin C. M.
   Ohno-Machado, Lucila
TI Privacy-preserving heterogeneous health data sharing
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
AB Objective Privacy-preserving data publishing addresses the problem of
disclosing sensitive data when mining for useful information. Among existing
privacy models, e-differential privacy provides one of the strongest privacy
guarantees and makes no assumptions about an adversary's background knowledge.
All existing solutions that ensure e-differential privacy handle the problem of
disclosing relational and set-valued data in a privacy-preserving manner
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separately. In this paper, we propose an algorithm that considers both relational and set-valued data in differentially private disclosure of healthcare data.

Methods The proposed approach makes a simple yet fundamental switch in differentially private algorithm design: instead of listing all possible records (ie, a contingency table) for noise addition, records are generalized before noise addition. The algorithm first generalizes the raw data in a probabilistic way, and then adds noise to guarantee e-differential privacy.

Results We showed that the disclosed data could be used effectively to build a decision tree induction classifier. Experimental results demonstrated that the proposed algorithm is scalable and performs better than existing solutions for classification analysis.

Limitation The resulting utility may degrade when the output domain size is very large, making it potentially inappropriate to generate synthetic data for large health databases.

Conclusions Unlike existing techniques, the proposed algorithm allows the disclosure of health data containing both relational and set-valued data in a differentially private manner, and can retain essential information for discriminative analysis.

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FU Natural Sciences and Engineering Research Council of Canada (NSERC) [356065-2008]; NIH [1K99LM 011392-01, R01LM009520, U54 HL108460, R01HS019913, UL1RR031980]
FX BCMF, NM, and RC are supported in part by Discovery Grants (356065-2008) and Canada Graduate Scholarships from the Natural Sciences and Engineering Research Council of Canada (NSERC). XJ and LO-M were funded in part by NIH grants 1K99LM 011392-01, R01LM009520, U54 HL108460, R01HS019913, and UL1RR031980.

CR BAUMER D, 2000, ACM COMPUTERS SOC, V30, P40
Benitez K, 2010, 1 ACM INT HLTH INF S, P163
Bhaskar B, 2007, P 26 ACM SIGMOD SIGA, P273
Bhaskar R., 2010, P 16 ACM SIGKDD INT, P503, DOI DOI 10.1145/1835804.1835869
Dinur I., 2003, P 22 ACM SIGMOD SIGA, P202, DOI DOI 10.1145/773153.773173
Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1
Dwork C, 2006, LECT NOTES COMPUT SC, V3876, P265
Frank A., 2010, UCI MACHINE LEARNING
Friedman A., 2010, P 16 ACM SIGKDD INT, P493, DOI DOI 10.1145/1835804.1835868
Fung BCM, 2007, IEEE T KNOWL DATA EN, V19, P711, DOI 10.1109/TKDE.2007.1015
Fung BCM, 2010, ACM COMPUT SURV, V42, DOI 10.1145/1749603.1749605
Ganta S. R., 2008, P 14 ACM SIGKDD INT, P265, DOI [10.1145/1401890.1401926, DOI 10.1145/1401890.1401926]
Hay M, 2010, PROC VLDB ENDOW, V3, P1021
Institute of Medicine, 2009, HIPAA PRIV RUL ENH P
Kifer D, 2009, ACM SIGMOD/PODS 2009 CONFERENCE, P127
Loukides G, 2010, J AM MED INFORM ASSN, V17, P322, DOI 10.1136/jamia.2009.002725
Machanavajjhala A, 2009, P VLDB ENDOWMENT, V2, P790
Machanavajjhala A., 2007, ACM T KNOWL DISCOV D, V1, P3, DOI DOI 10.1145/1217299.1217302
Madsen E, 2003, J AM MED INFORM ASSN, V10, P294, DOI 10.1197/jamia.M1355

Martin DJ, 2007, ICDE, P126
McGraw D., 2012, WHY HIPAA PRIVACY RU
McGraw D, 2013, J AM MED INFORM ASSN, V20, P29, DOI 10.1136/amiajnl-2012-000936
McSherry F., 2007, P 48 ANN IEEE S FDN, P94
O'Keefe CM, 2008, ELECT J HLTH INFORM, V3, pE5
Quinlan J. R., 1993, C4 5 PROGRAMS MACHIN
Roth A, 2010, ACM S THEORY COMPUT, P765
Saeed M, 2011, CRIT CARE MED, V39, P952, DOI 10.1097/CCM.0b013e31820a92c6
Samarati P., 1998, P IEEE S RES SEC PRI, P1
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Wong RCW, 2011, ACM T KNOWL DISCOV D, V5, DOI 10.1145/1993077.1993080
WONG RCW, 2007, P 33 INT C VER LARG, P543
Wong RCW, 2006, INT C KNOWL DISC DAT, P754
Xiao XK, 2011, IEEE T KNOWL DATA EN, V23, P1200, DOI 10.1109/TKDE.2010.247
NR 33
TC 17
Z9 17
U1 1
U2 43
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1067-5027
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD MAY
PY 2013
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IS 3
BP 462
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WC Computer Science, Information Systems; Computer Science, Interdisciplinary Applications; Health Care Sciences & Services; Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science & Library Science; Medical Informatics
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PT J
AU Agyemang, C
Kunst, A
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Nazroo, J
Nicolaou, M
Unwin, N
van Valkengoed, I
Redekop, K
Stronks, K

AF Agyemang, C.
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Nicolaou, M.
Unwin, N.
van Valkengoed, I.
Redekop, K.
Stronks, K.
TI Dutch versus English advantage in the epidemic of central and generalised obesity is not shared by ethnic minority groups: comparative secondary analysis of cross-sectional data
SO INTERNATIONAL JOURNAL OF OBESITY
LA English
DT Article
DE overweight; ethnic groups; England; Netherlands
ID AFRICAN-ORIGIN POPULATIONS; TO-HEIGHT RATIO; HEALTH; RISK; NETHERLANDS; ASSOCIATION; PREVALENCE; BLACK; INEQUALITIES; HYPERTENSION

AB Background: Ethnic minority groups in Western European countries tend to have higher levels of overweight than the majority populations for reasons that are poorly understood. Investigating relative differences between countries could enable an investigation of the importance of national context in determining these inequalities.

Objective: To explore: (1) whether Indian and African origin populations in England and the Netherlands are similarly disadvantaged compared with the White populations in terms of the prevalence of overweight and central obesity; (2) whether the previously known Dutch advantage of relatively low overweight prevalence is also observed in Dutch ethnic minority groups and (3) the contribution of health behaviour and socio-economic position to the differences observed.

Methods: Secondary analyses of population-based studies of 16 406 participants from England and the Netherlands. Prevalence ratios were estimated using regression models.

Results: Except for African men, ethnic minority groups in both countries had higher rates of overweight and central obesity than their White counterparts. However, the Dutch minority groups were relatively more disadvantaged than English minority groups as compared with the majority populations. The Dutch advantage of the low prevalence of obesity was only seen in White men and women and African men. In contrast, English-Indian (prevalence ratio = 0.87, 95% confidence interval (CI): 0.81-0.93) and English-Caribbean (prevalence ratio = 0.82, 95% CI: 0.76-0.89) women were less centrally obese than their Dutch equivalents. The Dutch-Indian men were very similar to the English-Indian men. The contribution of health behaviour and socio-economic position to the observed differences were small.

Conclusion: Contrary to the patterns in White groups, the Dutch ethnic minority women were more obese than their English equivalents. More work is needed to identify factors that may contribute to these observed differences. International Journal of Obesity (2011) 35, 1334-1346; doi: 10.1038/ijo.2010.281; published online 15 February 2011

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FU Board of the Council for Earth and Life Sciences (ALW) of the Netherlands Organisation for Scientific Research (NWO) [916.76.130]
FX This project was supported by a VENI fellowship (Grant number 916.76.130) awarded by the Board of the Council for Earth and Life Sciences (ALW) of the Netherlands Organisation for Scientific Research (NWO).
CR Agyemang C, 2005, J EPIDEMIOL COMMUN H, V59, P1014, DOI 10.1136/jech.2005.035964
Agyemang C, 2010, EUR J PUBLIC HEALTH, V20, P84
Agyemang C, 2009, GLOBAL HLTH, V11, P5
Agyemang C, 2005, J HYPERTENS, V23, P1971, DOI 10.1097/01.hjh.0000186835.63996.d4
Agyemang C, 2010, ETHNIC HEALTH, V15, P216
Agyemang C, 2010, NICOTINE TOB RES, V12, P557, DOI 10.1093/ntr/ntq044
Agyemang C, 2010, AM J HYPERTENS, V23, P639, DOI 10.1038/ajh.2010.39
Ashwell M, 1996, BRIT MED J, V312, P377
B Erens, 2001, HLTH SURVEY ENGLAND
Barba C, 2004, LANCET, V363, P157
Bhopal R, 1999, BRIT MED J, V319, P215, DOI 10.1136/bmj.319.7204.215
Bhopal R, 2004, J EPIDEMIOL COMMUN H, V58, P441, DOI 10.1136/jech.2003.013466
Bowie Janice V, 2007, Prev Chronic Dis, V4, pA10
Cai ZJ, 1999, WHO TECH REP SER, V887, P1
Chiolero A, 2007, OBESITY, V15, P1311, DOI 10.1038/oby.2007.153
de Wit TD, 2005, ACTA POLIT, V40, P50, DOI 10.1057/palgrave.ap.5500096
Dijkshoorn H, 2008, PUBLIC HEALTH, V122, P625, DOI 10.1016/j.puhe.2007.08.016
Flay BR, 1990, MASS COMMUNICATION P, P129
Gill PS, 2007, HLTH CARE NEEDS ASSE, P227
Henriksson KM, 2001, EUR J EPIDEMIOL, V17, P521, DOI 10.1023/A:1014508422504
Hsieh SD, 2003, INT J OBESITY, V27, P610, DOI 10.1038/sj.ijo.0802259
Lamacchia O, 2009, AM J NEPHROL, V29, P615, DOI 10.1159/000194454
Nazroo J, 2007, SOCIOL HEALTH ILL, V29, P811, DOI 10.1111/j.1467-9566.2007.01043.x
Ogden CL, 2006, JAMA-J AM MED ASSOC, V295, P1549, DOI 10.1001/jama.295.13.1549
Oldroyd J, 2005, POSTGRAD MED J, V81, P486, DOI 10.1136/pgmj.2004.029124
Rabin BA, 2007, EUR J PUBLIC HEALTH, V17, P53, DOI 10.1093/eurpub/ckl073
Schroder H, 2007, EUR J NUTR, V46, P369, DOI 10.1007/s00394-007-0674-7
Silventoinen K, 2004, INT J OBESITY, V28, P710, DOI 10.1038/sj.ijo.0802614
Sjostrom M, 2006, J PUBLIC HEALTH-HEID, V14, P291, DOI 10.1007/s10389-006-0031-y
Stronks K, 2009, ETHN HLTH, V14, P1
van Nierkerk M., 2000, IMMIGRANT INTEGRATIO, P64
Visscher TLS, 2001, ANNU REV PUBL HEALTH, V22, P355, DOI 10.1146/annurev.publhealth.22.1.355
Zhang Q, 2004, OBES RES, V12, P1622, DOI 10.1038/oby.2004.202
NR 33
TC 17
Z9 17
U1 0
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PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 0307-0565
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J9 INT J OBESITY
JI Int. J. Obes.
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DI 10.1038/ijo.2010.281
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WC Endocrinology & Metabolism; Nutrition & Dietetics
SC Endocrinology & Metabolism; Nutrition & Dietetics
GA 835UN
UT WOS:000296061600014
PM 21326206
OA Bronze
DA 2019-08-06
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PT J
AU Parkes, A
   Strange, V
   Wight, D
   Bonell, C
   Copas, A
   Henderson, M
   Buston, K
   Stephenson, J
   Johnson, A
   Allen, E
   Hart, G
AF Parkes, Alison
   Strange, Vicki
   Wight, Daniel
   Bonell, Chris
   Copas, Andrew
   Henderson, Marion
   Buston, Katie
   Stephenson, Judith
   Johnson, Anne
   Allen, Elizabeth
   Hart, Graham
TI Comparison of Teenagers' Early Same-Sex and Heterosexual Behavior: UK
   Data From the SHARE and RIPPLE Studies
SO JOURNAL OF ADOLESCENT HEALTH
LA English
DT Article
DE Sexual minority; Adolescence; Sexual behavior
ID HEALTH-RISK BEHAVIOR; MENTAL-HEALTH; BISEXUAL ADOLESCENTS; PROTECTIVE
   FACTORS; STATEWIDE SURVEY; NORTH-AMERICA; YOUNG-ADULTS; HIV-RISK;
   ORIENTATION; GAY
AB Purpose: North American research finds increased sexual risk-taking among
teenagers with same-sex partners, but understanding of underlying processes is
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limited. The research carried out in the United Kingdom compares teenagers' early sexual experiences according to same-or opposite-sex partner, focusing on unwanted sex in addition to risk-taking, and exploring underlying psychosocial differences.

Methods: Multivariate analyses combined self-reported data from two randomized control trials of school sex education programs(N = 10,250). Outcomes from sexually experienced teenagers(N = 3,766) were partner pressure to have first sex and subsequent regret, and sexual risk measures including pregnancy. Covariates included self-esteem, future expectations, substance use, and communication with mother.

Results: By the time of follow-up (mean age, 16), same-sex genital contact (touching or oral or anal) was reported by 2.3% of teenagers, with the majority also reporting heterosexual intercourse. A total of 39% reported heterosexual intercourse and no same-sex genital contact. Boys were more likely to report partner pressure (Odds ratio [OR] = 2.56, 95% confidence intervals [CI] = 1.29-5.08) and regret (OR = 2.32; 95% CI = 1.39-3.86) in relation to first same-sex genital contact than first heterosexual intercourse, but girls showed no differences according to partner type. Teenagers with bisexual behavior reported greater pregnancy or partner pregnancy risk than teenagers with exclusively opposite-sex partners (girls, OR = 4.51, 95% CI = 2.35-8.64; boys, OR = 4.43, 95% CI = 2.41-8.14), partially reduced by attitudinal and behavioral differences.

Conclusions: This UK study confirms greater reporting of sexual risk-taking among teenagers with same-sex partners, and suggests that boys in this group are vulnerable to unwanted sex. It suggests limitations to the interpretation of differences, in terms of psychosocial risk factors common to all adolescents. (C) 2011 Society for Adolescent Health and Medicine. All rights reserved.

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OI Henderson, Marion/0000-0001-7582-9516; Henderson, Marion/0000-0001-7582-9516; Copas, Andrew/0000-0001-8968-5963; Hart, Graham/0000-0001-9676-6577

FU National Institute for Health Research [NF-SI-0508-10244]; Medical Research Council [G9626797, MC_UP_A540_1108]

CR Blake SM, 2001, AM J PUBLIC HEALTH, V91, P940, DOI 10.2105/AJPH.91.6.940
Bontempo DE, 2002, J ADOLESCENT HEALTH, V30, P364, DOI 10.1016/S1054-139X(01)00415-3
Borowsky IW, 2001, PEDIATRICS, V107, P485, DOI 10.1542/peds.107.3.485
Brener ND, 2003, J ADOLESCENT HEALTH, V33, P436, DOI 10.1016/S1054-139X(03)00052-1
BUSSERI MA, 2006, J YOUTH ADOLESCENCE, V35, P561
Busseri MA, 2008, DEV PSYCHOL, V44, P69, DOI 10.1037/0012-1649.44.1.69
Buston K, 2001, J ADOLESCENCE, V24, P95, DOI 10.1006/jado.2000.0366
Carlin JB, 2008, STATA J, V8, P49, DOI 10.1177/1536867X0800800104
Diamond LM, 2004, J RES ADOLESCENCE, V14, P313, DOI 10.1111/j.1532-7795.2004.00077.x

Diamond LM, 2003, J CLIN CHILD ADOLESC, V32, P490, DOI 10.1207/S15374424JCCP3204_1
Ellis V, 2004, BRIT EDUC RES J, V30, P213, DOI 10.1080/0141192042000195281
Fergusson DM, 2005, PSYCHOL MED, V35, P971, DOI 10.1017/S0033291704004222
Garofalo R, 1998, PEDIATRICS, V101, P895, DOI 10.1542/peds.101.5.895
Goodenow C, 2002, AM J PUBLIC HEALTH, V92, P203, DOI 10.2105/AJPH.92.2.203
Goodenow C, 2008, AM J PUBLIC HEALTH, V98, P1051, DOI 10.2105/AJPH.2005.080531
Herek GM, 2007, ANNU REV CLIN PSYCHO, V3, P353, DOI 10.1146/annurev.clinpsy.3.022806.091510
Horn SS, 2006, COGNITIVE DEV, V21, P420, DOI 10.1016/j.cogdev.2006.06.007
Hunt R., 2007, SCH REPORT EXPERIENC
JESSOR R, 1995, DEV PSYCHOL, V31, P923, DOI 10.1037/0012-1649.31.6.923
Lewis NM, 2009, HEALTH PLACE, V15, P1029, DOI 10.1016/j.healthplace.2009.05.003
Marshal MP, 2008, ADDICTION, V103, P546, DOI 10.1111/j.1360-0443.2008.02149.x
Mercer CH, 2007, AM J PUBLIC HEALTH, V97, P1126, DOI 10.2105/AJPH.2006.086439
Mercer CH, 2004, AIDS, V18, P1453, DOI 10.1097/01.aids.0000131331.36386.de
Meyer IH, 2003, PSYCHOL BULL, V129, P674, DOI 10.1037/0033-2909.129.5.674
Park A, 2008, BRIT SOCIAL ATTITUDE
Pearson J, 2007, SOC PROBL, V54, P523, DOI 10.1525/sp.2007.54.4.523
Rosario M, 1999, HEALTH PSYCHOL, V18, P272, DOI 10.1037/0278-6133.18.3.272
Rosario M, 2006, AIDS EDUC PREV, V18, P444, DOI 10.1521/aeap.2006.18.5.444
Rotheram-Borus MJ, 1999, ARCH SEX BEHAV, V28, P159, DOI 10.1023/A:1018719922709
Royston P, 2005, STATA J, V5, P188, DOI 10.1177/1536867X0500500204
Rubin D. B., 1987, MULTIPLE IMPUTATION
Saewyc E, 2006, AM J PUBLIC HEALTH, V96, P1104, DOI 10.2105/AJPH.2005.065870
Saewyc EM, 2009, AM J PUBLIC HEALTH, V99, P110, DOI 10.2105/AJPH.2007.123109
Savin-Williams RC, 2001, J ADOLESCENCE, V24, P5, DOI 10.1006/jado.2000.0369
Savin-Williams RC, 2007, ARCH SEX BEHAV, V36, P385, DOI 10.1007/s10508-006-9088-5
SHARPE S, 2002, SEX ED, V0002
Stephenson JM, 2004, LANCET, V364, P338, DOI 10.1016/S0140-6736(04)16722-6
Udry JR, 2002, J ADOLESCENT HEALTH, V31, P84, DOI 10.1016/S1054-139X(02)00374-9
Wight D, 2002, BMJ-BRIT MED J, V324, P1430, DOI 10.1136/bmj.324.7351.1430
Wight D, 2008, PERSPECT SEX REPRO H, V40, P226, DOI 10.1363/4022608
NR 40
TC 17
Z9 17
U1 1
U2 13
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 1054-139X
J9 J ADOLESCENT HEALTH
JI J. Adolesc. Health
PD JAN
PY 2011
VL 48
IS 1
BP 27
EP 35
DI 10.1016/j.jadohealth.2010.05.010
PG 9
WC Psychology, Developmental; Public, Environmental & Occupational Health;

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SC Psychology; Public, Environmental & Occupational Health; Pediatrics
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PT J
AU Holmgren, AJ
Patel, V
Adler-Milstein, J
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Patel, Vaishali
Adler-Milstein, Julia
TI Progress In Interoperability: Measuring US Hospitals' Engagement In Sharing Patient Data
SO HEALTH AFFAIRS
LA English
DT Article
ID HEALTH INFORMATION EXCHANGE; NATIONAL COORDINATOR; RECORDS; OFFICE; USAGE
AB Achieving an interoperable health care system remains a top US policy priority. Despite substantial efforts to encourage interoperability, the first set of national data in 2014 suggested that hospitals' engagement levels were low. With 2015 data now available, we examined the first national trends in engagement in four domains of interoperability: finding, sending, receiving, and integrating electronic patient information from outside providers. We found small gains, with 29.7 percent of hospitals engaging in all four domains in 2015 compared to 24.5 percent in 2014. The two domains with the most progress were sending (with an increase of 8.1 percentage points) and receiving (an increase of 8.4 percentage points) information, while there was no change in integrating systems. Hospitals' use for patient care of data from outside providers was low, with only 18.7 percent of hospitals reporting that they "often" used these data. Our results reveal that hospitals' progress toward interoperability is slow and that progress is focused on moving information between hospitals, not on ensuring usability of information in clinical decisions.
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CR Adler-Milstein J, J AM MED INFORM ASS
Adler-Milstein J, 2014, HEALTHCARE, V2, P26, DOI 10.1016/j.hjdsi.2013.12.005
Adler-Milstein J, 2016, HEALTH AFFAIR, V35, P1278, DOI 10.1377/hlthaff.2015.1439
American Hospital Association, AHA DAT DIR AHA ANN
Charles D, 2015, PATEL V INTEROPERABI
CMS. gov, MACR DEL SYST REF ME
Delbanco SF, 2011, PROMISING PAYMENT RE
DeSalvo KB, 2015, ANN EMERG MED, V66, P507, DOI 10.1016/j.annemergmed.2015.03.032
Everson J, 2014, J AM MED INFORM ASS, V21

```
   Everson J, 2017, J AM MED INFORM ASSN, V24, pE103, DOI 10.1093/jamia/ocw116
   Everson J, 2016, HEALTH AFFAIR, V35, P1286, DOI 10.1377/hlthaff.2015.1215
   Government Accountability Office, 2015, EL HLTH REC NONF ER
   Grossman Joy M, 2008, Res Brief, P1
   Holmgren AJ, 2017, J HOSP MED, V12, P193, DOI 10.12788/jhm.2704
   Holmgren AJ, 2016, AM J MANAG CARE, V22, pE395
   Jha AK, 2009, NEW ENGL J MED, V360, P1628, DOI 10.1056/NEJMsa0900592
   Johnson KB, 2011, J AM MED INFORM ASSN, V18, P690, DOI 10.1136/amiajnl-2011-
000308
   Kern L, 2008, AM MED INF ASS ANN M
   Kern LM, 2017, POPUL HEALTH MANAG, V20, P99, DOI 10.1089/pop.2016.0021
   Office of the National Coordinator for Health Information Technology, CONN
HLTH CAR NAT SH
   Rudin RS, 2014, ANN INTERN MED, V161, P803, DOI 10.7326/M14-0877
   Stange KC, 2010, J GEN INTERN MED, V25, P601, DOI 10.1007/s11606-010-1291-3
   Thorn SA, 2014, ANN EMERG MED, V63, P329, DOI
10.1016/j.annemergmed.2013.09.024
   Vest JR, 2016, MILBANK Q, V94, P77, DOI 10.1111/1468-0009.12180
   Walker Jan, 2005, Health Aff (Millwood), VSuppl Web Exclusives, pW5
   Weiner JP, 2012, INT J QUAL HEALTH C, V24, P200, DOI 10.1093/intqhc/mzs011
   Williams C, 2012, HEALTH AFFAIR, V31, P527, DOI 10.1377/hlthaff.2011.1314
   Winden TJ, 2014, APPL CLIN INFORM, V5, P388, DOI 10.4338/ACI-2013-12-RA-0100
   Zhou Yuan, 2013, Inform Prim Care, V21, P21, DOI 10.14236/jhi.v21i1.36
NR 29
TC 16
Z9 16
U1 1
U2 5
PU PROJECT HOPE
PI BETHESDA
PA 7500 OLD GEORGETOWN RD, STE 600, BETHESDA, MD 20814-6133 USA
SN 0278-2715
J9 HEALTH AFFAIR
JI Health Aff.
PD OCT
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BP 1820
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WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA FI5TD
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PT J
AU Majumder, MA
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   McGuire, AL
AF Majumder, Mary A.
   Cook-Deegan, Robert
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TI Beyond Our Borders? Public Resistance to Global Genomic Data Sharing
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SO PLOS BIOLOGY
LA English
DT Article
ID BIOBANKS; DATASHIELD; ATTITUDES; PRIVACY; CONSENT

AB Prospects have never seemed better for a truly global approach to science to improve human health, with leaders of national initiatives laying out their vision of a worldwide network of related projects. An extensive literature addresses obstacles to global genomic data sharing, yet a series of public polls suggests that the scientific community may be overlooking a significant barrier: potential public resistance to data sharing across national borders. In several large United States surveys, university researchers in other countries were deemed the least acceptable group of data users, and a just-completed US survey found a marked increase in privacy and security concerns related to data access by non-US researchers. Furthermore, diminished support for sharing beyond national borders is not unique to the US, although the limited data from outside the US suggest variation across countries as well as demographic groups. Possible sources of resistance include apprehension about privacy and security protections. Strategies for building public support include making the affirmative case for global data sharing, addressing privacy, security, and other legitimate concerns, and investigating public concerns in greater depth.

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FX National Human Genome Research Institute https://projectreporter.nih.gov/project_info_description.cfm?aid=8661773 (grant number P50HG003391). Received by RCD. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript. National Human Genome Research Institute https://projectreporter.nih.gov/project_info_description.cfm?aid=9054592 (grant number R01HG008918). Received by MAM, RCD and ALM. The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

CR Ahram M, 2014, EUR J HUM GENET, V22, P445, DOI 10.1038/ejhg.2013.174
[Anonymous], 2014, 21 CENTURY CURES CAL
[Anonymous], 1996, PRINC AGR 1 INT STRA
BIRNEY E, 2009, NATURE, V461, P168, DOI DOI 10.1038/461168A
Buhrmester M, 2011, PERSPECT PSYCHOL SCI, V6, P3, DOI 10.1177/1745691610393980
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Carter KW, 2016, INT J EPIDEMIOL
Caulfield T, 2009, MED LAW INT, V10, P85, DOI [10.1177/096853320901000201, DOI 10.1177/096853320901000201]
Caulfield T, 2014, NAT REV GENET, V15, P220, DOI 10.1038/nrg3704
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Dove ES, 2016, SCIENCE, V351, P1399, DOI 10.1126/science.aad5269
Erlich Y, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001983
Fehr E, 2003, NATURE, V425, P785, DOI 10.1038/nature02043
Ferla R, 2007, ANN ONCOL, V18, P93, DOI 10.1093/annonc/mdm234
Garrison NA, 2016, GENET MED, V18, P663, DOI 10.1038/gim.2015.138
Gaye A, 2014, INT J EPIDEMIOL, V43, P1929, DOI 10.1093/ije/dyu188
Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN H

```
   Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
   Ipsos-MORI, 2016, ON WAY MIRR PUBL ATT
   Jao I, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135545
   Joly Y, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0129893
   Kaufman D, 2009, GENET MED, V11, P329, DOI 10.1097/GIM.0b013e31819994f8
   Kaufman DJ, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0160461
   Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-
082410-101454
   Manrai AK, 2016, NEW ENGL J MED, V375, P655, DOI 10.1056/NEJMsa1507092
   Merson L, 2016, NEW ENGL J MED, V374, P2414, DOI 10.1056/NEJMp1605148
   Modjarrad K, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001935
   Rothstein MA, 2016, J LAW MED ETHICS, V44, P161, DOI 10.1177/1073110516644207
   Sudlow C, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001779
   Tupasela A, 2010, SCAND J PUBLIC HEALT, V38, P46, DOI
10.1177/1403494809353824
   UNESCO, 1997, UN DECL HUM GEN HUM
   Wallace SE, 2014, PUBLIC HEALTH GENOM, V17, P149, DOI 10.1159/000360255
   Whitman W., LEAVES GRASS
   Williams HL, 2013, J POLIT ECON, V121, P1, DOI 10.1086/669706
   Zawati MH, 2014, PATHOBIOLOGY, V81, P276, DOI 10.1159/000357527
NR 35
TC 16
Z9 16
U1 0
U2 3
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
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J9 PLOS BIOL
JI PLoS. Biol.
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SC Biochemistry & Molecular Biology; Life Sciences & Biomedicine - Other
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ER

PT J
AU Merino-Martinez, R
   Norlin, L
   van Enckevort, D
   Anton, G
   Schuffenhauer, S
   Silander, K
   Mook, L
   Holub, P
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```

Swertz, M
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AF Merino-Martinez, Roxana
   Norlin, Loreana
   van Enckevort, David
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   Silander, Kaisa
   Mook, Linda
   Holub, Petr
   Bild, Raffael
   Swertz, Morris
   Litton, Jan-Eric
TI Toward Global Biobank Integration by Implementation of the Minimum
   Information About BIobank Data Sharing (MIABIS 2.0 Core)
SO BIOPRESERVATION AND BIOBANKING
LA English
DT Article
AB Biobanks are the biological back end of data-driven medicine, but lack standards and generic solutions for interoperability and information harmonization. The move toward a global information infrastructure for biobanking demands semantic interoperability through harmonized services and common ontologies. To tackle this issue, the Minimum Information About BIobank data Sharing (MIABIS) was developed in 2012 by the Biobanking and BioMolecular Resources Research Infrastructure of Sweden (BBMRI.se). The wide acceptance of the first version of MIABIS encouraged evolving it to a more structured and descriptive standard. In 2013 a working group was formed under the largest infrastructure for health in Europe, Biobanking and BioMolecular Resources Research Infrastructure (BBMRI-ERIC), with the remit to continue the development of MIABIS (version 2.0) through a multicountry governance process. MIABIS 2.0 Core has been developed with 22 attributes describing Biobanks, Sample Collections, and Studies according to a modular structure that makes it easier to adhere to and to extend the standard. This integration standard will make a great contribution to the discovery and exploitation of biobank resources and lead to a wider and more efficient use of valuable bioresources, thereby speeding up the research on human diseases. Many within the European Union have accepted MIABIS 2.0 Core as the de facto biobank information standard.
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   [184.021.007]; Center for Translational Molecular Medicine,
   Translational IT project (CTMM-TraIT); Academy of Finland [273527]

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   Translational IT project (CTMM-TraIT), and the Academy of Finland for
   financially supporting the BBMRI.fi network (grant no. 273527).
CR [Anonymous], 2009, GUID BUS AN BOD KNOW
   [Anonymous], 2009, NATURE, V462, P825
   Brochhausen M, 2013, J BIOMED SEMANT, V4, DOI 10.1186/2041-1480-4-23
   Fransson MN, 2015, EUR J HUM GENET, V23, P22, DOI 10.1038/ejhg.2014.45
   Halmos PR, 1960, NAIVE SET THEORY, P28
   Harris JR, 2012, EUR J HUM GENET, V20, P1105, DOI 10.1038/ejhg.2012.96
   Lehmann S, 2012, BIOPRESERV BIOBANK, V10, P366, DOI 10.1089/bio.2012.0012
   Norlin L, 2012, BIOPRESERV BIOBANK, V10, P343, DOI 10.1089/bio.2012.0003
   Swertz MA, 2010, BMC BIOINFORMATICS, V11, DOI 10.1186/1471-2105-11-S12-S12
   Wichmann HE, 2011, NAT BIOTECHNOL, V29, P795, DOI 10.1038/nbt.1958
   Yuille M, 2008, BRIEF BIOINFORM, V9, P14, DOI 10.1093/bib/bbm050
   Yuille M, 2010, CELL TISSUE BANK, V11, P241, DOI 10.1007/s10561-009-9150-3
NR 12
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Z9 18
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PU MARY ANN LIEBERT, INC
PI NEW ROCHELLE
PA 140 HUGUENOT STREET, 3RD FL, NEW ROCHELLE, NY 10801 USA
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J9 BIOPRESERV BIOBANK
JI Biopreserv. Biobank.
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PY 2016
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IS 4
BP 298
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DI 10.1089/bio.2015.0070
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WC Cell Biology; Chemistry, Applied; Medical Laboratory Technology
SC Cell Biology; Chemistry; Medical Laboratory Technology
GA DU9BD
UT WOS:000382510300006
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PT J
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   Tangseefa, D
   Somsaman, A
   Chunsuttiwat, T
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   Bull, S
   Parker, M
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TI Perceived Benefits, Harms, and Views About How to Share Data
   Responsibly: A Qualitative Study of Experiences With and Attitudes
   Toward Data Sharing Among Research Staff and Community Representatives
   in Thailand
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE Thailand; data sharing; consent; collaboration; research ethics
ID PUBLIC-HEALTH RESEARCH; FALCIPARUM-MALARIA; LEVEL DATA; TRIAL DATA;
   ACCESS; DRUG; CHILDREN; POLICY; ETHICS; TRUST
AB The Thailand Major Overseas Programme coordinates large multi-center studies
in tropical medicine and generates vast amounts of data. As the data sharing
movement gains momentum, we wanted to understand attitudes and experiences of
relevant stakeholders about what constitutes good data sharing practice. We
conducted 15 interviews and three focus groups discussions involving 25
participants and found that they generally saw data sharing as something
positive. Data sharing was viewed as a means to contribute to scientific
progress and lead to better quality analysis, better use of resources, greater
accountability, and more outputs. However, there were also important
reservations including potential harms to research participants, their
communities, and the researchers themselves. Given these concerns, several areas
for discussion were identified: data standardization, appropriate consent models,
and governance.
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FU Wellcome Trust [096527]; Wellcome Trust of Great Britain
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   equitable, ethical, and efficient, and will accelerate improvements in
   public health (www.wellcome.ac.uk/publichealthdata). The Thailand Major
   Overseas Programme is funded by the Wellcome Trust of Great Britain.
CR Ashley EA, 2014, NEW ENGL J MED, V371, P411, DOI 10.1056/NEJMoa1314981
```

Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
Dondorp AM, 2010, LANCET, V376, P1647, DOI 10.1016/S0140-6736(10)61924-1
Doshi P, 2013, TRENDS PHARMACOL SCI, V34, P645, DOI 10.1016/j.tips.2013.10.006
Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
European Medicines Agency, 2014, EUR MED AG POL PUBL
Faiz MA, 2005, LANCET, V366, P717
Gale NK, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-117
Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7888
Greenhalgh T., 2009, BRIT MED J, V338, P903
Haga SB, 2011, PUBLIC HEALTH GENOM, V14, P319, DOI 10.1159/000324705
Harris DJ, 2011, LANCET, V378, P1994, DOI 10.1016/S0140-6736(11)61869-2
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Kim SYH, 2009, J EMPIR RES HUM RES, V4, P3, DOI 10.1525/jer.2009.4.4.3
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Marsh V, 2008, SOC SCI MED, V67, P721, DOI 10.1016/j.socscimed.2008.02.007
Medical Research Council, 2011, MRC POL RES DAT SHAR
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Molster C, 2013, HEALTH EXPECT, V16, P211, DOI 10.1111/j.1369-7625.2011.00701.x
National Institutes of Health, 2003, FIN NIH STAT SHAR RE
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Onyamboko MA, 2014, ANTIMICROB AGENTS CH, V58, P5528, DOI 10.1128/AAC.02682-14
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Phrma, 2013, PRINC RESP CLIN TRIA
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Rabesandratana T, 2013, SCIENCE, V339, P1369, DOI 10.1126/science.339.6126.1369
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Research Information Network, 2008, SHAR NOT SHAR RES DA
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Thomas DR, 2006, AM J EVAL, V27, P237, DOI 10.1177/1098214005283748
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Wellcome Trust, 2009, POL DAT MAN SHAR

NR 40
TC 16
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PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
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JI J. Empir. Res. Hum. Res. Ethics
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PT J
AU Niesters, HG
   Rossen, JW
   van der Avoort, H
   Baas, D
   Benschop, K
   Claas, EC
   Kroneman, A
   van Maarseveen, N
   Pas, S
   van Pelt, W
   Rahamat-Langendoen, JC
   Schuurman, R
   Vennema, H
   Verhoef, L
   Wolthers, K
   Koopmans, M
AF Niesters, H. G.
   Rossen, J. W.
   van der Avoort, H.
   Baas, D.
   Benschop, K.
   Claas, E. C.
   Kroneman, A.
   van Maarseveen, N.
   Pas, S.
   van Pelt, W.
   Rahamat-Langendoen, J. C.
   Schuurman, R.
   Vennema, H.
   Verhoef, L.
   Wolthers, K.
   Koopmans, M.
TI Laboratory-based surveillance in the molecular era: the TYPENED model, a
   joint data-sharing platform for clinical and public health laboratories
SO EUROSURVEILLANCE
LA English
DT Article
ID ENTEROVIRUS SEROTYPES; DIRECT IDENTIFICATION; AMPLIFICATION; INFECTIONS;
   SPECIMENS; REGION
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AB Laboratory-based surveillance, one of the pillars of monitoring infectious disease trends, relies on data produced in clinical and/or public health laboratories. Currently, diagnostic laboratories worldwide submit strains or samples to a relatively small number of reference laboratories for characterisation and typing. However, with the introduction of molecular diagnostic methods and sequencing in most of the larger diagnostic and university hospital centres in high-income countries, the distinction between diagnostic and reference/public health laboratory functions has become less clear-cut. Given these developments, new ways of networking and data sharing are needed. Assuming that clinical and public health laboratories may be able to use the same data for their own purposes when sequence-based testing and typing are used, we explored ways to develop a collaborative approach and a jointly owned database (TYPENED) in the Netherlands. The rationale was that sequence data - whether produced to support clinical care or for surveillance - can be aggregated to meet both needs. Here we describe the development of the TYPENED approach and supporting infrastructure, and the implementation of a pilot laboratory network sharing enterovirus sequences and metadata.

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[van der Avoort, H.; Baas, D.; Benschop, K.; Kroneman, A.; van Pelt, W.; Vennema, H.; Verhoef, L.; Koopmans, M.] Natl Inst Publ Hlth & Environm RIVM, Ctr Infect Dis Control, Bilthoven, Netherlands.
[Benschop, K.; Wolthers, K.] Univ Amsterdam, Acad Med Ctr, Dept Med Microbiol, NL-1105 AZ Amsterdam, Netherlands.
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OI Rossen, John W/0000-0002-7167-8623; Verhoef, Linda/0000-0001-5988-8946; Pas, Suzan/0000-0003-1943-1217;

CR Aarestrup Frank M, 2012, Emerg Infect Dis, V18, pe1, DOI 10.3201/eid/1811.120453
Bean NH, 2001, EMERG INFECT DIS, V7, P773
Benson DA, 2013, NUCLEIC ACIDS RES, V41, pD36, DOI 10.1093/nar/gks1195
Deyde VM, 2011, EXPERT REV MOL DIAGN, V11, P41, DOI 10.1586/ERM.10.107
EMORI TG, 1993, CLIN MICROBIOL REV, V6, P428
Endimiani A, 2011, CLIN INFECT DIS, V52, pS373, DOI 10.1093/cid/cir054
Fournier-Wirth C, 2010, BIOLOGICALS, V38, P9, DOI 10.1016/j.biologicals.2009.10.010
Kroneman A, 2011, J CLIN VIROL, V51, P121, DOI 10.1016/j.jcv.2011.03.006
Leitch ECM, 2009, J CLIN VIROL, V44, P119, DOI 10.1016/j.jcv.2008.11.015
Manzara S, 2002, J CLIN MICROBIOL, V40, P4554, DOI 10.1128/JCM.40.12.4554-4560.2002
Nelson KE, 2011, EXPERT REV ANTI-INFE, V9, P1133, DOI [10.1586/ERI.11.138, 10.1586/eri.11.138]
Nix WA, 2006, J CLIN MICROBIOL, V44, P2698, DOI 10.1128/JCM.00542-06
Verhoef L, 2012, VIRUS GENES, V44, P8, DOI 10.1007/s11262-011-0673-x
Wolthers KC, 2008, CLIN INFECT DIS, V47, P358, DOI 10.1086/589752
Workman M R, 1995, Commun Dis Rep CDR Rev, V5, pR54
NR 15
TC 16

Z9 17
U1 0
U2 3
PU EUR CENTRE DIS PREVENTION & CONTROL
PI STOCKHOLM
PA TOMTEBODAVAGEN 11A, STOCKHOLM, 171 83, SWEDEN
SN 1560-7917
J9 EUROSURVEILLANCE
JI Eurosurveillance
PD JAN 24
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VL 18
IS 4
BP 51
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AR 20387
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WC Infectious Diseases
SC Infectious Diseases
GA 088DQ
UT WOS:000314814400006
PM 23369392
OA DOAJ Gold
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PT J
AU Maiorana, A
   Steward, WT
   Koester, KA
   Pearson, C
   Shade, SB
   Chakravarty, D
   Myers, JJ
AF Maiorana, Andre
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   Shade, Starley B.
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TI Trust, confidentiality, and the acceptability of sharing HIV-related
   patient data: lessons learned from a mixed methods study about Health
   Information Exchanges
SO IMPLEMENTATION SCIENCE
LA English
DT Article
DE Trust; Confidentiality; Acceptability; Health information exchanges;
   HIV; Patient data-sharing
ID ELECTRONIC MEDICAL-RECORDS; PRIMARY-CARE; PATIENTS ATTITUDES; PRIVACY;
   TECHNOLOGY; MANAGEMENT; PHYSICIANS; SYSTEM; PERCEPTIONS; EXPERIENCES
AB Background: Concerns about the confidentiality of personal health information
have been identified as a potential obstacle to implementation of Health
Information Exchanges (HIEs). Considering the stigma and confidentiality issues
historically associated with human immunodeficiency virus (HIV) disease, we
examine how trust-in technology, processes, and people-influenced the
acceptability of data sharing among stakeholders prior to implementation of six
HIEs intended to improve HIV care in parts of the United States. Our analyses

identify the kinds of concerns expressed by stakeholders about electronic data sharing and focus on the factors that ultimately facilitated acceptability of the new exchanges.

Methods: We conducted 549 surveys with patients and 66 semi-structured interviews with providers and other stakeholders prior to implementation of the HIEs to assess concerns about confidentiality in the electronic sharing of patient data. The patient quantitative data were analyzed using SAS 9.2 to yield sample descriptive statistics. The analysis of the qualitative interviews with providers and other stakeholders followed an open-coding process, and convergent and divergent perspectives emerging from those data were examined within and across the HIEs.

Results: We found widespread acceptability for electronic sharing of HIV-related patient data through HIEs. This acceptability appeared to be driven by growing comfort with information technologies, confidence in the security protocols utilized to protect data, trust in the providers and institutions who use the technologies, belief in the benefits to the patients, and awareness that electronic exchange represents an enhancement of data sharing already taking place by other means. HIE acceptability depended both on preexisting trust among patients, providers, and institutions and on building consensus and trust in the HIEs as part of preparation for implementation. The process of HIE development also resulted in forging shared vision among institutions.

Conclusions: Patients and providers are willing to accept the electronic sharing of HIV patient data to improve care for a disease historically seen as highly stigmatized. Acceptability depends on the effort expended to understand and address potential concerns related to data sharing and confidentiality, and on the trust established among stakeholders in terms of the nature of the systems and how they will be used.

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CR Adjerid Idris, 2011, AMIA Annu Symp Proc, V2011, P48
Als AB, 1997, FAM PRACT, V14, P17, DOI 10.1093/fampra/14.1.17
Anderson JG, 2007, INT J MED INFORM, V76, P480, DOI 10.1016/j.ijmedinf.2006.09.016
Barber B, 1986, LOGICS LIMITS TRUST
Barrows RC, 1996, J AM MED INFORM ASSN, V3, P139, DOI 10.1136/jamia.1996.96236282
Baumer D., 2000, Computers & Society, V30, P40
Bodenheimer T, 2003, JAMA-J AM MED ASSOC, V290, P259, DOI 10.1001/jama.290.2.259
Bowes Watson A, 2010, AMIA Annu Symp Proc, V2010, P66
Calnan MW, 2004, QUAL SAF HEALTH CARE, V13, P92, DOI 10.1136/qshc.2003.009001
CARMAN D, 1995, BRIT J GEN PRACT, V45, P485
Chambliss ML, 2001, J FAM PRACTICE, V50, P1063
Chaudhry B, 2006, ANN INTERN MED, V144, P742, DOI 10.7326/0003-4819-144-10-200605160-00125

Choi WH, 2006, ST HEAL T, V122, P288
Cochran David, 2010, Healthc Inform, V27, P58
DesRoches CM, 2008, NEW ENGL J MED, V359, P50, DOI 10.1056/NEJMsa0802005
Ebell MH, 2001, FAM MED, V33, P311
Fernandez Perez ER, 2007, AM J HEMATOL, V82, P631, DOI 10.1002/ajh.20888
Gantz S, 2009, BOOK ESTABLISHING MU
Greenberg MD, 2009, HEALTH AFFAIR, V28, P450, DOI 10.1377/hlthaff.28.2.450
Greene J, 2007, ANN EMERG MED, V50, P549, DOI 10.1016/j.annemergmed.2007.09.013
Halamka J, 2005, HEALTH AFFAIR, V24, P1170, DOI 10.1377/hlthaff.24.5.1170
Hall MA, 2002, MED CARE RES REV, V59, P293, DOI 10.1177/1077558702059003004
Hampton T, 2008, JAMA-J AM MED ASSOC, V299, P507, DOI 10.1001/jama.299.5.507
Hassol A, 2004, J AM MED INFORM ASSN, V11, P505, DOI 10.1197/jamia.M1593
Herek GM, 2002, AM J PUBLIC HEALTH, V92, P371, DOI 10.2105/AJPH.92.3.371
Heuwinkel K., 2003, BOOK INFORM LOGISTIC, P791
Jha AK, 2009, NEW ENGL J MED, V360, P1628, DOI 10.1056/NEJMsa0900592
Kennedy A, 2007, QUAL HEALTH RES, V17, P744, DOI 10.1177/1049732307302754
Lamberg L, 2001, JAMA-J AM MED ASSOC, V285, P3075, DOI 10.1001/jama.285.24.3075
Magnus M, 2009, AIDS PATIENT CARE ST, V23, P85, DOI 10.1089/apc.2008.0053
Marchibroda J, 2005, EMERGING TRENDS ISSU
Marquard Jenna L, 2009, J Healthc Inf Manag, V23, P26
McDonald CJ, 1998, JAMA-J AM MED ASSOC, V280, P1325, DOI 10.1001/jama.280.15.1325
McGraw D, 2009, HEALTH AFFAIR, V28, P416, DOI 10.1377/hlthaff.28.2.416
Mitchell E, 2004, STUD HEALTH TECHNOL, V107, P1157
Mitchell E, 2005, BRIT J GEN PRACT, V55, P94
Mitchell E, 2001, BMJ-BRIT MED J, V322, P279, DOI 10.1136/bmj.322.7281.279
Mitchell Elizabeth, 2003, Inform Prim Care, V11, P61
Nader CM, 2009, AIDS PATIENT CARE ST, V23, P521, DOI 10.1089/apc.2008.0209
Nelson SB, 2006, RESP CARE, V51, P183
O'Cathain A, 2007, BMC HEALTH SERV RES, V7, DOI 10.1186/1472-6963-7-85
Parry MF, 2004, AIDS CARE, V16, P690, DOI 10.1080/09540120412331269549
Phansalkar S, 2008, INT J MED INFORM, V77, P184, DOI 10.1016/j.ijmedinf.2007.02.002
Richter JG, 2010, CLIN EXP RHEUMATOL, V28, P261
RIDSDALE L, 1994, BRIT J GEN PRACT, V44, P367
Rudin RS, 2009, AM J PUBLIC HEALTH, V99, P950, DOI 10.2105/AJPH.2008.144873
Simon SR, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1164
Stone MA, 2005, BRIT J GEN PRACT, V55, P783
Strauss A, 1998, BASICS QUALITATIVE R
Teixeira Paul A, 2011, Patient Educ Couns, V84, pe9, DOI 10.1016/j.pec.2010.07.013
Terry NP, 2007, U ILLINOIS LAW REV, P681
Thom DH, 2002, FAM PRACT, V19, P476, DOI 10.1093/fampra/19.5.476
Tripathi M, 2009, HEALTH AFFAIR, V28, P435, DOI 10.1377/hlthaff.28.2.435
Tung FC, 2008, INT J MED INFORM, V77, P324, DOI 10.1016/j.ijmedinf.2007.06.006
Turkington RC, 1997, J LAW MED ETHICS, V25, P113, DOI 10.1111/j.1748-720X.1997.tb01887.x
Vest JR, 2010, J AM MED INFORM ASSN, V17, P288, DOI 10.1136/jamia.2010.003673
Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI 10.1016/j.ijmedinf.2005.08.009
Wright EB, 2004, BMJ-BRIT MED J, V328, P864, DOI 10.1136/bmj.38046.771308.7C
Yarbrough AK, 2007, MED CARE RES REV, V64, P650, DOI 10.1177/1077558707305942
NR 59
TC 16
Z9 16

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U1 1
U2 31
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
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J9 IMPLEMENT SCI
JI Implement. Sci.
PD APR 19
PY 2012
VL 7
AR 34
DI 10.1186/1748-5908-7-34
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WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
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ER

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AU Langat, P
   Pisartchik, D
   Silva, D
   Bernard, C
   Olsen, K
   Smith, M
   Sahni, S
   Upshur, R
AF Langat, Pinky
   Pisartchik, Dmitri
   Silva, Diego
   Bernard, Carrie
   Olsen, Kolby
   Smith, Maxwell
   Sahni, Sachin
   Upshur, Ross
TI Is There a Duty to Share? Ethics of Sharing Research Data in the Context
   of Public Health Emergencies
SO PUBLIC HEALTH ETHICS
LA English
DT Article
AB Making research data readily accessible during a public health emergency can
have profound effects on our response capabilities. The moral milieu of this
data sharing has not yet been adequately explored. This article explores the
foundation and nature of a duty, if any, that researchers have to share data,
specifically in the context of public health emergencies. There are three
notable reasons that stand in opposition to a duty to share one's data, relating
to: (i) data property and ownership, (ii) just distribution of benefits and
burdens and (iii) the contemporary ethos of science. We argue each reason can be
successfully met with corresponding rationale in favour of data sharing. Further
support for data sharing has been echoed in policies of health agencies, funding
bodies and academic institutions; in documents on the ethical conduct of
biomedical research; and in discussions on the nature of public health. From
this, we ascertain that sharing data is the morally sound default position. This
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article then highlights the key roles reciprocity and solidarity play in supporting the practice of data sharing. We conclude with recommendations to regard public health research data as a common-pool resource in order to build a framework for stable data sharing management.
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FX The authors thank the members of the CanPREP team who provided support during discussions of the ideas in this article. Dr Upshur is supported by the Canada Research Chair in Primary Care Research.; This work was supported by the Canadian Institutes of Health Research through a TEAM grant provided by the Pandemic Preparedness Strategic Research Initiative.
CR [Anonymous], 2010, LANCET, V375, P1940
[Anonymous], 2009, NATURE, V461, P168
Baust JG, 2008, CELL PRESERV TECHNOL, V6, P1, DOI 10.1089/cpt.2008.9996
Bernard C., 2009, WHITE PAPER SAMPLE D
Biological Innovation for Open Society, 2009, BIOS IN
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI 10.1001/jama.287.4.473
Canadian Program of Research on Ethics in a Pandemic, 2009, CAN PROGR RES ETH PA
Chan M, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000223
Council for International Organizations of Medical Sciences World Health Organization, 2002, INT ETH GUID BIOM RE
Emanuel EJ, 2000, JAMA-J AM MED ASSOC, V283, P2701, DOI 10.1001/jama.283.20.2701
Fienberg S. E., 1985, SHARING RES DATA
Grinnell Frederick, 1992, SCI ATTITUDE
Guston D., 2000, POLITICS SCI
Jasanoff S., 1990, 5 BRANCH SCI ADVISOR
Jasanoff Sheila, 1995, SCI BAR LAW SCI TECH
Katz J., 1996, JAMA-J AM MED ASSOC, V276, P1691
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Levine R., 1988, ETHICS REGULATION CL
Longino H, 1990, SCI SOCIAL KNOWLEDGE
National Commission for the Protection of Human Subjects of Biomedical and Behaviorial Research, 1979, BELM REP
*NIH, 1998, REP NAT I HLTH NIH W
*NIH, 2007, GUID COND RES INTR R
Office of Extramural Research, 2003, NIH DAT SHAR POL IMP
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Public Health Agency of Canada, 2003, LEARN SARS PUBL HLTH
Theologis A, 2004, PLANT PHYSIOL, V135, P4, DOI 10.1104/pp.104.043083
Thompson A. K., 2006, BMC MED ETHICS, V7, pE12, DOI DOI 10.1186/1472-6939-7-12
Vanderpool H.Y., 1996, ETHICS RES INVOLVING
*WHO, 1997, JAMA-J AM MED ASSOC, V277, P925
WHO, 2008, INT HLTH REG 2005
World Health Organization, 2007, AV PAND INFL BEST PR

```
NR 31
TC 16
Z9 16
U1 1
U2 14
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1754-9973
J9 PUBLIC HEALTH ETH-UK
JI Public Health Ethics
PD APR
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VL 4
IS 1
BP 4
EP 11
DI 10.1093/phe/phr005
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WC Ethics; Public, Environmental & Occupational Health; Medical Ethics
SC Social Sciences - Other Topics; Public, Environmental & Occupational
   Health; Medical Ethics
GA 891LP
UT WOS:000300218800002
DA 2019-08-06
ER

PT J
AU Knaup, P
   Garde, S
   Merzweiler, A
   Graf, N
   Schilling, F
   Weber, R
   Haux, R
AF Knaup, P
   Garde, S
   Merzweiler, A
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   Weber, R
   Haux, R
TI Towards shared patient records: An architecture for using routine data
   for nationwide research
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article; Proceedings Paper
CT Symposium on Electronic Health Record Healthcare Registers and
   Telemedicine
CY APR 12-15, 2004
CL Prague, CZECH REPUBLIC
SP European Federat Med Informat
DE electronic patient record; architecture; multiple use of data; shared
   data entry; medical informatics
ID INFORMATION-SYSTEMS; HEALTH-CARE; MODEL; TERMINOLOGY; INTEGRATION;
   COMPONENTS
AB Ubiquitous information is currently one of the most challenging slogans in
medical informatics research. An adequate architecture for shared electronic
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patient records is needed which can use data for multiple purposes and which is extensible for new research questions.

We introduce eardap as architecture for using routine data for nationwide clinical research in a multihospital environment. eardap can be characterized as terminology-based. Main advantage of our approach is the extensibility by new items and new research questions. Once the definition of items for a research question is finished, a consistent, corresponding database can be created without any informatics skills.

Our experiences in pediatric oncology in Germany have shown the applicability of eardap. The functions of our core system were in routine clinical use in several hospitals. We validated the terminology management system (TMS) and the module generation tool. with the basic data set of pediatric oncology. The multiple usability depends mainly on the quality of item planning in the TMS. High quality harmonization will lead to a higher amount of multiply used data.

When using eardap, special emphasis is to be placed on interfaces to local hospital information systems and data security issues. (c) 2005 Elsevier Ireland Ltd. All rights reserved.

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CR BESS A, 2003, NEW NAVIGATORS PROFE
Blobel B, 2001, INT J MED INFORM, V62, P51, DOI 10.1016/S1386-5056(01)00147-2
Blobel B, 2004, INT J MED INFORM, V73, P251, DOI 10.1016/j.ijmedinf.2003.11.018
BRANDNER R, 2002, LONG TERM CONSERVATI
Brown PJB, 2000, DIABETES NUTR METAB, V13, P215
BURKLE T, 1998, P IMIA WORK GROUP 17, P326
Celler BG, 2003, MED J AUSTRALIA, V179, P242
CIMINO JJ, 2001, METH INFORM MED
Clayton PD, 2003, METHOD INFORM MED, V42, P1
De Clercq E, 2002, METHOD INFORM MED, V41, P313
Garde S, 2003, INT J MED INFORM, V70, P183, DOI 10.1016/S1386-5056(03)00043-1
Garde S, 2004, METHOD INFORM MED, V43, P171
Guler I, 2001, COMPUT BIOL MED, V31, P513, DOI 10.1016/S0010-4825(01)00018-X
Harris MF, 2002, MED J AUSTRALIA, V177, P250
HENZE G, 2001, ONKOLOGIE, V24, P169
KAATSCH P, 1999, JAHRESBERICHT ANN RE
Knaup P, 2002, ARTIF INTELL MED, V24, P229, DOI 10.1016/S0933-3657(01)00106-3
KNAUP P, 1999, MED INFORM BIOSTATIS, P303
KNAUP P, 2000, P MED INF EUR MIE200, P890
Leiner F, 1996, METHOD INFORM MED, V35, P25
MERZWEILER A, 2001, P 10 WORLD C MED INF, P653
MERZWEILER A, 2000, P MED INF EUR MIE200, P696
Mori AR, 1998, METHOD INFORM MED, V37, P551
Muller ML, 2001, INT J MED INFORM, V64, P369, DOI 10.1016/S1386-5056(01)00218-0
Ramsaroop P, 2000, MD COMPUTING   JUL, V2000, P45
RECTOR AL, 1995, METHOD INFORM MED, V34, P147

Rector AL, 1999, ARTIF INTELL MED, V15, P1
SAUTER S, 1994, KLIN PADIATR, V206, P306, DOI 10.1055/s-2008-1046620
Tange HJ, 2003, METHOD INFORM MED, V42, P203
Thomson R, 1995, ST HEAL T, V24, P208
van der Haak M, 2002, METHOD INFORM MED, V41, P419
WEBER R, 2001, MEDINFO 1, V10, P58
Xu Y, 2003, ARTIF INTELL MED, V27, P283, DOI 10.1016/S0933-3657(03)00007-1
NR 33
TC 16
Z9 16
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PU ELSEVIER IRELAND LTD
PI CLARE
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PD MAR-APR
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IS 3-4
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WC Computer Science, Information Systems; Health Care Sciences & Services; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA 026RT
UT WOS:000236360500003
PM 16115794
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PT J
AU Dove, ES
AF Dove, Edward S.
TI Biobanks, Data Sharing, and the Drive for a Global Privacy Governance Framework
SO JOURNAL OF LAW MEDICINE & ETHICS
LA English
DT Article
ID DATA PROTECTION REGULATION; HUMAN-GENOME-PROJECT; GENETIC DISCRIMINATION; BROAD CONSENT; LEGAL; HARMONIZATION; INFORMATION; HEALTH; PARTICIPATION; POPULATIONS
AB Biobanks are a key emerging biomedical research infrastructure. They manifest the turn towards greater global sharing of genomic and health-related data, which is considered by many to be an ethical and scientific imperative. Our collective interests lie in improving the health and welfare of individuals, communities, and populations; improving health and welfare requires access to, and use of, widely dispersed quality data. But sharing these individual and familial data requires in turn that due thought be given to the ethical and legal interests at stake. Most critically, data sharing must occur in an environment whereby privacy interests are safeguarded throughout the lifecycle of biobank initiatives, and regardless of the locations where the data are

stored, to which they are sent, and where they are ultimately processed. In this article, I outline the complex dimensions of data privacy regulation that challenge data sharing within the biobanking context. I discuss how harmonization may be a remedy for the gaps and marked differences of approach in data privacy regulation. Finally, I encourage the development of foun- dational responsible data sharing principles set within an overarching governance framework that provides assurance that reasonable expectations of privacy will be met.

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CR Ahram M, 2014, EUR J HUM GENET, V22, P445, DOI 10.1038/ejhg.2013.174
Allen Anita L., 1997, GENETIC SECRETS PROT, P31
[Anonymous], 2007, GEN DAT SAMPL COD CA
[Anonymous], 2008, GUID IND E15 DEF GEN
[Anonymous], 2014, TRI COUNC POL STAT E
[Anonymous], 2009, INT C DAT PROT PRIV
Austin L, 2009, NEW CHALLENGES BIOBA, p[111, 118]
Bailey JNC, 2014, GENES-BASEL, V5, P518, DOI 10.3390/genes5030518
Blume P., 2014, INT DATA PRIVACY LAW, V4, P269
Budin-Ljosne I., 2012, Norsk Epidemiologi, V21, P155
Budin-Ljosne I, 2014, EUR J HUM GENET, V22, P317, DOI 10.1038/ejhg.2013.131
Burton PR, 2009, HUMAN GENOME EPIDEMI, P77
Bygrave L., 1998, INT J LAW INFORM TEC, V6, P247, DOI [10.1093/ijlit/6.3.247, DOI 10.1093/IJLIT/6.3.247]
Casali PG, 2014, ANN ONCOL, V25, P1458, DOI 10.1093/annonc/mdu218
Chadwick R, 2011, CAMB Q HEALTHC ETHIC, V20, P546, DOI 10.1017/S0963180111000284
Chalmers D, 2011, METHODS MOL BIOL, V675, P1, DOI 10.1007/978-1-59745-423-0_1
Chalmers DRC, 2014, APPL TRANSL GENOM, V3, P116, DOI 10.1016/j.atg.2014.09.011
Colledge F, 2013, BIOPRESERV BIOBANK, V11, P339, DOI 10.1089/bio.2013.0039
Collins FS, 2011, SCI TRANSL MED, V3, DOI 10.1126/scitranslmed.3002747
Costa L, 2012, COMPUT LAW SECUR REV, V28, P254, DOI 10.1016/j.clsr.2012.03.015
Council of Canadian Academies, 2015, ACC HLTH HLTH REL DA
De Hert P, 2012, COMPUT LAW SECUR REV, V28, P130, DOI 10.1016/j.clsr.2012.01.011
de Terwangne C, 2009, REINVENTING DATA PROTECTION, P175, DOI 10.1007/978-1-4020-9498-9_10
Di Iorio CT, 2014, J MED ETHICS, V40, P488, DOI 10.1136/medethics-2013-101603
Doiron D, 2013, EMERG THEMES EPIDEMI, V10, DOI 10.1186/1742-7622-10-12
Dove E. S., GENOMIC PERSONALIZED, VII
Dove E. S., 2013, HLTH LAW J, V20, P1, DOI DOI 10.1163/15718093-12341249
Dove E. S., MED DATA PR IN PRESS
Dove ES, 2015, EUR J HUM GENET, V23, P1271, DOI 10.1038/ejhg.2014.196
Dove ES, 2014, J LAW BIOSCI, V1, P3, DOI 10.1093/jlb/lst002

Dove ES, 2014, LANCET, V384, P855, DOI 10.1016/S0140-6736(14)61488-4
Dove Edward S., 2011, Current Pharmacogenomics & Personalized Medicine, V9, P252
Elger BS, 2006, EMBO REP, V7, P661, DOI 10.1038/sj.embor.7400740
Erlich Y, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001983
Erlich Y, 2014, NAT REV GENET, V15, P409, DOI 10.1038/nrg3723
Fears R, 2014, QJM-INT J MED, V107, P3, DOI 10.1093/qjmed/hct236
Forsberg JS, 2014, NAT REV GENET, V15, P6, DOI 10.1038/nrg3646
Fortier I, 2011, INT J EPIDEMIOL, V40, P1314, DOI 10.1093/ije/dyr106
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
Franc MA, 2011, CLIN PHARMACOL THER, V89, P537, DOI 10.1038/clpt.2010.306
Fransson MN, 2015, EUR J HUM GENET, V23, P22, DOI 10.1038/ejhg.2014.45
Gan R., 2015, BIOPRESERV BIOBANK, V13, P4
Gassner UM, 2007, PATHOBIOLOGY, V74, P270, DOI 10.1159/000104456
Gibbons SMC, 2007, J LAW SOC, V34, P163, DOI 10.1111/j.1467-6478.2007.00387.x
Gisler M, 2011, RES POLICY, V40, P1412, DOI 10.1016/j.respol.2011.05.019
Global Alliance for Genomics and Health, 2015, PRIV SEC POL
Government Accountability Office, 1999, MED REC PRIV ACC NEE
Government Accountability Office, 1999, MED REC PRIV US OV P
Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162
Greenbaum D, 2011, PLOS COMPUT BIOL, V7, DOI 10.1371/journal.pcbi.1002278
Greenleaf G, 2012, INT DATA PRIV LAW, V2, P68, DOI 10.1093/idpl/ips006
Gunasekara G, 2014, INT J LAW INFORM TEC, V22, P141, DOI 10.1093/ijlit/eat013
Hansson MG, 2011, BIOPRESERV BIOBANK, V9, P165, DOI 10.1089/bio.2010.0037
Harris JR, 2012, EUR J HUM GENET, V20, P1105, DOI 10.1038/ejhg.2012.96
Heeney C, 2011, PUBLIC HEALTH GENOM, V14, P17, DOI 10.1159/000294150
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Horn EJ, 2014, EXPERT OPIN ORPHAN D, V2, P1, DOI 10.1517/21678707.2014.859072
Hu XD, 2015, SCI BULL, V60, P65, DOI 10.1007/s11434-014-0692-9
Huang KG, 2010, RES POLICY, V39, P567, DOI 10.1016/j.respol.2010.02.004
Hudson TJ, 2013, J INTERN MED, V274, P440, DOI 10.1111/joim.12097
Hudson TJ, 2010, NATURE, V464, P993, DOI 10.1038/nature08987
Human Genome Organization (HUGO), 1996, SUMM PRINC AGR 1 INT
Hyman SE, 2011, SCIENCE, V331, P1026, DOI 10.1126/science.1203544
Igbe MA, 2012, BMC MED ETHICS, V13, DOI 10.1186/1472-6939-13-27
Im HK, 2012, AM J HUM GENET, V90, P591, DOI 10.1016/j.ajhg.2012.02.008
Joly Y, 2013, BMC MED, V11, DOI 10.1186/1741-7015-11-25
Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Kaye J, 2006, EUR J HUM GENET, V14, P245, DOI 10.1038/sj.ejhg.5201530
Kaye J, 2015, INT LIBR ETH LAW TEC, V14, P101, DOI 10.1007/978-94-017-9573-9_8
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kaye J, 2014, MED LAW REV, V22, P64, DOI 10.1093/medlaw/fwt027
Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
Kaye J, 2011, HUM GENET, V130, P377, DOI 10.1007/s00439-011-1063-0
Kiehntopf M, 2011, HUM GENET, V130, P369, DOI 10.1007/s00439-011-1068-8
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Knoppers BM, 2012, ANNU REV GENOM HUM G, V13, P395, DOI 10.1146/annurev-genom-090711-163834
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Knoppers BM, 2011, J MED ETHICS, V37, P515, DOI 10.1136/jme.2011.043042
Knoppers BM, 2005, NAT BIOTECHNOL, V23, P925, DOI 10.1038/nbt0805-925
Knoppers BM, 2005, NAT REV GENET, V6, P75, DOI 10.1038/nrg1505
Knoppers BM, 2007, KINGS LAW J, V18, P291
Kohane IS, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3007340
Kosseim P, 2014, GENOME BIOL, V15, DOI 10.1186/s13059-014-0430-2
Lander ES, 2011, NATURE, V470, P187, DOI 10.1038/nature09792

Laurie G, 2010, MED LAW INT, P315, DOI DOI 10.1177/096853321001000404
Laurie G., 2014, REV EVIDENCE RELATIN
Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
Lowrance W. W., 2002, LEARNING EXPERIENCE, P34
Lowrance WW, 2007, SCIENCE, V317, P600, DOI 10.1126/science.1147699
Malin B, 2004, J BIOMED INFORM, V37, P179, DOI 10.1016/j.jbi.2004.04.005
McEwen JE, 2013, TRENDS GENET, V29, P375, DOI 10.1016/j.tig.2013.02.001
McGregor JL, 2007, J LAW MED ETHICS, V35, P356, DOI 10.1111/j.1748-720X.2007.00160.x
Melham K., 2014, LIFE SCI SOC POLICY, V10, P1
Moraia L., 2015, MED LAW INT, P1, DOI [10.1177/0968533215571956, DOI 10.1177/0968533215571956]
Moreham N., 2008, EUROPEAN HUMAN RIGHT, P44
Nik-Zainal S, 2012, CELL, V149, P979, DOI 10.1016/j.cell.2012.04.024
Nuffield Council on Bioethics, 2015, COLL LINK US DAT BIO
Nyholt DR, 2009, EUR J HUM GENET, V17, P147, DOI 10.1038/ejhg.2008.198
OECD, 1980, OECD GUID PROT PRIV
Ohno-Machado L, 2012, SCI TRANSL MED, V4, DOI 10.1126/scitranslmed.3004454
Olson JE, 2014, CLIN GENET, V86, P50, DOI 10.1111/cge.12370
Otlowski M, 2012, ANNU REV GENOM HUM G, V13, P433, DOI 10.1146/annurev-genom-090711-163800
Ploem MC, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f3534
Quinn G., 2015, GENETIC DISCRIMINATI
Rahm AK, 2013, J COMMUN GENET, V4, P445, DOI 10.1007/s12687-013-0146-0
Rezeli M, 2014, TRANSL BIOINFORM, V6, P137, DOI 10.1007/978-94-017-9202-8_7
Rial-Sebbag E, 2012, J LAW SOC, V39, P113, DOI 10.1111/j.1467-6478.2012.00573.x
Rothstein MA, 2009, GENET SOC, P127
Rothstein MA, 2010, AM J BIOETHICS, V10, P3, DOI 10.1080/15265161.2010.494215
Sandor J, 2011, INT LIBR ETH LAW TEC, V8, P213, DOI 10.1007/978-94-007-1673-5_14
Schadt EE, 2012, NAT GENET, V44, P603, DOI 10.1038/ng.2248
Schulte T., 2010, GENOMICS SOC POLICY, V6, P33
Sethi N, 2014, EUR J HEALTH LAW, V21, P271, DOI 10.1163/15718093-12341323
Shaw DM, 2014, CLIN GENET, V85, P223, DOI 10.1111/cge.12268
Starkbaum J, 2014, BIOPRESERV BIOBANK, V12, P121, DOI 10.1089/bio.2013.0071
Steinsbekk KS, 2013, EUR J HUM GENET, V21, P897, DOI 10.1038/ejhg.2012.282
Stranger M, 2009, PRINCIPLES PRACTICE, P1
Stratton MR, 2009, NATURE, V458, P719, DOI 10.1038/nature07943
Tasse AM, 2012, STUDIES ETHICS LAW T, DOI [10.1515/1941-6008.1180, DOI 10.1515/1941-6008.1180]
Terry SF, 2007, NAT REV GENET, V8, P157, DOI 10.1038/nrg1991
Thompson R, 2014, J GEN INTERN MED, V29, pS780, DOI 10.1007/s11606-014-2908-8
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
Tracy RP, 2008, CURR OPIN LIPIDOL, V19, P151, DOI 10.1097/MOL.0b013e3282f73893
Ursin L.O., 2012, Norsk Epidemiologi, V21, P269
Vaught J, 2014, BIOPRESERV BIOBANK, V12, P1, DOI 10.1089/bio.2014.1211
Vaught JB, 2010, CANCER EPIDEM BIOMAR, V19, P912, DOI 10.1158/1055-9965.EPI-10-0058
Verlinden M, 2014, BIOPRESERV BIOBANK, V12, P415, DOI 10.1089/bio.2014.0034
Wang Y., 2014, HUMAN POPULATION GEN, P121
Warren S.D., 1890, HARVARD LAW REV, V4, P193, DOI DOI 10.2307/1321160
Weber RH, 2013, INT DATA PRIV LAW, V3, P117, DOI 10.1093/idpl/ipt001
Weinstein JN, 2013, NAT GENET, V45, P1113, DOI 10.1038/ng.2764
Wellcome Trust, 2011, SHAR RES DAT IMPR PU
Wellcome Trust, 2003, SHAR DAT LARG SCAL B

```
   White House, 2015, FACT SHEET PRES OB P
   Whitman JQ, 2004, YALE LAW J, V113, P1151, DOI 10.2307/4135723
   Wjst M, 2010, BMC MED ETHICS, V11, DOI 10.1186/1472-6939-11-21
   Yeo M., 2007, AN PAP COMM OFF PRIV, P33
   Zika E, 2011, PUBLIC HEALTH GENOM, V14, P96, DOI 10.1159/000296278
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U2 27
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TI Biomedical Data Sharing and Reuse: Attitudes and Practices of Clinical
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AB Background
   Significant efforts are underway within the biomedical research community to
encourage sharing and reuse of research data in order to enhance research
reproducibility and enable scientific discovery. While some technological
challenges do exist, many of the barriers to sharing and reuse are social in
nature, arising from researchers' concerns about and attitudes toward sharing
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their data. In addition, clinical and basic science researchers face their own unique sets of challenges to sharing data within their communities. This study investigates these differences in experiences with and perceptions about sharing data, as well as barriers to sharing among clinical and basic science researchers.

Methods

Clinical and basic science researchers in the Intramural Research Program at the National Institutes of Health were surveyed about their attitudes toward and experiences with sharing and reusing research data. Of 190 respondents to the survey, the 135 respondents who identified themselves as clinical or basic science researchers were included in this analysis. Odds ratio and Fisher's exact tests were the primary methods to examine potential relationships between variables. Worst-case scenario sensitivity tests were conducted when necessary.

Results and Discussion

While most respondents considered data sharing and reuse important to their work, they generally rated their expertise as low. Sharing data directly with other researchers was common, but most respondents did not have experience with uploading data to a repository. A number of significant differences exist between the attitudes and practices of clinical and basic science researchers, including their motivations for sharing, their reasons for not sharing, and the amount of work required to prepare their data.

Conclusions

Even within the scope of biomedical research, addressing the unique concerns of diverse research communities is important to encouraging researchers to share and reuse data. Efforts at promoting data sharing and reuse should be aimed at solving not only technological problems, but also addressing researchers' concerns about sharing their data. Given the varied practices of individual researchers and research communities, standardizing data practices like data citation and repository upload could make sharing and reuse easier.

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CR Altman D, 1991, PRACTICAL STAT MED R
Anderson BJ, 2009, PEDIATR ANESTH, V19, P1005, DOI 10.1111/j.1460-9592.2009.03051.x
[Anonymous], 2007, NAT BIOTECHNOL, V25, P262
Antman E, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g237
Ardini MA, 2014, CLIN BIOCHEM, V47, P252, DOI 10.1016/j.clinbiochem.2013.11.014
Baker M, 2012, NAT METHODS, V9, P39, DOI 10.1038/nmeth.1815
Barsnes H, 2009, NAT BIOTECHNOL, V27, P598, DOI 10.1038/nbt0709-598
Benitez K, 2010, J AM MED INFORM ASSN, V17, P169, DOI 10.1136/jamia.2009.000026
Berlin JA, 2014, CLIN TRIALS, V11, P7, DOI 10.1177/1740774513514497
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Brakewood B, 2013, NEUROIMAGE, V82, P671, DOI 10.1016/j.neuroimage.2013.02.040
Breeze JL, 2012, GIGASCIENCE, V1, DOI 10.1186/2047-217X-1-9
Butte AJ, 2012, CLIN PHARMACOL THER, V91, P949, DOI 10.1038/clpt.2012.55
Callier S, 2014, FRONT GENET, V5, DOI 10.3389/fgene.2014.00034
Choi In Young, 2013, Genomics & Informatics, V11, P186, DOI 10.5808/GI.2013.11.4.186
Chokshi DA, 2006, B WORLD HEALTH ORGAN, V84, P382, DOI 10.2471/BLT.06.029843
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201

Collins FS, 2014, NATURE, V505, P612, DOI 10.1038/505612a
Curtis LH, 2014, HEALTH AFFAIR, V33, P1178, DOI 10.1377/hlthaff.2014.0121
Dobkin BH, 2013, CURR OPIN NEUROL, V26, P602, DOI 10.1097/WCO.0000000000000026
Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
European Commission, 2011, COMM OP DAT ENG INN
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Hayden EC, 2013, NATURE, V498, P16, DOI 10.1038/498017a
International committee of Medical Journal Editors, DEF ROL AUTH CONTR
Jisc, VAL IMP DAT SHAR CUR
Jones RB, 2012, CURR ONCOL REP, V14, P486, DOI 10.1007/s11912-012-0271-7
Juengst Eric T, 2014, N C Med J, V75, P214
Krischer JP, 2014, J GEN INTERN MED, V29, pS739, DOI 10.1007/s11606-014-2894-x
Lee ES, 2009, INT J MED INFORM, V78, P10, DOI 10.1016/j.ijmedinf.2008.06.011
MedCalc, MEDCALC ONL CLIN CAL
Milia N, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0037552
NIH Intramural Research Program, ORG LEAD 2014
Office of Science and Technology Policy, INCR ACC RES FED FUN
Peat G, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001671
Perrino T, 2013, PERSPECT PSYCHOL SCI, V8, P433, DOI 10.1177/1745691613491579
R Core Team, 2014, R LANG ENV STAT COMP, DOI [10.1016/j.jneumeth.2014.06.019, DOI 10.1016/J.JNEUMETH.2014.06.019]
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI 10.1161/CIRCOUTCOMES.112.965798
RStudio, 2012, RSTUDIO INT DEV ENV
So D, 2013, PUBLIC HEALTH GENOM, V16, P322, DOI 10.1159/000355941
Trans NIH BioMedical Informatics Coordinating Committe (BMIC), NIH DAT SHAR REP
Wickham H, 2009, USE R, P1, DOI 10.1007/978-0-387-98141-3_1
NR 44
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U2 36
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TI Healthcare professionals' acceptance of BelRAI, a web-based system
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AB Background: Healthcare and social care environments are increasingly confronted with older persons with long-term care needs. Consequently, the need for integrated and coordinated assessment systems increases. In Belgium, feasibility studies have been conducted on the implementation and use of interRAI instruments offering opportunities to improve continuity and quality of care. However, the development and implementation of information technology to support a shared dataset is a difficult and gradual process. We explore the applicability of the UTAUT theoretical model in the BelRAI healthcare project to analyse the acceptance of the BelRAI web application by healthcare professionals in home care, nursing home care and acute hospital care for older people with disabilities.

Methods: A structured questionnaire containing items based on constructs validated in the original UTAUT study was distributed to 661 Flemish caregivers. We performed a complete case analysis using data from 282 questionnaires to obtain information regarding the effects of performance expectancy (PE), effort expectancy (EE), social influence (SI), facilitating conditions (FC), anxiety (ANX), self-efficacy (SE) and attitude towards using technology (ATUT) on behavioural intention (BI) to use the BelRAI web application.

Results: The values of the internal consistency evaluation of each construct demonstrated adequate reliability of the survey instrument. Convergent and discriminant validity were established. However, the items of the ATUT construct cross-loaded on PE. FC proved to have the most significant influence on BI to use BelRAI, followed by SE. Other constructs (PE, EE, SI, ANX, ATUT) had no significant influence on BI. The 'direct effects only' model explained 30.8% of the variance in BI to use BelRAI.

Conclusions: Critical factors in stimulating the behavioural intention to use new technology are good-quality software, interoperability and compatibility with other information systems, easy access to computers, training facilities, built-in and online help and ongoing IT support. These findings can be used by policy makers to maximise the acceptance and the success of new technology. For researchers, the conclusions of the original UTAUT study with regards to the item and scale construction should not be copied blindly across different information systems. A bottom-up approach is preferred when building upon the UTAUT model.

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CR Achterberg WP, 1999, SCAND J REHABIL MED, V31, P131
Achterberg WP, 2001, J ADV NURS, V35, P268, DOI 10.1046/j.1365-2648.2001.01843.x
Al-Azmi SF, 2009, HEALTH INF MANAG J, V38, P33, DOI 10.1177/183335830903800205
[Anonymous], 2012, EXP GROUP M LONG TER, V30
Bandura A., 1986, SOCIAL FDN THOUGHT A
Bayegan E, 2002, THESIS NORWEGIAN U S
Bergman H, 2004, GERONTOLOGIE SOC, V109, P15, DOI DOI 10.3917/GS.109.0015
Bergman H, 2007, J GERONTOL A-BIOL, V62, P731, DOI 10.1093/gerona/62.7.731
Bernabei R, 2008, J GERONTOL A-BIOL, V63, P308, DOI 10.1093/gerona/63.3.308
Boorsma M, 2013, BMC HEALTH SERV RES, V13, DOI 10.1186/1472-6963-13-8
Boorsma M, 2011, CAN MED ASSOC J, V183, pE724, DOI 10.1503/cmaj.101498
Brown SA, 2010, J MANAGE INFORM SYST, V27, P9, DOI 10.2753/MIS0742-1222270201
Carpenter GI, 2006, AGE AGEING, V35, P327, DOI 10.1093/ageing/afl038
Chau PYK, 2002, INFORM MANAGE-AMSTER, V39, P297, DOI 10.1016/S0378-7206(01)00098-2
Chin W. W., 1998, QUANT METH SER, P295, DOI DOI 10.1016/J.AAP.2008.12.010
Chin W.W., 2001, PLS GRAPH USERS GUID
Chin WW, 2000, FREQUENTLY ASKED QUE
Chin WW, P INT C INF SYST 16
Coleman EA, 2003, J AM GERIATR SOC, V51, P556, DOI 10.1046/j.1532-5415.2003.51186.x
Coleman EA, 2004, ANN INTERN MED, V141, P533, DOI 10.7326/0003-4819-141-7-200410050-00009
Currie W., 2009, INTEGRATING HEALTHCA
DAVIS FD, 1989, MIS QUART, V13, P319, DOI 10.2307/249008
DAVIS FD, 1992, J APPL SOC PSYCHOL, V22, P1111, DOI 10.1111/j.1559-1816.1992.tb00945.x
de Veer AJE, 2011, BMC MED INFORM DECIS, V11, DOI 10.1186/1472-6947-11-67
Declercq A, 2008, ACTIEPROJECT BELRAI
Declercq A, 2011, BELRAI 6 WETENSCHAPP
Declercq A, 2010, BELRAI IV ACTIE ONDE
Declercq A, 2009, ACTIEPROJECT BELRAI
Declercq A, 2007, ACTIE ONDERZOEKNAAR
Declercq A, 2010, BEIRAI 2010 TUSSEN T
DILLMAN DA, 1991, ANNU REV SOCIOL, V17, P225, DOI 10.1146/annurev.so.17.080191.001301
Dosa D, 2006, J AM GERIATR SOC, V54, P659, DOI 10.1111/j.1532-5415.2006.00654.x
Duyck P, 2008, METHOD INFORM MED, V47, P149, DOI 10.3414/ME0477
Fishbein M., 1975, BELIEF ATTITUDE INTE
FORNELL C, 1981, J MARKETING RES, V18, P39, DOI 10.2307/3151312
Fries BE, 1997, J AM GERIATR SOC, V45, P994, DOI 10.1111/j.1532-5415.1997.tb02972.x
Fries BE, 2007, J AM GERIATR SOC, V55, P1139, DOI 10.1111/j.1532-5415.2007.01207.x
Gaskin S, 2012, BMC GERIATR, V12, DOI 10.1186/1471-2318-12-40
Gefen D., 2000, COMMUN AIS, V4, P1, DOI DOI 10.1.1.25.781
Gefen D, 2005, COMMUN ASSOC INF SYS, V16, P91, DOI 10.17705/1CAIS.01605
Genuardi P, 2004, THESIS GEORGETOWN U
Gray L, 2006, TRAINING MANUAL RESO
Gray LC, 2009, BMC HEALTH SERV RES, V9, DOI 10.1186/1472-6963-9-71

Griffin MA, 2007, J ORGAN BEHAV, V28, P859, DOI 10.1002/job.489
GUILLEMIN F, 1993, J CLIN EPIDEMIOL, V46, P1417, DOI 10.1016/0895-4356(93)90142-N
Haenlein M., 2004, Understanding Statistics, V3, P283, DOI 10.1207/s15328031us0304_4
Haux R, 2002, INT J MED INFORM, V66, P3, DOI 10.1016/S1386-5056(02)00030-8
Hirdes J P, 1999, Healthc Manage Forum, V12, P30
Hirdes JP, 2008, BMC HEALTH SERV RES, V8, DOI 10.1186/1472-6963-8-277
Holtkamp CCM, 2003, THESIS VRIJE U AMSTE
Ikegami N., 1997, CANADIAN J QUALITY H, V14, P23
Johns G, 2006, ACAD MANAGE REV, V31, P386, DOI 10.5465/AMR.2006.20208687
Kane RL, 2000, ANNU REV PUBL HEALTH, V21, P659, DOI 10.1146/annurev.publhealth.21.1.659
Kowitlawakul Y, 2011, CIN-COMPUT INFORM NU, V29, P411, DOI 10.1097/NCN.0b013e3181f9dd4a
Kuechler WL, 2009, DECIS SCI-J INNOV ED, V7, P463, DOI 10.1111/j.1540-4609.2009.00231.x
LaMantia MA, 2010, J AM GERIATR SOC, V58, P777, DOI 10.1111/j.1532-5415.2010.02776.x
Landi F, 2000, MED CARE, V38, P1184, DOI 10.1097/00005650-200012000-00005
Leichsenring K., 2012, INT J INTEGR CARE, V12, P10
Mello JD, 2012, BMC PUBLIC HEALTH, V12, DOI 10.1186/1471-2458-12-615
Mor V, 1997, J AM GERIATR SOC, V45, P1002, DOI 10.1111/j.1532-5415.1997.tb02973.x
Morris JN, 2006, INTERRAI HOME CARE V
Nunnally J. C., 1994, PSYCHOMETRIC THEORY
Nunnally JC, 1978, PSYCHOMETRIC THEORY
Onder G, 2012, BMC HEALTH SERV RES, V12, DOI 10.1186/1472-6963-12-5
Oshlyansky L., 2007, P HCI 2007 BCS, V2, P83
Phillips CD, 1997, J AM GERIATR SOC, V45, P986, DOI 10.1111/j.1532-5415.1997.tb02971.x
Phillips CD, 1997, AGE AGEING, V26, P77, DOI 10.1093/ageing/26.suppl_2.77
Plsek PE, 2001, BRIT MED J, V323, P625, DOI 10.1136/bmj.323.7313.625
Rogers EM, 1995, DIFFUSION INNOVATION
Straub D., 2004, COMMUN ASS INF SYST, P380
TAYLOR S, 1995, INFORM SYST RES, V6, P144, DOI 10.1287/isre.6.2.144
Taylor S, 1995, MIS QUART, V19, P561, DOI 10.2307/249633
THOMPSON RL, 1991, MIS QUART, V15, P125, DOI 10.2307/249443
Venkatesh V, 2003, MIS QUART, V27, P425
Venkatesh V, 2000, MIS QUART, V24, P115, DOI 10.2307/3250981
Venkatesh V., 2011, P 44 HAW INT C SYST, P1, DOI [10. 1109/HICSS. 2011. 1, DOI 10.1109/HICSS.2011.1]
Venkatesh V, 2010, J GLOB INF TECH MAN, V13, P5, DOI 10.1080/1097198X.2010.10856507
Vinzi V. E, 2010, HDB PARTIAL LEAST SQ, P47, DOI DOI 10.1007/978-3-540-32827-8
Watson R, 2010, BRIT MED J, V341, DOI 10.1136/bmj.c5195
Wills M. J., 2008, ISSUES INFORM SYSTEM, V9, P396
Wolfson M, 2012, MEASURING UP IMPROVI, P133
Yu P, 2009, INT J MED INFORM, V78, P219, DOI 10.1016/j.ijmedinf.2008.07.006
Zimmerman DR, 2003, INT J GERIATR PSYCH, V18, P250, DOI 10.1002/gps.820

NR 83
TC 15
Z9 16
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PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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J9 BMC MED INFORM DECIS
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PT J
AU Verropoulou, G
AF Verropoulou, Georgia
TI Determinants of change in self-rated health among older adults in
   Europe: a longitudinal perspective based on SHARE data
SO EUROPEAN JOURNAL OF AGEING
LA English
DT Article
DE Self-rated health; SHARE; Longitudinal; Decline; Improvement
ID SOCIOECONOMIC INEQUALITIES; PERCEIVED HEALTH; ASSESSED HEALTH;
   FOLLOW-UP; MORTALITY; INDEX; SURVIVAL; PEOPLE; GENDER; LEVEL
AB The present study aims at detecting factors which may predict a decline or an improvement in self-rated health (SRH) of older adults (persons aged 50 or higher) among socio-demographic characteristics, physical and mental health indicators and risky health behaviours. In the analysis, multinomial logistic regression models are applied to data from waves 1 and 2 of the Survey of Health Ageing and Retirement in Europe (carried out about 3 years apart); persons who report a decline or an improvement in SRH at wave 2 are compared to those who report no change while controlling for SRH at baseline and country of residence. The analysis was carried out for the whole sample and two subgroups, persons aged 50-64 and 65 or higher. The results indicate that female sex and higher educational attainment have a strong protective effect against decline in SRH. Worse health at baseline is an important predictor of subsequent decline but changes occurring between the waves have a more pronounced effect, implying that SRH is influenced more by recent developments. The findings also indicate that improvement in SRH is a more complex concept than decline and is strongly affected by factors other than health. Among behavioural risk factors, low levels of physical activity and a decrease in the levels of activity between the waves are significantly related to decline while frequent drinking seems associated with improvement. Differentiations by age are modest and probably suggest that advancing age is related to a milder view of one's health.
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CR Andersen FK, 2007, SCAND J PUBLIC HEALT, V35, P164, DOI 10.1080/14034940600975674
   ANGEL R, 1989, SOC SCI MED, V28, P1229, DOI 10.1016/0277-9536(89)90341-9

Appels A, 1996, SOC SCI MED, V42, P681, DOI 10.1016/0277-9536(95)00195-6
Arber S, 1999, SOC SCI MED, V48, P61, DOI 10.1016/S0277-9536(98)00289-5
Avendano M, 2009, J EUR SOC POLICY, V19, P301, DOI 10.1177/1350506809341512
d'Uva TB, 2008, INT J EPIDEMIOL, V37, P1375, DOI 10.1093/ije/dyn146
Bailis DS, 2003, SOC SCI MED, V56, P203, DOI 10.1016/S0277-9536(02)00020-5
Bardage Carola, 2005, Eur J Ageing, V2, P149, DOI 10.1007/s10433-005-0032-7
Baron-Epel O, 2001, SOC SCI MED, V53, P1373, DOI 10.1016/S0277-9536(00)00426-3
Borawski EA, 1996, J GERONTOL B-PSYCHOL, V51, pS157, DOI 10.1093/geronb/51B.3.S157
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
Chan Y. H., 2005, SMJ Singapore Medical Journal, V46, P259
Chandola T, 2007, BRIT MED J, V334, P990, DOI 10.1136/bmj.39167.439792.55
Delbes C, 2006, WOMEN GROW OLD ALONE, V419
DeSalvo KB, 2006, J GEN INTERN MED, V21, P267, DOI 10.1111/j.1525-1497.2005.00291.x
Dewey ME, 2005, HLTH AGEING RETIREME
Eriksson I, 2001, INT J EPIDEMIOL, V30, P326, DOI 10.1093/ije/30.2.326
Eurostat, 2011, CAUS DEATH STAT DOC
Fonda S., 2004, DOCUMENTATION PHYS F
Gilmore ABC, 2002, SOC SCI MED, V55, P2177, DOI 10.1016/S0277-9536(01)00361-6
Grundy E, 2001, J EPIDEMIOL COMMUN H, V55, P895, DOI 10.1136/jech.55.12.895
Hasson D, 2006, POPUL HEALTH METR, V4, P1
Huisman M, 2003, SOC SCI MED, V57, P861, DOI 10.1016/S0277-9536(02)00454-9
IDLER EL, 1991, J GERONTOL, V46, pS55, DOI 10.1093/geronj/46.2.S55
Idler EL, 1997, J HEALTH SOC BEHAV, V38, P21, DOI 10.2307/2955359
Jang Y, 2009, J IMMIGR MINOR HEALT, V11, P7, DOI 10.1007/s10903-007-9112-4
Jurges H, 2007, HEALTH ECON, V16, P163, DOI 10.1002/hec.1134
KATZ S, 1983, J AM GERIATR SOC, V31, P721, DOI 10.1111/j.1532-5415.1983.tb03391.x
KATZ S, 1963, JAMA-J AM MED ASSOC, V185, P914, DOI 10.1001/jama.1963.03060120024016
KATZ S, 1970, GERONTOLOGIST, V10, P20, DOI 10.1093/geront/10.1_Part_1.20
Kunst AE, 2005, INT J EPIDEMIOL, V34, P295, DOI 10.1093/ije/dyh342
LAWTON MP, 1969, GERONTOLOGIST, V9, P9, DOI 10.1093/geront/9.1.9
Leinonen R, 2001, SOC SCI MED, V52, P1329, DOI 10.1016/S0277-9536(00)00249-5
Lindeboom M, 2004, J HEALTH ECON, V23, P1083, DOI 10.1016/j.jhealeco.2004.01.002
MACKENBACH JP, 1994, INT J EPIDEMIOL, V23, P1273, DOI 10.1093/ije/23.6.1273
McCullough ME, 2004, HEALTH PSYCHOL, V23, P651, DOI 10.1037/0278-6133.23.6.651
ONGARO F, 1995, EUR J POPUL, V11, P123, DOI 10.1007/BF01264908
Orfila F, 2000, J CLIN EPIDEMIOL, V53, P563, DOI 10.1016/S0895-4356(99)00230-9
Perlman F, 2008, INT J EQUITY HEALTH, V7, DOI 10.1186/1475-9276-7-19
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Sacker A, 2007, AM J PUBLIC HEALTH, V97, P812, DOI 10.2105/AJPH.2006.092320
Sargent-Cox KA, 2010, BMC GERIATR, V10, DOI 10.1186/1471-2318-10-18
Schroder M, 2008, 1 RESULTS SURVEY HLT
SHARE, 2011, SAMPL
Shields M, 2001, HLTH REP STAT CANADA, V13, P33
Simon JG, 2005, EUR J PUBLIC HEALTH, V15, P200, DOI 10.1093/eurpub/cki102
SMITH AMA, 1994, SOC SCI MED, V39, P77, DOI 10.1016/0277-9536(94)90167-8
Steel N, 2003, HLTH WEALTH LIFESTYL, P249
Tsimbos C, 2010, INT J PUBLIC HEALTH, V55, P5, DOI 10.1007/s00038-009-0083-1

```
   van Doorslaer E, 2003, SOC SCI MED, V57, P1621, DOI 10.1016/S0277-
9536(02)00559-2
   Verropoulou G, 2009, EUR J AGEING, V6, P213, DOI 10.1007/s10433-009-0125-9
   Vuorisalmi M, 2005, J CLIN EPIDEMIOL, V58, P680, DOI
10.1016/j.jclinepi.2004.11.025
   Vuorisalmi M, 2008, EUR J AGEING, V5, P327, DOI 10.1007/s10433-008-0093-5
   Zimmer Z, 2000, J HEALTH SOC BEHAV, V41, P465, DOI 10.2307/2676298
NR 55
TC 15
Z9 15
U1 0
U2 29
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 1613-9372
EI 1613-9380
J9 EUR J AGEING
JI Eur. J. Ageing
PD DEC
PY 2012
VL 9
IS 4
BP 305
EP 318
DI 10.1007/s10433-012-0238-4
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WC Gerontology
SC Geriatrics & Gerontology
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AU Langella, S
   Hastings, S
   Oster, S
   Pan, T
   Sharma, A
   Permar, J
   Ervin, D
   Cambazoglu, BB
   Kurc, T
   Saltz, J
AF Langella, Stephen
   Hastings, Shannon
   Oster, Scott
   Pan, Toiy
   Sharma, Ashish
   Permar, Justin
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   Cambazoglu, B. Barla
   Kurc, Tahsin
   Saltz, Joel
TI Sharing data and analytical resources securely in a biomedical research
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grid environment
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
ID INFRASTRUCTURE; INFORMATICS; MODELS

AB Objectives: To develop a security infrastructure to support controlled and secure access to data and analytical resources in a biomedical research Grid environment, while facilitating resource sharing among collaborators.

Design: A Grid security infrastructure, called Grid Authentication and Authorization with Reliably Distributed Services (GAARDS), is developed as a key architecture component of the NCI-funded cancer Biomedical Informatics Grid (caBIG (TM)). The GAARDS is designed to support in a distributed environment 1) efficient provisioning and federation of user identities and credentials; 2) group-based access control support with which resource providers can enforce policies based on community accepted groups and local groups; and 3) management of a trust fabric so that policies can be enforced based on required levels of assurance.

Measurements: GAARDS is implemented as a suite of Grid services and administrative tools. It provides three core services: Dorian for management and federation of user identities, Grid Trust Service for maintaining and provisioning a federated trust fabric within the Grid environment, and Grid Grouper for enforcing authorization policies based on both local and Grid-level groups.

Results: The GAARDS infrastructure is available as a stand-alone system and as a component of the caGrid infrastructure. More information about GAARDS can be accessed at http://www.cagrid.org.

Conclusions: GAARDS provides a comprehensive system to address the security challenges associated with environments in which resources may be located at different sites, requests to access the resources may cross institutional boundaries, and user credentials are created, managed, revoked dynamically in a de-centralized manner.

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CR AHSANT M, 2006, P 4 INT C TRUST MAN
AZZEDIN F, 2002, P IEEE CAN C EL COMP, P1424
Bacon J., 2002, ACM Transactions on Information and Systems Security, V5, P492, DOI 10.1145/581271.581276
Basney J, 2005, SOFTWARE PRACT EXPER, V35, P801, DOI 10.1002/spe.688
Bhatia K., 2005, 1 INT C E SCI GRID C
Butler R, 2000, COMPUTER, V33, P60, DOI 10.1109/2.889094
Covitz PA, 2003, BIOINFORMATICS, V19, P2404, DOI 10.1093/bioinformatics/btg335
Czajkowski K., 2004, WS RESOURCE FRAMEWOR
DWOSKIN J, 2003, 37 AS C SIGN SYST CO
Foster I, 2005, P IEEE, V93, P604, DOI 10.1109/JPROC.2004.842766
Foster I, 1997, INT J SUPERCOMPUT AP, V11, P115, DOI 10.1177/109434209701100205
Foster I., 2006, J COMPUTATIONAL SCI, V21, P523
GRANDISON T, 2003, 1 INT C TRUST MAN
Gurcan MN, 2007, J DIGIT IMAGING, V20, P160, DOI 10.1007/s10278-007-9020-0

Humphrey M, 2005, P IEEE, V93, P644, DOI 10.1109/JPROC.2004.842776
LANGELLA S, 2007, P 2007 AM MED INF AS
LANGELLA S, 2007, 6 ANN PKI R D WORKSH
Manchala DW, 2000, IEEE INTERNET COMPUT, V4, P36, DOI 10.1109/4236.832944
Oster S., 2006, 19 IEEE S COMP BAS M
OSTER S, 2007, P 2007 AM MED INF AS
Pan TC, 2007, RADIOGRAPHICS, V27, P889, DOI 10.1148/rg.273065153
Pearlman L, 2002, THIRD INTERNATION WORKSHOP ON POLICIES FOR DISTRIBUTED SYSTEMS AND NETWORKS, PROCEEDINGS, P50, DOI 10.1109/POLICY.2002.1011293
QUILLINAN T, 2004, 3 INT S PAR DISTR CO, P184
RAMAKRISHNAN L, 2002, P 3 INT WORKSH GRID
Saltz J, 2006, BIOINFORMATICS, V22, P1910, DOI 10.1093/bioinformatics/btl272
Sandhu RS, 1996, COMPUTER, V29, P38, DOI 10.1109/2.485845
SIEGEL E, 2005, INFORAD RAD SOC N AM
SINNOTT RO, 2006, 2 IEEE INT C E SCI 0
Thomas R. K., 1997, P 2 ACM WORKSH ROL B, P13, DOI DOI 10.1145/266741.266748
Weaver AC, 2003, INDIN 2003: IEEE INTERNATIONAL CONFERENCE ON INDUSTRIAL INFORMATICS, PROCEEDINGS, P162, DOI 10.1109/INDIN.2003.1300264
NR 30
TC 15
Z9 16
U1 0
U2 5
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD MAY-JUN
PY 2008
VL 15
IS 3
BP 363
EP 373
DI 10.1197/jamia.M2662
PG 11
WC Computer Science, Information Systems; Computer Science, Interdisciplinary Applications; Health Care Sciences & Services; Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science & Library Science; Medical Informatics
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UT WOS:000255965500016
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PT J
AU Mello, MM
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AF Mello, Michelle M.
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TI Clinical Trial Participants' Views of the Risks and Benefits of Data

Sharing

SO NEW ENGLAND JOURNAL OF MEDICINE

LA English

DT Article

ID BIOBANK RESEARCH; JOURNAL EDITORS; CANCER-PATIENTS; ATTITUDES; PERSPECTIVES; CONSENT; ACCESS; TRANSPARENCY; WILLINGNESS; INFORMATION

AB BACKGROUND

Sharing of participant-level clinical trial data has potential benefits, but concerns about potential harms to research participants have led some pharmaceutical sponsors and investigators to urge caution. Little is known about clinical trial participants' perceptions of the risks of data sharing.

METHODS

We conducted a structured survey of 771 current and recent participants from a diverse sample of clinical trials at three academic medical centers in the United States. Surveys were distributed by mail (350 completed surveys) and in clinic waiting rooms (421 completed surveys) (overall response rate, 79%).

RESULTS

Less than 8% of respondents felt that the potential negative consequences of data sharing outweighed the benefits. A total of 93% were very or somewhat likely to allow their own data to be shared with university scientists, and 82% were very or somewhat likely to share with scientists in for-profit companies. Willingness to share data did not vary appreciably with the purpose for which the data would be used, with the exception that fewer participants were willing to share their data for use in litigation. The respondents' greatest concerns were that data sharing might make others less willing to enroll in clinical trials (37% very or somewhat concerned), that data would be used for marketing purposes (34%), or that data could be stolen (30%). Less concern was expressed about discrimination (22%) and exploitation of data for profit (20%).

CONCLUSIONS

In our study, few clinical trial participants had strong concerns about the risks of data sharing. Provided that adequate security safeguards were in place, most participants were willing to share their data for a wide range of uses.

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CR Alemayehu D, 2014, CONTEMP CLIN TRIALS, V39, P28, DOI 10.1016/j.cct.2014.07.002
[Anonymous], 2012, NAT BIOTECHNOL, V30, P371, DOI 10.1038/nbt.2237
[Anonymous], 2013, FED REG
Bauchner H, 2016, JAMA-J AM MED ASSOC, V315, P1237, DOI 10.1001/jama.2016.2420
Berlin JA, 2014, CLIN TRIALS, V11, P7, DOI 10.1177/1740774513514497
Bertagnolli MM, 2017, NEW ENGL J MED, V376, P1178, DOI 10.1056/NEJMsb1702054
Beskow LM, 2008, CANCER EPIDEM BIOMAR, V17, P1440, DOI 10.1158/1055-9965.EPI-08-0086
Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
Castellani J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1881
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201

Davis AL, 2017, JAMA-J AM MED ASSOC, V317, P905, DOI 10.1001/jama.2017.0918
Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
European Medicines Agency, CLIN DAT PUBL
Garrison NA, 2016, GENET MED, V18, P663, DOI 10.1038/gim.2015.138
Gornick MC, 2014, J EMPIR RES HUM RES, V9, P22, DOI 10.1177/1556264614544277
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Grande D, 2013, JAMA INTERN MED, V173, P1798, DOI 10.1001/jamainternmed.2013.9166
Green AK, 2015, ONCOLOGIST, V20, P464, DOI 10.1634/theoncologist.2014-0431
Hapgood R, 2004, 0405 HEDS
Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
Haug CJ, 2017, NEW ENGL J MED, V376, P2203, DOI 10.1056/NEJMp1704485
Helft PR, 2007, J EMPIR RES HUM RES, V2, P15, DOI [10.1525/jer.2007.2.3.15, 10.1525/JERHRE.2007.2.3.15]
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Johnsson L, 2010, EUR J HUM GENET, V18, P1261, DOI 10.1038/ejhg.2010.106
Jumbe NL, 2016, NEW ENGL J MED, V374, P2415, DOI 10.1056/NEJMp1605441
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Krumholz HM, 2016, NEW ENGL J MED, V375, P403, DOI 10.1056/NEJMp1607342
Krumholz HM, 2014, CIRC-CARDIOVASC QUAL, V7, P499, DOI 10.1161/CIRCOUTCOMES.114.001166
Krumholz HM, 2011, JAMA-J AM MED ASSOC, V306, P1593, DOI 10.1001/jama.2011.1459
Lemmens T, 2013, J LAW MED ETHICS, V41, P163, DOI 10.1111/jlme.12012
Loder E, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f4794
Long MD, 2015, INFLAMM BOWEL DIS, V21, P132, DOI 10.1097/MIB.0000000000000263
Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
Majumder MA, 2017, GENET MED, V19, P1289, DOI 10.1038/gim.2017.59
Melas PA, 2010, J MED ETHICS, V36, P93, DOI 10.1136/jme.2009.032367
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Pentz RD, 2006, AM J MED GENET A, V140A, P733, DOI 10.1002/ajmg.a.31154
PhRMA, 2014, PRINC RESP CLIN TRIA
Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
Rogith D, 2014, J AM MED INFORM ASSN, V21, pE320, DOI 10.1136/amiajnl-2013-002579
Rosenblatt M, 2015, ANN INTERN MED, V162, P306, DOI 10.7326/M14-1299
Sample I., 2013, GUARDIAN
Sanderson SC, 2017, AM J HUM GENET, V100, P414, DOI 10.1016/j.ajhg.2017.01.021
Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI 10.1586/14737159.2014.961917
Storr CL, 2014, J COMMUN GENET, V5, P363, DOI 10.1007/s12687-014-0191-3
Strom BL, 2016, NEW ENGL J MED, V375, P1608, DOI 10.1056/NEJMp1610336
Stunkel L, 2011, CONTEMP CLIN TRIALS, V32, P342, DOI 10.1016/j.cct.2010.12.003
Taichman DB, 2017, NEW ENGL J MED, V376, P2277, DOI 10.1056/NEJMe1705439
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
Truong TH, 2011, CLIN TRIALS, V8, P616, DOI 10.1177/1740774511414444
Truven Health Analytics, 2014, HLTH POLL DAT PRIV
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Warren E, 2016, NEW ENGL J MED, V375, P401, DOI 10.1056/NEJMp1607282
Whitty CJM, 2015, LANCET, V386, P1797, DOI 10.1016/S0140-6736(15)00758-8

```
   Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
NR 60
TC 14
Z9 14
U1 0
U2 7
PU MASSACHUSETTS MEDICAL SOC
PI WALTHAM
PA WALTHAM WOODS CENTER, 860 WINTER ST,, WALTHAM, MA 02451-1413 USA
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J9 NEW ENGL J MED
JI N. Engl. J. Med.
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PT J
AU McIlvennan, CK
   Thompson, JS
   Matlock, DD
   Cleveland, JC
   Dunlay, SM
   LaRue, SJ
   Lewis, EF
   Patel, CB
   Walsh, MN
   Allen, LA
AF McIlvennan, Colleen K.
   Thompson, Jocelyn S.
   Matlock, Daniel D.
   Cleveland, Joseph C., Jr.
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   Walsh, Mary Norine
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TI A Multicenter Trial of a Shared Decision Support Intervention for
   Patients and Their Caregivers Offered Destination Therapy for Advanced
   Heart Failure: DECIDE-LVAD Rationale, Design, and Pilot Data
SO JOURNAL OF CARDIOVASCULAR NURSING
LA English
DT Article
DE health education; decision aids; ventricular assist device;
   patient-centered care; shared decision-making
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ID DAILY PHYSICAL-ACTIVITY; QUALITY-OF-LIFE; RANDOMIZED CONTROLLED-TRIAL; DAILY ENERGY-EXPENDITURE; CARDIAC REHABILITATION; OLDER-ADULTS; PROGRAM PARTICIPATION; MYOCARDIAL-INFARCTION; EXERCISE CAPACITY; SPORTS-MEDICINE

AB Background: Shared decision making is important to ensure that patients receive therapies aligned with their goals and values. Based upon a detailed needs assessment with diverse stakeholders, pamphlet and video decision aids for destination therapy left ventricular assist devices (DT LVAD) were developed to help patients and their caregivers think through, forecast, and deliberate their options. These decision aids are the foundation of the Multicenter Trial of a Shared Decision Support Intervention for Patients and their Caregivers Offered Destination Therapy for End-Stage Heart Failure (DECIDE-LVAD) study, a multicenter, randomized trial aimed at understanding the effectiveness and implementation of a shared decision support intervention for patients considering DT LVAD.

Methods/Design: A stepped-wedge randomized controlled trial was designed, guided by the RE-AIM framework and modeled after an effectiveness-implementation hybrid type II design. Six DT LVAD programs from across the United States will participate. Primary outcomes include knowledge and values-treatment concordance. Patients with advanced heart failure who are being considered for DT LVAD and their caregivers are eligible with a target enrollment of 168 dyads. From August 2014 to January 2015, an acceptability and feasibility pilot study was performed, which clarified opportunities and challenges around decision support for DT LVAD and resulted in significant modifications to the DECIDE-LVAD study.

Discussion: Study findings will provide a foundation for implementing decision support interventions, including decision aids, with patients who have chronic progressive illness facing end-of-life decisions involving invasive, preference-sensitive therapy options.

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CR Ades PA, 2001, NEW ENGL J MED, V345, P892, DOI 10.1056/NEJMra001529
Ainsworth BE, 2009, BRIT J SPORT MED, V43, P6, DOI 10.1136/bjsm.2008.052449
Blair J, 2011, RURAL REMOTE HEALTH, V11
Blanchard CM, 2010, J CARDIOPULM REHABIL, V30, P240, DOI 10.1097/HCR.0b013e3181d0c4ae
Bock BC, 2003, BEHAV MODIF, V27, P37, DOI 10.1177/0145445502238692
Buijs David M, 2015, Can J Cardiovasc Nurs, V25, P10
Carlson JJ, 2000, AM J CARDIOL, V86, P17, DOI 10.1016/S0002-9149(00)00822-5
Chase JAD, 2011, J CARDIOVASC NURS, V26, P351, DOI 10.1097/JCN.0b013e3182049f00
Colley Rachel C, 2011, Health Rep, V22, P7
Cowie A, 2011, EUR J CARDIOV PREV R, V18, P158, DOI 10.1177/1741826710389389
Dogra S., 2012, J AGING RES, V2012, DOI [10.1155/2012/190654, DOI 10.1155/2012/190654]
Dontje ML, 2014, J CARDIOVASC NURS, V29, P218, DOI 10.1097/JCN.0b013e318283ba14
Fletcher GF, 2001, CIRCULATION, V104, P1694, DOI 10.1161/hc3901.095960
Garber CE, 2011, MED SCI SPORT EXER, V43, P1334, DOI 10.1249/MSS.0b013e318213fefb
Goran MI, 1992, AM J PHYSL 1, V263, pE950
Hamilton MT, 2004, EXERC SPORT SCI REV, V32, P161
Haskell WL, 2007, MED SCI SPORT EXER, V39, P1423, DOI 10.1249/mss.0b013e3180616b27
Healy GN, 2008, DIABETES CARE, V31, P369, DOI 10.2337/dc07-1795
Healy GN, 2007, DIABETES CARE, V30, P1384, DOI 10.2337/dc07-0114
Houle J, 2011, PATIENT EDUC COUNS, V85, pE237, DOI 10.1016/j.pec.2011.03.018
Johannsen DL, 2010, MED SCI SPORT EXER, V42, P2134, DOI 10.1249/MSS.0b013e3181e0b3ff
Karjalainen JJ, 2012, CLIN PHYSIOL FUNCT I, V32, P445, DOI 10.1111/j.1475-097X.2012.01148.x
Katzmarzyk PT, 2009, MED SCI SPORT EXER, V41, P998, DOI 10.1249/MSS.0b013e3181930355
Mackey DC, 2011, J GERONTOL A-BIOL, V66, P1108, DOI 10.1093/gerona/glr101
Manini TM, 2006, JAMA-J AM MED ASSOC, V296, P171, DOI 10.1001/jama.296.2.171
Manns PJ, 2012, PHYS THER, V92, P614, DOI 10.2522/ptj.20110284
Marchionni N, 2003, CIRCULATION, V107, P2201, DOI 10.1161/01.CIR.0000066322.21016.4A
Martin BJ, 2012, OBESITY, V20, P2377, DOI 10.1038/oby.2012.119
Matthews CE, 2007, AM J EPIDEMIOL, V165, P1343, DOI 10.1093/aje/kwm088
Matthews CE, 2012, AM J CLIN NUTR, V95, P437, DOI 10.3945/ajcn.111.019620
Meijer EP, 1999, EUR J APPL PHYSIOL O, V80, P16, DOI 10.1007/s004210050552
Owen N, 2010, MAYO CLIN PROC, V85, P1138, DOI 10.4065/mcp.2010.0444
PATE RR, 1995, JAMA-J AM MED ASSOC, V273, P402, DOI 10.1001/jama.273.5.402
Pate RR, 2008, EXERC SPORT SCI REV, V36, P173, DOI 10.1097/JES.0b013e3181877d1a
Ramadi A, 2015, J CARDIOPULM REHABIL, V35, P21, DOI 10.1097/HCR.0000000000000084
Ramadi A, 2014, HEART LUNG, V44, P9, DOI 10.1016/j.hrtlng.2014.11.001
Reeve MD, 2014, J SCI MED SPORT, V17, P630, DOI 10.1016/j.jsams.2013.08.007
Rodgers WM, 2008, RES Q EXERCISE SPORT, V79, P222, DOI 10.5641/193250308X13086753543590
Smith KM, 2011, HEART, V97, P1169, DOI 10.1136/hrt.2010.202036

```
   Smith KM, 2004, EUR J CARDIOV PREV R, V11, P313, DOI
10.1097/01.hjr.0000136414.40017.10
   Stahle A, 1999, EUR HEART J, V20, P1475, DOI 10.1053/euhj.1999.1581
   Stone JA, 2011, INT J CARDIOL, V150, P355, DOI 10.1016/j.ijcard.2011.05.041
   Tremblay MS, 2010, APPL PHYSIOL NUTR ME, V35, P725, DOI 10.1139/H10-079
   Tudor-Locke C, 2011, INT J BEHAV NUTR PHY, V8, DOI 10.1186/1479-5868-8-80
   van den Berg-Emons H, 2001, PHYS THER, V81, P1502
   Vanhees L, 2005, EUR J CARDIOV PREV R, V12, P102, DOI 10.1097/00149831-
200504000-00004
   Witham MD, 2005, AM J CARDIOL, V95, P1120, DOI 10.1016/j.amjcard.2005.01.031
   Wolkanin-Bartnik J, 2011, J CARDIOPULM REHABIL, V31, P249, DOI
10.1097/HCR.0b013e31821c1391
   WOOD R, 1989, ACAD MANAGE REV, V14, P361, DOI 10.5465/AMR.1989.4279067
NR 49
TC 14
Z9 14
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U2 12
PU LIPPINCOTT WILLIAMS & WILKINS
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PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
SN 0889-4655
EI 1550-5049
J9 J CARDIOVASC NURS
JI J. Cardiovasc. Nurs.
PD NOV-DEC
PY 2016
VL 31
IS 6
BP E8
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DI 10.1097/JCN.0000000000000343
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WC Cardiac & Cardiovascular Systems; Nursing
SC Cardiovascular System & Cardiology; Nursing
GA EA9QP
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AU Fedorov, A
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TI DICOM for quantitative imaging biomarker development: a standards based approach to sharing clinical data and structured PET/CT analysis results in head and neck cancer research
SO PEERJ
LA English
DT Article
DE Quantitative imaging; Imaging biomarker; Imaging informatics; DICOM; PET/CT imaging; Head and neck cancer; Image analysis; Cancer imaging; Interoperability; Open science
ID FDG UPTAKE; TERMINOLOGY; ONCOLOGY; PLATFORM; IMAGES

AB Background. Imaging biomarkers hold tremendous promise in the precision medicine clinical applications. Development of such biomarkers relies heavily on image post-processing tools for automated image quantitation. Their deployment in the context of clinical research necessitates interoperability with the clinical systems. Comparison with the established outcomes and evaluation motivate integration of the clinical and imaging data, and the use of standardized approaches to sharing analysis results and semantics. We develop the methodology and supporting tools to perform these tasks in Positron Emission Tomography and Computed Tomography (PET/CT) quantitative imaging (QI) biomarker development applied to head and neck cancer (HNC) treatment response assessment, using the Digital Imaging and Communications in Medicine (DICOM (R)) international standard and free open-source software.

Methods. Quantitative analysis of PET/CT imaging data collected on patients undergoing treatment for HNC was conducted. Processing steps included Standardized Uptake Value (SUV) normalization of the images, segmentation of the tumor and reference regions of interest using manual and semi-automatic approaches, and extraction of the volumetric segmentation-based measurements. Suitable components of the DICOM standard were identified to model the various types of data produced by the analysis. A developer toolkit of conversion routines and an Application Programming Interface (API) were contributed and applied to create a standards-based representation of the data.

Results. DICOM Real World Value Mapping, Segmentation and Structured Reporting objects were utilized for standards-compliant representation of the PET/CT QI analysis results. A number of correction proposals to the standard were developed. The open source DICOM toolkit (DCMTK) was improved to simplify the task of encoding via new API abstractions. Conversion and visualization tools utilizing this toolkit were developed. The encoded objects were validated for consistency and interoperability. The resulting dataset was deposited to the QIN-HEADNECK collection of The Cancer Imaging Archive. Supporting tools for data analysis and DICOM conversion were made available as free open source software.

Discussion. We presented a detailed investigation of the development and application of the DICOM model, as well as the supporting open source tools and toolkits, to accommodate representation of the research data in QI biomarker development. We demonstrated that DICOM standard can be used to represent various types of the analysis results and encode their complex relationships. The resulting annotated objects are amenable for data mining applications, and are interoperable with a variety of systems that support the DICOM standard.

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CR [Anonymous], 2010, 247652010 ISOIECIEEE
[Anonymous], 2015, SEMANTIC WEB W3C
Bauer C, 2012, MED PHYS, V39, P3112, DOI 10.1118/1.4711815
Beichel RR, 2016, MED PHYS, V43, P2948, DOI 10.1118/1.4948679
Bidgood W. D. Jr., 1997, International Journal on Digital Libraries, V1, P278, DOI 10.1007/s007990050022
Bidgood WD, 1998, METHOD INFORM MED, V37, P404
Bidgood WD, 1997, J AM MED INFORM ASSN, P424
Bodenreider O, 2004, NUCLEIC ACIDS RES, V32, pD267, DOI 10.1093/nar/gkh061
Boellaard R, 2009, J NUCL MED, V50, p11S, DOI 10.2967/jnumed.108.057182
Boulton G, 2011, LANCET, V377, P1633, DOI 10.1016/S0140-6736(11)60647-8
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Clark K, 2013, J DIGIT IMAGING, V26, P1045, DOI 10.1007/s10278-013-9622-7
Clunie D., 2016, DICOM STANDARD STATU
Clunie D., 2015, DICOM VALIDATOR DCIO
Clunie D, 2000, DICOM STRUCTURED REP
Clunie D., 2009, DICOM3TOOLS SOFTWARE
Clunie D., 2015, DICOMSRVALIDATOR
Clunie D., 2015, PIXELMED JAVA DICOM
Common TK, 2015, DCMJS BY COMMONTK
Cornet R, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-S1-S2
Eichelberg M, 2004, PRO BIOMED OPT IMAG, V5, P57, DOI 10.1117/12.534853

Fedorov A, 2015, INTEROPERABLE COMMUN
Fedorov A, 2015, PEERJ PREPRINTS, V4, DOI [10.7287/peerj.preprints.1541v3, DOI 10.7287/PEERJ.PREPRINTS.1541V3]
Fedorov A, 2012, MAGN RESON IMAGING, V30, P1323, DOI 10.1016/j.mri.2012.05.001
Graham MM, 2000, NUCL MED BIOL, V27, P647, DOI 10.1016/S0969-8051(00)00143-8
Haak D, 2015, P SOC PHOTO-OPT INS, V9418
Ibanez L., 2005, ITK SOFTWARE GUIDE 2
Interoperability Working Group (AFUL), 2015, DEF INT
Katzan IL, 2012, SCI TRANSL MED, V4, DOI 10.1126/scitranslmed.3004583
Kindlmann G, 2004, TEEM NRRD NEARLY RAW
Krishnaraj A, 2014, J AM COLL RADIOL, V11, P20, DOI 10.1016/j.jacr.2013.08.017
Larson SM, 1999, CLIN POSITRON IMAGIN, V2, P159, DOI DOI 10.1016/S1095-0397(99)00016-3
Lucignani G, 2004, NUCL MED COMMUN, V25, P651, DOI 10.1097/01.mnm.0000134329.30912.49
Malaterre M, 2015, GRASSROOTS DICOM GDC
Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
McDonald CJ, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3005700
Mongkolwat P, 2015, AIM ON CLEARCANVAS
Moore SM, 2015, RADIOGRAPHICS, V35, P727, DOI 10.1148/rg.2015140244
MRC Cognition and Brain Sciences Unit, 2013, ANAL DAT FORM
National Electrical Manufacturers Association (NEMA), 2016, PS316 NEMA DICOM
National Electrical Manufacturers Association (NEMA), 2016, PS315 NEMA DICOM
National Electrical Manufacturers Association (NEMA), 2016, PS33 NEMA DICOM
National Electrical Manufacturers Association (NEMA), 2015, PS3192015C NEMA DICO
National Electrical Manufacturers Association (NEMA), 2016, PS35 NEMA DICOM
NIfTI Data Format Working Group, 2005, NIFTI NEUR INF TECHN
OFFIS, 2014, DCMTK DICOM TOOLK
Piwowar HA, 2013, PEERJ, V1, DOI 10.7717/peerj.175
QIICR, 2015, QIICR IOWAHNCLINICAL
QIICR, 2015, QIICR PET INDIC
QIICR, 2015, DIC DUMP DICOM VIEW
QIICR, 2016, QIICR DSR2CSV
QIICR, 2016, DCMQI
QIICR, 2015, QIICR IOWA2DICOM
QIICR, 2015, SEARCH IND DICOM BAS
QIICR, 2015, QIICR PETTUMORSEGMEN
QIICR, 2015, QIICR SLIC PETDICOME
Schadow G, 1999, J AM MED INFORM ASSN, V6, P151, DOI 10.1136/jamia.1999.0060151
Schroeder W., 2006, VISUALIZATION TOOLKI
Stanford Medicine, 2015, EPAD WEB BAS PLATF Q
Vanderhoek M, 2012, J NUCL MED, V53, P4, DOI 10.2967/jnumed.111.093443
Wahl RL, 2009, J NUCL MED, V50, p122S, DOI 10.2967/jnumed.108.057307
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Waterton JC, 2012, EUR J CANCER, V48, P409, DOI 10.1016/j.ejca.2011.11.037
Weber WA, 2006, J CLIN ONCOL, V24, P3282, DOI 10.1200/JCO.2006.06.6068
Yale Law Sch Roundtable Data Code, 2010, COMPUT SCI ENG, V12, P8
Yin Y, 2010, IEEE T MED IMAGING, V29, P2023, DOI 10.1109/TMI.2010.2058861
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PA 341-345 OLD ST, THIRD FLR, LONDON, EC1V 9LL, ENGLAND
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PT J
AU Hoven, H
   Wahrendorf, M
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AF Hoven, H.
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TI Occupational position, work stress and depressive symptoms: a pathway
   analysis of longitudinal SHARE data
SO JOURNAL OF EPIDEMIOLOGY AND COMMUNITY HEALTH
LA English
DT Article
ID EFFORT-REWARD IMBALANCE; CORONARY-HEART-DISEASE; EURO-D SCALE;
   PSYCHOSOCIAL FACTORS; MEDIATION ANALYSIS; SOCIAL GRADIENT; HEALTH; RISK
AB Background Several studies tested whether stressful work mediates the
association between socioeconomic position (SEP) and health. Although providing
moderate support, evidence is still inconclusive, partly due to a lack of
theory-based measures of SEP and work stress, and because of methodological
limitations. This contribution aims at overcoming these limitations.
   Methods We conduct pathway analysis and investigate indirect effects of SEP
on mental health via stressful work. Data are derived from the first two waves
of the 'Survey of Health, Ageing and Retirement in Europe' (SHARE) with
information from employed men and women aged 50-64 across 11 European countries
(N=2798). SEP is measured according to two alternative measures of occupational
position: occupational class (focus on employment relations) and occupational
status (focus on prestige). We assess work stress according to the effort-reward
imbalance and the demand-control model (wave 1), and we use newly occurring
depressive symptoms as health outcome (wave 2).
   Results Effort-reward imbalance and, less consistently, low control mediate
the effect of occupational class and occupational status on depressive symptoms.
   Conclusions Our findings point to two important aspects of work stress
(effort-reward imbalance and low control) in explaining socioeconomic
differences in health. Further, we illustrate the significance of two
alternative dimensions of occupational position, occupational class and
occupational status.
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FU European Community [278350]
FX European Community (FP7) under grant agreement no 278350.
CR Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
Bonde JPE, 2008, OCCUP ENVIRON MED, V65, P438, DOI 10.1136/oem.2007.038430
Borrell C, 2004, SOC SCI MED, V58, P1869, DOI 10.1016/S0277-9536(03)00408-8
Borsch-Supan A, 2005, SURVEY HLTH AGEING R
Chandola T, 2005, OCCUP ENVIRON MED, V62, P223, DOI 10.1136/oem.2004.016675
Chandola T, 1998, SOC SCI MED, V47, P525, DOI 10.1016/S0277-9536(98)00141-5
Clougherty JE, 2010, ANN NY ACAD SCI, V1186, P102, DOI 10.1111/j.1749-6632.2009.05338.x
du Prel JB, 2014, INT J PUBLIC HEALTH, V59, P945, DOI 10.1007/s00038-014-0613-3
Erikson Robert., 1992, CONSTANT FLUX STUDY
Ganzeboom HBG, 1996, SOC SCI RES, V25, P201, DOI 10.1006/ssre.1996.0010
Hayes AF, 2009, COMMUN MONOGR, V76, P408, DOI 10.1080/03637750903310360
Hoven H, 2013, OCCUP ENVIRON MED, V70, P663, DOI 10.1136/oemed-2012-101331
International Labor Office, 1990, ISCO88 INT LAB OFF
Juvani A, 2014, SCAND J WORK ENV HEA, V40, P266, DOI 10.5271/sjweh.3402
Karasek R., 1990, HLTH WORK STRESS PRO
Landsbergis PA, 2010, AM J IND MED, V53, P95, DOI 10.1002/ajim.20766
Larraga L, 2006, INT J GERIATR PSYCH, V21, P1199, DOI 10.1002/gps.1642
Lynch J, 2000, SOCIAL EPIDEMIOLOGY, P13
Mackenbach JP, 2008, NEW ENGL J MED, V358, P2468, DOI 10.1056/NEJMsa0707519
MacKinnon DP, 2009, CURR DIR PSYCHOL SCI, V18, P16, DOI 10.1111/j.1467-8721.2009.01598.x
MacKinnon DP, 2004, MULTIVAR BEHAV RES, V39, P99, DOI 10.1207/s15327906mbr3901_4
MacKinnon DP, 2002, PSYCHOL METHODS, V7, P83, DOI 10.1037//1082-989X.7.1.83
Marmot MG, 1998, MILBANK Q, V76, P403, DOI 10.1111/1468-0009.00097
Marmot MG, 1997, LANCET, V350, P235, DOI 10.1016/S0140-6736(97)04244-X
Marmot Review Team, 2010, FAIR SOC HLTH LIV ST
Montano D, 2014, J OCCUP MED TOXICOL, V9, DOI 10.1186/1745-6673-9-28
Mood C, 2010, EUR SOCIOL REV, V26, P67, DOI 10.1093/esr/jcp006
Muthen L. K., 2010, MPLUS USERS GUIDE
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Schnall PL, 2009, UNHEALTHY WORK CAUSE
Siegrist J, 2004, SOC SCI MED, V58, P1483, DOI 10.1016/S0277-9536(03)00351-4
Siegrist J., 2009, OXFORD HDB ORG WELL, P109
Siegrist J, 2006, SOCIAL INEQUALITIES, P73, DOI DOI 10.1093/ACPR0F:0S0/9780198568162.003.0004]
Siegrist J, 2014, INT ARCH OCC ENV HEA, V87, P249, DOI 10.1007/s00420-013-0855-z
Siegrist J, 2012, GLOBALIZATION HEALTH, V8, DOI 10.1186/1744-8603-8-27
Steenland K, 1997, AM J IND MED, V31, P256, DOI 10.1002/(SICI)1097-0274(199702)31:2<256::AID-AJIM16>3.0.CO;2-0
Steptoe A, 2012, NAT REV CARDIOL, V9, P360, DOI 10.1038/nrcardio.2012.45
Wahrendorf M, 2013, EUR SOCIOL REV, V29, P792, DOI 10.1093/esr/jcs058
World Health Organization, 2014, REV SOC DET HLTH DIV
NR 39
TC 14
Z9 17
U1 1
U2 27

```
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 0143-005X
EI 1470-2738
J9 J EPIDEMIOL COMMUN H
JI J. Epidemiol. Community Health
PD MAY
PY 2015
VL 69
IS 5
BP 447
EP 452
DI 10.1136/jech-2014-205206
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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OA Other Gold, Green Published
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PT J
AU Ge, YR
   Ahn, DK
   Unde, B
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   Carr, JJ
AF Ge, Yaorong
   Ahn, David K.
   Unde, Bhagyashree
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TI Patient-controlled sharing of medical imaging data across unaffiliated
   healthcare organizations
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
ID INFORMATION EXCHANGE; ARCHITECTURE; TECHNOLOGY; PRIVACY; CONSENT;
   RECORDS
AB Background Current image sharing is carried out by manual transportation of
CDs by patients or organization-coordinated sharing networks. The former places
a significant burden on patients and providers. The latter faces challenges to
patient privacy.
   Objective To allow healthcare providers efficient access to medical imaging
data acquired at other unaffiliated healthcare facilities while ensuring strong
protection of patient privacy and minimizing burden on patients, providers, and
the information technology infrastructure.
   Methods An image sharing framework is described that involves patients as an
integral part of, and with full control of, the image sharing process. Central
to this framework is the Patient Controlled Access-key REgistry (PCARE) which
manages the access keys issued by image source facilities. When digitally signed
by patients, the access keys are used by any requesting facility to retrieve the
associated imaging data from the source facility. A centralized patient portal,
called a PCARE patient control portal, allows patients to manage all the access
keys in PCARE.
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Results A prototype of the PCARE framework has been developed by extending open-source technology. The results for feasibility, performance, and user assessments are encouraging and demonstrate the benefits of patient-controlled image sharing.

Discussion The PCARE framework is effective in many important clinical cases of image sharing and can be used to integrate organization-coordinated sharing networks. The same framework can also be used to realize a longitudinal virtual electronic health record.

Conclusion The PCARE framework allows prior imaging data to be shared among unaffiliated healthcare facilities while protecting patient privacy with minimal burden on patients, providers, and infrastructure. A prototype has been implemented to demonstrate the feasibility and benefits of this approach.

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FU NIH/NIBIB [5 RC2 EB011406]

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CR Adler-Milstein J, 2011, ANN INTERN MED, V154, P666, DOI 10.7326/0003-4819-154-10-201105170-00006
Beckjord EB, 2011, J ONCOL PRACT, V7, P237, DOI 10.1200/JOP.2011.000324
Bergmann J, 2007, INT J MED INFORM, V76, P130, DOI 10.1016/j.ijmedinf.2006.07.013
Caumanns J, 2009, ACCESS CONTROL
Connors Bill, 2009, Behav Healthc, V29, P52
Dixon BE, 2010, J AM MED INFORM ASSN, V17, P295, DOI 10.1136/jamia.2009.000570
Donnelly John, 2006, J Healthc Inf Manag, V20, P29
Edwards Ashley, 2010, J Healthc Inf Manag, V24, P22
Flanders AE, 2009, RADIOGRAPHICS, V29, P1247, DOI 10.1148/rg.295095151
Frisse Mark E, 2008, AMIA Annu Symp Proc, P212
Gadd CS, 2011, J AM MED INFORM ASSN, V18, P711, DOI 10.1136/amiajnl-2011-000281
Goldstein MM, 2010, J LAW MED ETHICS, V38, P27, DOI 10.1111/j.1748-720X.2010.00463.x
Gravely Steve D, 2009, J Healthc Inf Manag, V23, P33
Halamka JD, 2008, J AM MED INFORM ASSN, V15, P1, DOI 10.1197/jamia.M2562
Just Beth Haenke, 2009, J AHIMA, V80, P62
Kalra D, 2002, STUD HEALTH TECHNOL, V87, P47
Kuperman GJ, 2011, J AM MED INFORM ASSN, V18, P678, DOI 10.1136/amiajnl-2010-000021
Mandl KD, 2001, BMJ-BRIT MED J, V322, P283, DOI 10.1136/bmj.322.7281.283
Mandl KD, 2007, BMC MED INFORM DECIS, V7, DOI 10.1186/1472-6947-7-25
McDonald C, 2009, HEALTH AFFAIR, V28, P447, DOI 10.1377/hlthaff.28.2.447
McGraw D, 2009, HEALTH AFFAIR, V28, P416, DOI 10.1377/hlthaff.28.2.416
McMurry AJ, 2007, J AM MED INFORM ASSN, V14, P527, DOI 10.1197/jamia.M2371
Mendelson DS, 2008, RADIOGRAPHICS, V28, P1817, DOI 10.1148/rg.287085174
Mendelson DS, 2011, APPL RADIOL, V40
ONC- HIT, 2010, NHIN ARCH OV
Prestigiacomo J., 2010, HEALTHC INFORM, V27, P32
Prestigiacomo J., 2010, HEALTHC INFORM, V27, P55
Prestigiacomo Jennifer, 2010, Healthc Inform, V27, P55
Rode Dan, 2005, J AHIMA, V76, P20

```
   SAML Tokens and Claims, 2012, SAML TOK CLAIMS
   Sharma A, 2009, J DIGIT IMAGING, V22, P1, DOI 10.1007/s10278-007-9074-z
   Stevenson C, 2011, CRIM BEHAV MENT HEAL, V21, P157, DOI 10.1002/cbm.790
   Sweeney L, 2010, MOD HEALTHC
   Ullman Kurt, 2010, Healthc Inform, V27, P32
   Unertl KM, 2012, J AM MED INFORM ASSN, V19, P392, DOI 10.1136/amiajnl-2011-
000432
   Vest JR, 2010, J AM MED INFORM ASSN, V17, P288, DOI 10.1136/jamia.2010.003673
   Wilcox Adam, 2006, AMIA Annu Symp Proc, P814
   Zhang JG, 2011, INT J COMPUT ASS RAD, V6, P273, DOI 10.1007/s11548-010-0522-8
NR 38
TC 14
Z9 14
U1 0
U2 0
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1067-5027
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD JAN
PY 2013
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IS 1
BP 157
EP 163
DI 10.1136/amiajnl-2012-001146
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WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
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PT J
AU Aljunid, SM
   Srithamrongsawat, S
   Chen, W
   Bae, SJ
   Pwu, RF
   Ikeda, S
   Xu, L
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   Srithamrongsawat, Samrit
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   Bae, Seung Jin
   Pwu, Raoh-Fang
   Ikeda, Shunya
   Xu, Ling
TI Health-Care Data Collecting, Sharing, and Using in Thailand, China
   Mainland, South Korea, Taiwan, Japan, and Malaysia
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SO VALUE IN HEALTH
LA English
DT Article
DE Asia Pacific; collection; health-care data; sharing; using

AB This article sought to describe the health-care data situation in six selected economies in the Asia-Pacific region. Authors from Thailand, China mainland, South Korea, Taiwan, Japan, and Malaysia present their analyses in three parts. The first part of the article describes the data-collection process and the sources of data. The second part of the article presents issues around policies of data sharing with the stake-holders. The third and final part of the article focuses on the extent of health-care data use for policy reform in these different economies. Even though these economies differ in their economic structure and population size, they share some similarities on issues related to health-care data. There are two main institutions that collect and manage the health-care data in these economies. In Thailand, China mainland, Taiwan, and Malaysia, the Ministry of Health is responsible through its various agencies for collecting and managing the health-care data. On the other hand, health insurance is the main institution that collects and stores health-care data in South Korea and Japan. In all economies, sharing of and access to data is an issue. The reasons for limited access to some data are privacy protection, fragmented health-care system, poor quality of routinely collected data, unclear policies and procedures to access the data, and control on the freedom on publication. The primary objective of collecting health-care data in these economies is to aid the policymakers and researchers in policy decision making as well as create an awareness on health-care issues for the general public. The usage of data in monitoring the performance of the heath system is still in the process of development. In conclusion, for the region under discussion, health-care data collection is under the responsibility of the Ministry of Health and health insurance agencies. Data are collected from health-care providers mainly from the public sector. Routinely collected data are supplemented by national surveys. Accessibility to the data is a major issue in most of the economies under discussion. Accurate health-care data are required mainly to support policy making and evidence-based decisions.

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CR Academia Sinica Survey Research Data Archive Nutrition and Health Survey in Taiwan, LARG SCAL SURV NUTR
Aljunid S, 1995, THESIS LONDON SCH HY
Aljunid S, 2008, WHO C PUBL HLTH INF
[Anonymous], NAT HLTH INS RES DAT
Bae SJ, 2010, ESTIMATING BURDEN DI
Bureau of Health Promotion, HOUS SURV HYP HYP HY
Center for Disease Control, SURV SYST
Council of Labor Affairs, OCC INJ STAT

Garrison LP, 2007, VALUE HEALTH, V10, P326, DOI 10.1111/j.1524-4733.2007.00186.x
Han Q, LANCET, V372, P1439
Health Metrics Network, 2006, CHIN HLTH INF SYST R
International Health Policy Program, 2011, NAT HLTH ACC THAIL 2
Jang SM, 2009, HLTH CARE UTILIZATIO
Jeong HS, 2008, KOREAN J HLTH EC POL, V14, P151
Limwattananon C, 2009, ANAL PRACTICE VARIAT
Liu YL, 2008, LANCET, V372, P1914, DOI 10.1016/S0140-6736(08)61362-8
Ministry of Health Malaysia, 2008, HLTH FACTS
Ministry of Health Malaysia, 2010, REP 3 NAT HLTH MORB
National Bureau of Statistics of China, 2010, CHIN STAT YB 2010
National Health Insurance Corporation, ANN NAT HLTH STAT RE
National Health Research Institute, COLL J ART US NHIRD
Pannarunothai S., 2001, DIAGNOSIS RELATED GR
Park B., 2003, VALIDITY DIAGNOSIS C
Prakongsai P, 2002, J HEALTH SCI, V11, P599
Rahmat R., 2004, 1 AS PAC C PUBL HLTH
Sakunphanit T, 2006, THESIS MAASTRICHT U
Srithamrongsawat S, 2007, J HLTH SYSTEM RES, V1, P47
Tangcharoensathien V, 2001, J HEALTH SCI, V10, P381
Tisayaticom K, 2004, J HEALTH SCI, V12, P907
Vasavid J, 2004, IMPACT UNIVERSAL HEA, P127
World Health Organization, 2009, COUNTR HLTH SYST SUR
World Health Organization and Rockefeller Foundation, 2008, COUNTR HLTH SYST SUR
Zainal Ehsan F, TELEPRIMARY CARE TPC
NR 33
TC 14
Z9 14
U1 0
U2 27
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 1098-3015
J9 VALUE HEALTH
JI Value Health
PD JAN-FEB
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IS 1
SU S
BP S132
EP S138
DI 10.1016/j.jval.2011.11.004
PG 7
WC Economics; Health Care Sciences & Services; Health Policy & Services
SC Business & Economics; Health Care Sciences & Services
GA 879GF
UT WOS:000299317000024
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OA Bronze
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PT J
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```
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AF Haddow, Gill
   Bruce, Ann
   Sathanandam, Shiva
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TI Nothing is really safe': a focus group study on the processes of
   anonymizing and sharing of health data for research purposes
SO JOURNAL OF EVALUATION IN CLINICAL PRACTICE
LA English
DT Article
DE anonymized data; consent; lay views; warehouse model
ID MEDICAL-RECORDS; CONSENT; TRUST
AB Rationale and objectives The availability of anonymized data is a keystone of
medical research, yet little is known about lay views towards the process of
anonymization or on the way that anonymized medical data are transferred to
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FU Chief Scientist's Office; Economic and Social Research Council
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CR Al-Shahi R, 2000, BMJ-BRIT MED J, V321, P1031, DOI 10.1136/bmj.321.7268.1031
   Beck U., 1992, RISK SOC NEW MODERNI
   Damschroder LJ, 2007, SOC SCI MED, V64, P223, DOI
10.1016/j.socscimed.2006.08.045
   Giddens A., 1990, CONSEQUENCES MODERNI
   Haddow G, 2007, SOC SCI MED, V64, P272, DOI 10.1016/j.socscimed.2006.08.028
   Lincoln Y., 1985, NATURALISTIC INQUIRY
   Medical Research Council and Ipsos MORI, 2007, US PERS HLTH INF MED
   O'Neill O, 2003, J MED ETHICS, V29, P4, DOI 10.1136/jme.29.1.4
   O'Neill O., 2002, AUTONOMY TRUST BIOET
   Parker Michael, 2005, J Health Serv Res Policy, V10, P183, DOI
10.1258/1355819054338960
   *PARL OFF SCI TECH, 2005, DAT PROT MED RES
   Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
   Willison DJ, 2003, BRIT MED J, V326, P373, DOI 10.1136/bmj.326.7385.373
   Wynne B, 2006, COMMUNITY GENET, V9, P211, DOI 10.1159/000092659
NR 14
TC 14
Z9 14
U1 1
U2 11
PU WILEY-BLACKWELL
PI MALDEN
```

```
PA COMMERCE PLACE, 350 MAIN ST, MALDEN 02148, MA USA
SN 1356-1294
J9 J EVAL CLIN PRACT
JI J. Eval. Clin. Pract.
PD DEC
PY 2011
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BP 1140
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DI 10.1111/j.1365-2753.2010.01488.x
PG 7
WC Health Care Sciences & Services; Medical Informatics; Medicine, General
   & Internal
SC Health Care Sciences & Services; Medical Informatics; General & Internal
   Medicine
GA 861TR
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ER

PT J
AU Tangcharoensathien, V
   Boonperm, J
   Jongudomsuk, P
AF Tangcharoensathien, Viroj
   Boonperm, Jirawan
   Jongudomsuk, Pongpisut
TI Sharing health data: developing country perspectives
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Editorial Material
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CR LAINE C, 2009, 6 INT C PEER REV BIO
   Lumbiganon P, 2010, LANCET, V375, P490, DOI 10.1016/S0140-6736(09)61870-5
   Mayhew Susannah H, 2008, Health Res Policy Syst, V6, P8, DOI 10.1186/1478-
4505-6-8
   Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   PITAYARANGSARIT S, 2007, SOUND CHOICES ENHANC
   Pitayarangsarit S, 2009, B WORLD HEALTH ORGAN, V87, P72, DOI
10.2471/BLT.07.044479
NR 6
TC 14
Z9 14
U1 0
U2 4
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
J9 B WORLD HEALTH ORGAN
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JI Bull. World Health Organ.
PD JUN
PY 2010
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IS 6
BP 468
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DI 10.2471/BLT.10.079129
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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ER

PT J
AU Callahan, A
   Anderson, KD
   Beattie, MS
   Bixby, JL
   Ferguson, AR
   Fouad, K
   Jakeman, LB
   Nielson, JL
   Popovich, PG
   Schwab, JM
   Lemmon, VP
AF Callahan, Alison
   Anderson, Kim D.
   Beattie, Michael S.
   Bixby, John L.
   Ferguson, Adam R.
   Fouad, Karim
   Jakeman, Lyn B.
   Nielson, Jessica L.
   Popovich, Phillip G.
   Schwab, Jan M.
   Lemmon, Vance P.
CA FAIR Share Workshop Participants
TI Developing a data sharing community for spinal cord injury research
SO EXPERIMENTAL NEUROLOGY
LA English
DT Review
DE FAIR data principles; Reproducibility; Neuroscience; Informatics;
   Workshop proceedings; Open Data Commons
ID COMMON DATA ELEMENTS; BIG DATA; SCALE; INFORMATICS; OPTIMIZE; RECOVERY;
   PATH; BIAS
AB The rapid growth in data sharing presents new opportunities across the
spectrum of biomedical research. Global efforts are underway to develop
practical guidance for implementation of data sharing and open data resources.
These include the recent recommendation of 'FAIR Data Principles', which assert
that if data is to have broad scientific value, then digital representations of
that data should be (F) under bar indable, (A) under bar ccessible, (I) under
bar nteroperable and (R) under bar eusable (FAIR). The spinal cord injury (SCI)
research field has a long history of collaborative initiatives that include
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sharing of pre-clinical research models and outcome measures. In addition, new tools and resources are being developed by the SCI research community to enhance opportunities for data sharing and access. With this in mind, the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH) hosted a workshop on October 5-6, 2016 in Bethesda, MD, in collaboration with the Open Data Commons for Spinal Cord Injury (ODC-SCI) titled "Preclinical SCI Data: Creating a FAIR Share Community". Workshop invitees were nominated by the workshop steering committee (co-chairs: ARF and VPL; members: AC, KDA, MSB, KF, LBJ, PGP, JMS), to bring together junior and senior level experts including preclinical and basic SCI researchers from academia and industry, data science and bioinformatics experts, investigators with expertise in other neurological disease fields, clinical researchers, members of the SCI community, and program staff representing federal and private funding agencies. The workshop and ODC-SCI efforts were sponsored by the International Spinal Research Trust (ISRT), the Rick Hansen Institute, Wings for Life, the Craig H. Neilsen Foundation and NINDS. The number of attendees was limited to ensure active participation and feedback in small groups. The goals were to examine the current landscape for data sharing in SCI research and provide a path to its future. Below are highlights from the workshop, including perspectives on the value of data sharing in SCI research, workshop participant perspectives and concerns, descriptions of existing resources and actionable directions for further engaging the SCI research community in a model that may be applicable to many other areas of neuroscience. This manuscript is intended to share these initial findings with the broader research community, and to provide talking points for continued feedback from the SCI field, as it continues to move forward in the age of data sharing. (C) 2017 Published by Elsevier Inc.

C1 [Callahan, Alison] Stanford Univ, Stanford Ctr Biomed Informat Res, Stanford, CA 94305 USA.
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CR Aguilar RM, 2010, EXP NEUROL, V221, P38, DOI 10.1016/j.expneurol.2009.09.028
Anderson KD, 2009, EXP NEUROL, V220, P23, DOI 10.1016/j.expneurol.2009.08.020
BASSO DM, 1995, J NEUROTRAUM, V12, P1, DOI 10.1089/neu.1995.12.1
Basso DM, 1996, J NEUROTRAUM, V13, P343, DOI 10.1089/neu.1996.13.343
Biering-Sorensen F, 2015, SPINAL CORD, V53, P265, DOI 10.1038/sc.2014.246
Bourne PE, 2015, NATURE, V527, pS16, DOI 10.1038/527S16a
Briggs K. A., 2016, DRUG DISCOV TODAY
Burke DA, 2013, J NEUROTRAUM, V30, P797, DOI 10.1089/neu.2012.2704
Callahan A, 2016, DATABASE-OXFORD, DOI 10.1093/database/baw040
Charlifue S, 2016, ARCH PHYS MED REHAB, V97, P1805, DOI 10.1016/j.apmr.2016.03.030
Courtine G, 2007, NAT MED, V13, P561, DOI 10.1038/nm1595
Dimagl U., 2014, STROKE, V45, P1510
Ferguson AR, 2014, NAT NEUROSCI, V17, P1442, DOI 10.1038/nn.3838
Ferguson AR, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0059712
Ferguson AR, 2011, TRANSL STROKE RES, V2, P438, DOI 10.1007/s12975-011-0121-1
Ferguson AR, 2004, J NEUROTRAUM, V21, P1601, DOI 10.1089/neu.2004.21.1601
Friedli L, 2015, SCI TRANSL MED, V7, DOI 10.1126/scitranslmed.aac5811
Galanopoulou AS, 2013, EPILEPSIA, V54, P1, DOI 10.1111/epi.12293
Irvine KA, 2014, FRONT NEUROL, V5, DOI 10.3389/fneur.2014.00116
Lammertse DP, 2013, SPINAL CORD, V51, P2, DOI 10.1038/sc.2012.137
Landis SC, 2012, NATURE, V490, P187, DOI 10.1038/nature11556
Lemmon VP, 2014, J NEUROTRAUM, V31, P1354, DOI 10.1089/neu.2014.3400
Macleod MR, 2009, STROKE, V40, pE50, DOI 10.1161/STROKEAHA.108.525386
McKiernan EC, 2016, ELIFE, V5, DOI 10.7554/eLife.16800
Nielson JL, 2015, NAT COMMUN, V6, DOI 10.1038/ncomms9581
Nielson JL, 2015, BRAIN RES, V1619, P124, DOI 10.1016/j.brainres.2014.10.048
Nielson JL, 2014, J NEUROTRAUM, V31, P1789, DOI 10.1089/neu.2014.3399
Read KB, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0132735
Sejnowski TJ, 2014, NAT NEUROSCI, V17, P1440, DOI 10.1038/nn.3839
Simard JM, 2012, EXP NEUROL, V233, P829, DOI 10.1016/j.expneurol.2011.11.048
Smith DH, 2015, J NEUROTRAUM, V32, P1725, DOI 10.1089/neu.2014.3861
Stead WW, 1998, J AM MED INFORM ASSN, V5, P583, DOI 10.1136/jamia.1998.0050583
Steckler T, 2015, EUR NEUROPSYCHOPHARM, V25, P1803, DOI 10.1016/j.euroneuro.2015.05.011
Steward O, 2012, EXP NEUROL, V233, P597, DOI 10.1016/j.expneurol.2011.06.017
Thompson HJ, 2015, ANNU REV NURS RES-SE, V33, P1, DOI 10.1891/0739-6686.33.1
Watzlawick R, 2014, JAMA NEUROL, V71, P91, DOI 10.1001/jamaneurol.2013.4684
Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
Young W, 2002, PROG BRAIN RES, V137, P231

```
   Zinner DE, 2016, ACAD MED, V91, P433, DOI 10.1097/ACM.0000000000001028
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U1 0
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TI Promises and pitfalls of data sharing in qualitative research
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LA English
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DE Confidentiality; Data sharing; Ethnography; Mixed methods; Qualitative
   research; Reproducibility; Transparency
ID REPRODUCIBLE RESEARCH; NURSES HEALTH; REPLICATION; DEPRESSION;
   ETHNOGRAPHY; SUPPORT; SCIENCE; ETHICS; TRIAL; SEX
AB The movement for research transparency has gained irresistible momentum over
the past decade. Although qualitative research is rarely published in the high-
impact journals that have adopted, or are most likely to adopt, data sharing
policies, qualitative researchers who publish work in these and similar venues
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will likely encounter questions about data sharing within the next few years. The fundamental ways in which qualitative and quantitative data differ should be considered when assessing the extent to which qualitative and mixed methods researchers should be expected to adhere to data sharing policies developed with quantitative studies in mind. We outline several of the most critical concerns below, while also suggesting possible modifications that may help to reduce the probability of unintended adverse consequences and to ensure that the sharing of qualitative data is consistent with ethical standards in research. (C) 2016 Elsevier Ltd. All rights reserved.

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CR Abramowitz S, 2015, PA STUD HUM RIGHTS, P1, DOI 10.9783/9780812291698
Alexander A, 2012, PERSPECT PSYCHOL SCI, V7, P657, DOI 10.1177/1745691612462588
Ashenfelter O., 1986, AM EC REV, V76
Atkins D, 2004, BMJ-BRIT MED J, V328, P1490
Baez B, 2002, QUALITATIVE RES, V2, P35, DOI DOI 10.1177/1468794102002001638
Bernanke BS, 2004, AM ECON REV, V94, P404
Bernard H. R., 2009, ANAL QUALITATIVE DAT
Bernard H. R., 2006, RES METHODS ANTHR QU
Bloom T, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001607
Broom A, 2009, SOCIOLOGY, V43, P1163, DOI 10.1177/0038038509345704
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI 10.1001/jama.287.4.473
Chandra A, 2015, ETHNOGRAPHY IS LEGIT
Christopoulos KA, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001863
Claerbout J. F., 1992, P 62 ANN INT M SOC E, P601, DOI [10.1190/1.1822162, DOI 10.1190/1.1822162]
Clark JP, 2003, PEER REV HLTH SCI, P219
Clemens M.A., 2016, J EC SURV IN PRESS
Closser S., 2010, CHASING POLIO PAKIST
COHEN J, 1960, EDUC PSYCHOL MEAS, V20, P37, DOI 10.1177/001316446002000104
Colditz GA, 2005, NAT REV CANCER, V5, P388, DOI 10.1038/nrc1608
Colditz GA, 1997, J WOMENS HEALTH, V6, P49, DOI 10.1089/jwh.1997.6.49
Connell L, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001711
Creswell JW, 2011, BEST PRACTICES MIXED

DEWALD WG, 1986, AM ECON REV, V76, P587
Doshi P, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001201
ELLIS C, 1995, J CONTEMP ETHNOGR, V24, P68, DOI 10.1177/089124195024001003
Ellis C., 1986, FISHER FOLK 2 COMMUN
Gandrud Christopher, 2013, REPROD RES R R STUDI
Glaser B, 1967, DISCOVERY GROUNDED T
Glaser BG, 1978, THEORETICAL SENSITIV
Goffman A., 2014, RUN FUGITIVE LIFE AM
Goodman SN, 2016, SCI TRANSL MED, V8, DOI 10.1126/scitranslmed.aaf5027
Goodwin D, 2003, QUAL HEALTH RES, V13, P567, DOI 10.1177/1049732302250723
Greenhalgh T, 2016, BMJ-BRIT MED J, V352, DOI 10.1136/bmj.i563
Groleau Danielle, 2006, Transcult Psychiatry, V43, P671, DOI 10.1177/1363461506070796
Groves T, 2010, BRIT MED J, V340, DOI 10.1136/bmj.c564
Guba E, 1981, EFFECTIVE EVALUATION
GUYATT GH, 1995, JAMA-J AM MED ASSOC, V274, P1800, DOI 10.1001/jama.274.22.1800
Hamermesh DS, 2007, CAN J ECON, V40, P715, DOI 10.1111/j.1365-2966.2007.00428.x
Hanson B, 2011, SCIENCE, V331, P649, DOI 10.1126/science.1203354
Horton R, 1997, LANCET, V349, P6, DOI 10.1016/S0140-6736(05)62158-7
Hrynaszkiewicz I, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-9
Jefferson T, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g2263
Kaiser J, 1997, SCIENCE, V277, P466, DOI 10.1126/science.277.5325.466
Kelly J T, 2011, Confl Health, V5, P25, DOI 10.1186/1752-1505-5-25
KING G, 1995, PS, V28, P444, DOI 10.2307/420301
King R, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0082937
Kohrt B. A., 2010, WAR MACHINE GLOBAL H, P89
Laine C, 2007, ANN INTERN MED, V146, P450, DOI 10.7326/0003-4819-146-6-200703200-00154
LAROSSA R, 1981, J MARRIAGE FAM, V43, P303, DOI 10.2307/351382
Le Noury J, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h4320
LeCompte M. D., 1999, DESIGNING CONDUCTING
Lewis O, 1951, LIFE MEXICAN VILLAGE
Lewis-Kraus G., 2016, NY TIMES MAGAZI 0117, p[31, 56]
Lo C, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0146615
Lounsbury DW, 2007, SOC SCI MED, V64, P213, DOI 10.1016/j.socscimed.2006.08.035
Maman S, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0087091
Markowitz L, 2001, HUM ORGAN, V60, P40, DOI 10.17730/humo.60.1.5777xq9cr9ke4k0e
McCullough BD, 2003, AM ECON REV, V93, P873, DOI 10.1257/000282803322157133
McLellan E., 2003, FIELD METHOD, V15, P63, DOI [10.1177/1525822x02239573, DOI 10.1177/1525822X02239573]
MEIER KJ, 1995, PS, V28, P456, DOI 10.2307/420303
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Michaels D, 2005, AM J PUBLIC HEALTH, V95, pS39, DOI 10.2105/AJPH.2004.043059
Miguel E, 2014, SCIENCE, V343, P30, DOI 10.1126/science.1245317
Morley CA, 2013, J AGGRESS MALTREAT T, V22, P714, DOI 10.1080/10926771.2013.813882
Morse J. M., 2002, INT J QUAL METH, V1, P1, DOI DOI 10.1177/160940690200100202
Muggli ME, 2001, AM J PUBLIC HEALTH, V91, P1419, DOI 10.2105/AJPH.91.9.1419
Nader L, 1969, REINVENTING ANTHR, P284
Natoli L, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0145993
Nosek BA, 2015, SCIENCE, V348, P1422, DOI 10.1126/science.aab2374
O'Brien BC, 2014, ACAD MED, V89, P1245, DOI 10.1097/ACM.0000000000000388
Olken BA, 2015, J ECON PERSPECT, V29, P61, DOI 10.1257/jep.29.3.61

Parkinson SE, 2013, AM POLIT SCI REV, V107, P418, DOI 10.1017/S0003055413000208
Patton M. Q., 2002, QUALITATIVE RES EVAL
Peng RD, 2006, AM J EPIDEMIOL, V163, P783, DOI 10.1093/aje/kwj093
Peng RD, 2009, BIOSTATISTICS, V10, P405, DOI 10.1093/biostatistics/kxp014
Redfield Robert, 1930, TEPORTLAN MEXICAN VI
Rennie D, 1997, JAMA-J AM MED ASSOC, V277, P1238, DOI 10.1001/jama.277.15.1238
Rotheram-Borus MJ, 2015, AM J PREV MED, V49, P715, DOI 10.1016/j.amepre.2015.05.004
RUST RT, 1994, J MARKETING RES, V31, P1, DOI 10.2307/3151942
SCHEPERHUGHES N, 1977, SAINTS SCHOLARS SCHI
SCHEPERHUGHES N, 2000, ETHNOGRAPHY, V1, P117, DOI DOI 10.1177/14661380022230660
Schneider C.J., 2012, RES ELITES CHALLENGE
Shuchman M., 2005, DRUG TRIAL N OLIVIER
Shuval K, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0016937
Smith CT, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0532-z
Stein A, 2010, J CONTEMP ETHNOGR, V39, P554, DOI 10.1177/0891241610375955
Stein Arlene, 2001, STRANGER NEXT DOOR S
Stenbacka C., 2001, MANAGE DECIS, V39, P551, DOI DOI 10.1108/EUM0000000005801
Stodden V., 2014, IMPLEMENTING REPROD
Stodden V, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067111
Tang XF, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0137555
Tolich M., 2004, QUALITATIVE SOCIOLOG, V27, P101, DOI DOI 10.1023/B:QUAS.0000015546.20441.4A
Tong A, 2007, INT J QUAL HEALTH C, V19, P349, DOI 10.1093/intqhc/mzm042
Tsai AC, 2016, SOC SCI MED, V151, P69, DOI 10.1016/j.socscimed.2015.12.042
Tsai AC, 2011, AM J BIOETHICS, V11, P42, DOI 10.1080/15265161.2011.563151
U.S. National Institute of Justice, 2007, PRIV CERT GUID
van den Hoonaard W. C., 2003, J ACAD ETHICS, V1, P141, DOI DOI 10.1023/B:JAET.0000006919.58804.4C
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
Wade AS, 2005, AIDS, V19, P2133, DOI 10.1097/01.aids.0000194128.97640.07
Wolcott H, 1973, MAN PRINCIPALS OFFIC
NR 100
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U2 16
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
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TI Sharing health-related data: a privacy test?
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ID CONFIDENTIALITY; ATTITUDES; RISKS; CARE
AB Greater sharing of potentially sensitive data raises important ethical, legal
and social issues (ELSI), which risk hindering and even preventing useful data
sharing if not properly addressed. One such important issue is respecting the
privacy-related interests of individuals whose data are used in genomic research
and clinical care. As part of the Global Alliance for Genomics and Health
(GA4GH), we examined the ELSI status of health-related data that are typically
considered `sensitive' in international policy and data protection laws. We
propose that 'tiered protection' of such data could be implemented in contexts
such as that of the GA4GH Beacon Project to facilitate responsible data sharing.
To this end, we discuss a Data Sharing Privacy Test developed to distinguish
degrees of sensitivity within categories of data recognised as 'sensitive'.
Based on this, we propose guidance for determining the level of protection when
sharing genomic and health- related data for the Beacon Project and in other
international data sharing initiatives.
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CR Acquisti A, 2015, SCIENCE, V347, P509, DOI 10.1126/science.aaa1465
   American Psychiatric Association, 2013, 5 ED DIAGN STAT MAN
   [Anonymous], 2011, ADV PAP SPEC CAT DAT
   [Anonymous], 2006, GUID DOC TAK PRIV AC
   [Anonymous], 2010, PROT SENS HLTH INF C
```

Balaji D, 2015, GENET TEST MOL BIOMA, V19, P648, DOI 10.1089/gtmb.2015.29008.sjt
Beyleveld D., 2005, DATA PROTECTION DIRE
Bobrow M, 2015, NATURE, V522, P129, DOI 10.1038/522129a
Bovenberg JA, 2016, EUR J HUM GENET, V24, P155, DOI 10.1038/ejhg.2015.43
Bygrave L., 2014, DATA PRIVACY LAW INT
CHENG TL, 1993, JAMA-J AM MED ASSOC, V269, P1404, DOI 10.1001/jama.269.11.1404
Dyke S. O. M., EUR J HUM GENE UNPUB
Dyke SOM, 2015, GENOME BIOL, V16, DOI 10.1186/s13059-015-0723-0
Foster MW, 2004, NAT REV GENET, V5, P467, DOI 10.1038/nrg1351
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Green RC, 2013, GENET MED, V15, P565, DOI 10.1038/gim.2013.73
Greenhalgh T, 2008, BMJ-BRIT MED J, V336, P1290, DOI 10.1136/bmj.a114
Greenleaf G, 2013, PL B INT REP, V123, P10
Hens K, 2011, EUR J HUM GENET, V19, P735, DOI 10.1038/ejhg.2011.29
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Longstaff J, 2005, MED INFORM INTERNET, V30, P157, DOI [10.1080/14639230500298792, 10.1080/14639230500293792]
Lothen-Kline C, 2003, J ADOLESCENT HEALTH, V33, P385, DOI 10.1016/S1054-139X(03)00184-8
Lucente K., 2014, DATA PROTECTION LAWS
Mascalzoni D, 2013, NAT REV GENET, V14, P372, DOI 10.1038/nrg3494
Sankar P, 2003, J GEN INTERN MED, V18, P659, DOI 10.1046/j.1525-1497.2003.20823.x
Shringarpure SS, 2015, AM J HUM GENET, V97, P631, DOI 10.1016/j.ajhg.2015.09.010
Smart A, 2008, SOC STUD SCI, V38, P407, DOI 10.1177/0306312707083759
Vayena E, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001937
Watson MS, 2015, GENET MED, V17, DOI [10.1038/gim.2015.94, 10.1038/gim.2014.151]
Wertz DC, 2002, AM J MED GENET, V108, P29, DOI 10.1002/ajmg.10212
World Health Organization, 2015, INT STAT CLASS DIS R

NR 31
TC 13
Z9 13
U1 1
U2 2

PU SPRINGER NATURE, CO-PUBL CTR EXCELLENCE GENOMIC MED RES
PI LONDON
PA KING ABDULAZIZ UNIV, JEDDAH, SAUDI ARABIA, CAMPUS, 4 CRINAN ST, LONDON, N1 9XW, ENGLAND
SN 2056-7944
J9 NPJ GENOM MED
JI npj Genom. Med.
PD AUG 17
PY 2016
VL 1
AR 16024
DI 10.1038/npjgenmed.2016.24
PG 6

WC Genetics & Heredity
SC Genetics & Heredity
GA FK1JR
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OA DOAJ Gold, Green Accepted, Green Published
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ER

PT J
AU McGrath, SP
Coleman, J
Najjar, L
Fruhling, A
Bastola, DR
AF McGrath, Scott P.
Coleman, Jason
Najjar, Lotfollah
Fruhling, Ann
Bastola, Dhundy R.
TI Comprehension and Data-Sharing Behavior of Direct-To-Consumer Genetic Test Customers
SO PUBLIC HEALTH GENOMICS
LA English
DT Article
DE Data-sharing behavior; Direct-to-consumer genetic test; Honest brokers; Risk comprehension
ID PUBLIC-HEALTH PRACTICE; PERSONALIZED MEDICINE; LITERACY; GENOMICS; SERVICES; IMPACT; TWIN

AB Aim: The aim of this study was to evaluate current direct-to consumer (DTC) genetic customers' ability to interpret and comprehend test results and to determine if honest brokers are needed. Method: One hundred and twenty-two customers of the DTC genetic testing company 23andMe were polled in an online survey. The subjects were asked about their personal test results and to interpret the results of two mock test cases (type 2 diabetes and multiple sclerosis), where results were translated into disease probability for an individual compared to the public. Results: When asked to evaluate the risk, 72.1% correctly assessed the first case and 77% were correct on the second case. Only 23.8% of those surveyed were able to interpret both cases correctly. X-2 and logistic regression were used to interpret the results. Participants who took the time to read the DTC test-provided supplemental material were 3.93 times (p = 0.040) more likely to correctly interpret the test results than those who did not. The odds for correctly interpreting the test cases were 3.289 times (p = 0.011) higher for those who made more than USD 50,000 than those who made less. Survey results were compared to the Health Information National Trends Survey (HINTS) phase 4 cycle 3 data to evaluate national trends. Conclusions: Most of the subjects were able to correctly interpret the test cases, yet a majority did not share their results with a health-care professional. As the market for DTC genetic testing grows, test comprehension will become more critical. Involving more health professionals in this process may be necessary to ensure proper interpretations. (C) 2016 S. Karger AG, Basel

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CR Annas GJ, 2014, NEW ENGL J MED, V370, P985, DOI 10.1056/NEJMp1316367
Bureau of Labor Statistics, 2014, BUR LAB STAT OCC OUT
Collins FS, 2010, LANGUAGE LIFE DNA RE
Commission of the European Communities, 2007, TOG HLTH STRAT APPR
Cornel MC, 2014, J COMMUN GENET, V5, P7, DOI 10.1007/s12687-012-0121-1
Davis TC, 2004, FAM MED, V36, P595
DeBoer GE, 2000, J RES SCI TEACH, V37, P582, DOI 10.1002/1098-2736(200008)37:6<582::AID-TEA5>3.0.CO;2-L

```
   DeNavas-Walt C, 2013, CURRENT POPULATION R, VP60-245
   Dvoskin R, 2011, GPPC RELEASE UPDATED
   Hawkes CH, 1997, QJM-INT J MED, V90, P311, DOI 10.1093/qjmed/90.5.311
   Hogarth S, 2008, ANNU REV GENOM HUM G, V9, P161, DOI
10.1146/annurev.genom.9.081307.164319
   Hunter DJ, 2008, NEW ENGL J MED, V358, P105, DOI 10.1056/NEJMp0708162
   Institute of Medicine (US) Roundtable on Translating Genomic-Based Research
for Health, 2009, INN SERV DEL AG GEN
   Jain KK, 2002, CURR OPIN MOL THER, V4, P548
   Kaufman DJ, 2012, J GENET COUNS, V21, P413, DOI 10.1007/s10897-012-9483-0
   Khoury MJ, 2008, HEALTH AFFAIR, V27, P1600, DOI 10.1377/hlthaff.27.6.1600
   Khoury MJ, 2011, AM J PREV MED, V40, P486, DOI 10.1016/j.amepre.2010.12.009
   Kutner M, 2006, 2006470 NCES
   Lachance CR, 2010, GENET MED, V12, P304, DOI 10.1097/GIM.0b013e3181dbd8b2
   LEIGHTON J, 2011, PUBLIC HEALTH GENOM, V15, P11
   Manolio TA, 2008, J CLIN INVEST, V118, P1590, DOI 10.1172/JCI34772
   National Cancer Institute, 2014, HLTH INF NAT TRENDS
   Nielsen-Bohlman L., 2004, HLTH LITERACY PRESCR
   Ostergren JE, 2015, PUBLIC HEALTH GENOM, V18, P216, DOI 10.1159/000431250
   Poulsen P, 1999, DIABETOLOGIA, V42, P139, DOI 10.1007/s001250051131
   Rubin R., 2015, JAMA, V313, P1306
   Sorensen K, 2012, BMC PUBLIC HEALTH, V12, DOI 10.1186/1471-2458-12-80
   Uscher J., 2013, INCREASING RANKS MED
   Weston AD, 2004, J PROTEOME RES, V3, P179, DOI 10.1021/pr0499693
   Zimmern RL, 2012, PUBLIC HEALTH GENOM, V15, P118, DOI 10.1159/000334840
NR 30
TC 13
Z9 13
U1 1
U2 116
PU KARGER
PI BASEL
PA ALLSCHWILERSTRASSE 10, CH-4009 BASEL, SWITZERLAND
SN 1662-4246
EI 1662-8063
J9 PUBLIC HEALTH GENOM
JI Pub. Health Genomics
PY 2016
VL 19
IS 2
BP 116
EP 124
DI 10.1159/000441177
PG 9
WC Genetics & Heredity; Public, Environmental & Occupational Health
SC Genetics & Heredity; Public, Environmental & Occupational Health
GA DK9GN
UT WOS:000375239000007
PM 26950077
DA 2019-08-06
ER

PT J
AU Whitty, CJM
   Mundel, T
   Farrar, J
   Heymann, DL
   Davies, SC
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   Walport, MJ
AF Whitty, Christopher J. M.
   Mundel, Trevor
   Farrar, Jeremy
   Heymann, David L.
   Davies, Sally C.
   Walport, Mark J.
TI Providing incentives to share data early in health emergencies: the role
   of journal editors
SO LANCET
LA English
DT Editorial Material
ID OUTBREAK
C1 [Whitty, Christopher J. M.] Univ London London Sch Hyg & Trop Med, Dept Clin
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CR Aylward B, 2014, NEW ENGL J MED, V371, P1481, DOI 10.1056/NEJMoa1411100
   De Angelis C, 2004, LANCET, V364, P911, DOI 10.1016/S0140-6736(04)17034-7
   Gire SK, 2014, SCIENCE, V345, P1369, DOI 10.1126/science.1259657
   Groves T., 2015, THE BMJ BLOGS   0908
   Heymann DL, 2004, PHILOS T ROY SOC B, V359, P1127, DOI 10.1098/rstb.2004.1484
   Stanley DA, 2014, NAT MED, V20, P1126, DOI 10.1038/nm.3702
   WHO, 2015, DEV GLOB NORMS SHAR
NR 7
TC 13
Z9 13
U1 0
U2 1
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0140-6736
EI 1474-547X
J9 LANCET
JI Lancet
PD NOV 7
PY 2015
VL 386
IS 10006
BP 1797
EP 1798
DI 10.1016/S0140-6736(15)00758-8
PG 2
WC Medicine, General & Internal
SC General & Internal Medicine
GA CV3VO
UT WOS:000364194700008
PM 26843294
DA 2019-08-06
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ER

PT J
AU Hate, K
   Meherally, S
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   Bull, S
   Parker, M
   Osrin, D
AF Hate, Ketaki
   Meherally, Sanna
   More, Neena Shah
   Jayaraman, Anuja
   Bull, Susan
   Parker, Michael
   Osrin, David
TI Sweat, Skepticism, and Uncharted Territory: A Qualitative Study of
   Opinions on Data Sharing Among Public Health Researchers and Research
   Participants in Mumbai, India
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE data sharing; poverty areas; Mumbai; India; ethics
ID BIG DATA; ETHICS
AB Efforts to internalize data sharing in research practice have been driven
largely by developing international norms that have not incorporated opinions
from researchers in low- and middle-income countries. We sought to identify the
issues around ethical data sharing in the context of research involving women
and children in urban India. We interviewed researchers, managers, and research
participants associated with a Mumbai non-governmental organization, as well as
researchers from other organizations and members of ethics committees. We
conducted 22 individual semi-structured interviews and involved 44 research
participants in focus group discussions. We used framework analysis to examine
ideas about data and data sharing in general; its potential benefits or harms,
barriers, obligations, and governance; and the requirements for consent. Both
researchers and participants were generally in favor of data sharing, although
limited experience amplified their reservations. We identified three themes:
concerns that the work of data producers may not receive appropriate
acknowledgment, skepticism about the process of sharing, and the fact that the
terrain of data sharing was essentially uncharted and confusing. To increase
data sharing in India, we need to provide guidelines, protocols, and examples of
good practice in terms of consent, data preparation, screening of applications,
and what individuals and organizations can expect in terms of validation,
acknowledgment, and authorship.
C1 [Hate, Ketaki; Meherally, Sanna; More, Neena Shah; Jayaraman, Anuja] Soc Nutr
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FU Wellcome Trust [096527]
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behalf of the Public Health Research Data Forum. The Forum brings together more than 20 health research funders, who are committed to increasing the availability of health research data in ways that are equitable, ethical, and efficient, and will accelerate improvements in public health (www.wellcome.ac.uk/publichealthdata).

CR Anderson James R, 2009, IRB, V31, P17
Attride-Stirling J., 1999, QUALITATIVE RES, V1, P385, DOI [10.1177/146879410100100307, DOI 10.1177/146879410100100307]
Bersoff Donald N, 1992, Ethics Behav, V2, P311
Bishop L, 2009, AUST J SOC ISSUES, V44, P255, DOI 10.1002/j.1839-4655.2009.tb00145.x
Budin-Ljosne I, 2014, EUR J HUM GENET, V22, P317, DOI 10.1038/ejhg.2013.131
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Chandramohan D, 2008, PLOS MED, V5, P169, DOI 10.1371/journal.pmed.0050057
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Cooper M, 2007, J EMPIR RES HUM RES, V2, P3, DOI 10.1525/JERHRE.2007.2.1.3
Dawson A, 2011, PUBLIC HEALTH ETH-UK, V4, P1, DOI 10.1093/phe/phr011
Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
Dicks B, 2007, METHODOLOGICAL ISSUE
Greenhalgh T., 2009, BRIT MED J, V338
Harding A, 2012, ENVIRON HEALTH PERSP, V120, P6, DOI 10.1289/ehp.1103904
Indian Council of Medical Research, 2006, ETH GUID BIOM RES HU
Ioannidis JPA, 2013, AM J BIOETHICS, V13, P40, DOI 10.1080/15265161.2013.768864
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Lacey A., 2007, QUALITATIVE DATA ANA
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Larson EB, 2013, JAMA-J AM MED ASSOC, V309, P2443, DOI 10.1001/jama.2013.5914
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Mohammed SA, 2012, NURS INQ, V19, P116, DOI 10.1111/j.1440-1800.2011.00557.x
National Committee for Ethics in Social Science Research in Health, 2000, ETH GUID SOC SCI RES
Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
Office of the Registrar General & Census Commissioner, 2011, 1 GOV IND MIN HOM AF
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pope C, 2000, BMJ-BRIT MED J, V320, P114, DOI 10.1136/bmj.320.7227.114
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Ritchie J, 1994, ANAL QUALITATIVE DAT, P173, DOI DOI 10.4324/9780203413081
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Smith Joanna, 2011, Nurse Res, V18, P52
Srivastava A., 2009, J ADM GOVERNANCE, V4, P72, DOI DOI 10.7748/NR2011.01.18.2.52.C8284
TANGCHAROENSATHIEN V., 2010, B WORLD HEALTH ORGAN, V88, P467
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
Wellcome Trust, 2011, SHAR RES DAT IMPR PU

NR 40
TC 13
Z9 13
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U2 25
PU SAGE PUBLICATIONS INC

PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1556-2646
EI 1556-2654
J9 J EMPIR RES HUM RES
JI J. Empir. Res. Hum. Res. Ethics
PD JUL
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VL 10
IS 3
SI SI
BP 239
EP 250
DI 10.1177/1556264615592383
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WC Ethics; Medical Ethics
SC Social Sciences - Other Topics; Medical Ethics
GA CQ0LF
UT WOS:000360286700004
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OA Green Published, Other Gold
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ER

PT J
AU Jiang, XQ
   Sarwate, AD
   Ohno-Machado, L
AF Jiang, Xiaoqian
   Sarwate, Anand D.
   Ohno-Machado, Lucila
TI Privacy Technology to Support Data Sharing for Comparative Effectiveness
   Research A Systematic Review
SO MEDICAL CARE
LA English
DT Article
DE health privacy; comparative effectiveness research; data sharing
ID GENOMIC DATA PRIVACY; DATA ANONYMIZATION; K-ANONYMITY; MICROAGGREGATION;
   CONFIDENTIALITY; AGGREGATION; FRAMEWORK; ACCURACY; QUERIES; ATTACKS
AB Objective: Effective data sharing is critical for comparative effectiveness research (CER), but there are significant concerns about inappropriate disclosure of patient data. These concerns have spurred the development of new technologies for privacy-preserving data sharing and data mining. Our goal is to review existing and emerging techniques that may be appropriate for data sharing related to CER.

   Materials and Methods: We adapted a systematic review methodology to comprehensively search the research literature. We searched 7 databases and applied 3 stages of filtering based on titles, abstracts, and full text to identify those works most relevant to CER.

   Results: On the basis of agreement and using the arbitrage of a third party expert, we selected 97 articles for meta-analysis. Our findings are organized along major types of data sharing in CER applications (ie, institution-to-institution, institution hosted, and public release). We made recommendations based on specific scenarios. Limitation: We limited the scope of our study to methods that demonstrated practical impact, eliminating many theoretical studies of privacy that have been surveyed elsewhere. We further limited our study to data sharing for data tables, rather than complex genomic, set valued, time series, text, image, or network data.

Conclusion: State-of-the-art privacy-preserving technologies can guide the development of practical tools that will scale up the CER studies of the future. However, many challenges remain in this fast moving field in terms of practical evaluations and applications to a wider range of data types.

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CR Aggarwal G, 2005, LECT NOTES COMPUT SC, V3363, P246
Arasu A, 2011, P 2011 INT C MAN DAT
Barak B, 2007, PRINC DAT SYST PODS
Barak B, 2007, P 26 ACM SIGMOD SIGA
Baumer D., 2000, Computers & Society, V30, P40
BAYARDO RJ, 2005, 21 INT C DAT ENG ICD
Benitez K, 2010, 1 ACM INT HLTH INF S
Bertino E, 2008, ADV DATABASE SYST, V34, P183
Blum A., 2008, P 40 ANN ACM S THEOR
Blum A., 2005, P 24 ACM SIGMOD SIGA
California HealthCare Foundation, 2005, NAT CONS HLTH PRIV S, P1
Cano I, 2009, 2009 IEEE INT C FUZZ
Chaytor R, 2009, 2009 9 IEEE INT C DA
Chen R, 2011, 37 INT C VER LARG DA
Chi-Wing R, 2006, 12 ACM SIGKDD INT C
CLIFTON C, 2006, PRIVACY PRESERVING D
Cormode G., 2011, P 17 ACM SIGKDD INT
Cormode G, 2010, PROC VLDB ENDOW, V3, P1045, DOI 10.14778/1920841.1920972
Dinur Irit, 2003, P 22 ACM SIGMOD SIGA
Domingo-Ferrer J, 2005, DATA MIN KNOWL DISC, V11, P195, DOI 10.1007/s10618-005-0007-5
Domingo-Ferrer J, 2002, IEEE T KNOWL DATA EN, V14, P189, DOI 10.1109/69.979982
Domingo-Ferrer J, 2008, CRITIQUE K ANONYMITY
Domingo-Ferrer J, 2010, INFORM SCIENCES, V180, P2834, DOI 10.1016/j.ins.2010.04.005
DOMINGOFERRER J, 2009, P 2009 EDBT ICDT WOR
Dwork C, 2006, THEOR CRYPT C TCC NE
Dwork C, 2008, LECT NOTES COMPUT SC, V4978, P1, DOI 10.1007/978-3-540-79228-4_1
Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1
El Emam K, 2008, J AM MED INFORM ASSN, V15, P627, DOI 10.1197/jamia.M2716
El Emam K, 2011, J AM MED INFORM ASSN, V18, P212, DOI 10.1136/amiajnl-2011-000100
El Emam K, 2009, J AM MED INFORM ASSN, V16, P670, DOI 10.1197/jamia.M3144
Fayyoumi E, 2010, SOFTWARE PRACT EXPER, V40, P1161, DOI 10.1002/spe.992
Fefferman NH, 2005, J PUBLIC HEALTH POL, V26, P430, DOI 10.1057/palgrave.jphp.3200029
Friedman A, 2010, 16 ACM SIGKDD INT C
Friedman A, 2008, VLDB J, V17, P789, DOI 10.1007/s00778-006-0039-5
Fung BCM, 2009, ACM COMPUT SURV, V42, P1

Fung BCM, 2010, ACM COMPUT SURV, V42, DOI 10.1145/1749603.1749605
Fung BCM, 2009, DATA KNOWL ENG, V68, P552, DOI 10.1016/j.datak.2008.12.001
Ganta S.R., 2008, P 14 ACM SIGKDD INT
Gardner J, 2009, P 12 INT C EXT DAT T
Ghinita G, 2009, ACM T DATABASE SYST, V34, DOI 10.1145/1538909.1538911
Goldberger J, 2009, INT CONF DAT MIN WOR, P106, DOI 10.1109/ICDMW.2009.15
Gouweleeuw J. M., 1998, J OFF STAT, V14, P463
Hansell S, 2006, NY TIMES, V8, pC4
Hay M, 2010, PROC VLDB ENDOW, V3, P1021
Inan A, 2007, DATA KNOWL ENG, V63, P646, DOI 10.1016/j.datak.2007.03.015
Jiang X., 2011, P 2011 WORKSH DAT MI, P64
Jin X, 2010, P 16 ACM SIGKDD INT
Kasiviswanathan SP, 2010, P 42 ACM S THEOR COM
Kifer D., 2006, P 2006 ACM SIGMOD IN
Lasko TA, 2010, IEEE T KNOWL DATA EN, V22, P437, DOI 10.1109/TKDE.2009.88
LEFEVRE K, 2006, 22 INT C DAT ENG ICD
LeFevre K, 2008, ACM T DATABASE SYST, V33, DOI 10.1145/1386118.1386123
Li L., 2011, 5 INT C BIOINF BIOM, P1
Li N, 2007, 23 INT C DAT ENG ICD
Li Y, 2011, WORKSH PRIV EL SOC W
Lindell Y., 2009, J PRIVACY CONFIDENT, V1, P59, DOI DOI 10.29012/JPC.V1I1.566)
Machanavajjhala A., 2007, ACM T KNOWL DISCOV D, V1, P3, DOI DOI 10.1145/1217299.1217302
Machanavajjhala A, 2008, PROC INT CONF DATA, P277, DOI 10.1109/ICDE.2008.4497436
Malin B, 2000, J AM MED INFORM ASSN, P537
Malin B, 2004, J BIOMED INFORM, V37, P179, DOI 10.1016/j.jbi.2004.04.005
Malin B A, 2002, Pac Symp Biocomput, P41
Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
Malin B, 2011, HUM GENET, V130, P383, DOI 10.1007/s00439-011-1042-5
Matthews GJ, 2011, STAT SURV, V5, P1, DOI 10.1214/11-SS074
McGraw D., 2008, WHY HIPAA PRIVACY RU
McGraw D, 2013, J AM MED INFORM ASSN, V20, P29, DOI 10.1136/amiajnl-2012-000936
McSherry F, 2010, COMMUN ACM, V53, P89, DOI 10.1145/1810891.1810916
Mishra DK, 2010, 2010 2 INT C COMP IN, pxxiv
Mohammed N, 2011, INT C KNOWL DISC DAT
Mohammed N, 2010, ACM T KNOWL DISCOV D, V4, DOI 10.1145/1857947.1857950
Muralidhar K, 2010, P 2010 INT C PRIV ST
Murphy SN, 2011, J AM MED INFORM ASSN, V18, pI103, DOI 10.1136/amiajnl-2011-000316
Narayanan A, 2008, 2008 IEEE S SEC PRIV
Nergiz ME, 2011, ACM T DATABASE SYST, V36, DOI 10.1145/1929934.1929936
Nergiz ME, 2010, IEEE T KNOWL DATA EN, V22, P868, DOI 10.1109/TKDE.2009.125
Nergiz Mehmet Ercan, 2007, P 2007 ACM SIGMOD IN, P665
Ohno-Machado L, 2004, INT J MED INFORM, V73, P599, DOI 10.1016/j.ijmedinf.2004.05.002
Ohno-Machado L, 2002, J AM MED INFORM ASSN, V9, pS115, DOI 10.1197/jamia.M1241
Ohrn A, 1999, ARTIF INTELL MED, V15, P235, DOI 10.1016/S0933-3657(98)00056-6
Rastogi V, 2007, 33 INT C VER LARG DA
Rebollo-Monedero D, 2011, DATA KNOWL ENG, V70, P892, DOI 10.1016/j.datak.2011.06.005
Roth A., 2010, P 42 ACM S THEOR COM
Roy I., 2010, P 7 USENIX C NETW SY
Sacharidis D, 2010, IEEE T KNOWL DATA EN, V22, P392, DOI 10.1109/TKDE.2009.120

Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Sweeney L., 1998, 11 INT C DAT SEC 11
Szarvas G, 2007, J AM MED INFORM ASSN, V14, P574, DOI 10.1197/j.jamia.M2441
Tacconelli E, 2010, LANCET INFECT DIS, V10, P1
Tao YF, 2009, IEEE T KNOWL DATA EN, V21, P1073, DOI 10.1109/TKDE.2009.65
Vaidya J, 2002, P 8 ACMSIGKDD INT C
Vaidya J, 2008, KNOWL INF SYST, V14, P161, DOI 10.1007/s10115-007-0073-7
Vinterbo SA, 2011, AMIA SUMM CLIN RES I
Vinterbo SA, 2012, J AM MED INFORM ASSN, V19, P750, DOI 10.1136/amiajnl-2011-000459
Wang K, 2010, INT C DAT MIN
Wasserman L, 2010, J AM STAT ASSOC, V105, P375, DOI 10.1198/jasa.2009.tm08651
Wong R, 2009, J INTELL INF SYST, V33, P209, DOI 10.1007/s10844-008-0075-2
Wong RCW, 2011, ACM T KNOWL DISCOV D, V5, DOI 10.1145/1993077.1993080
Wong RCW, 2009, ACM T DATABASE SYST, V34, DOI 10.1145/1538909.1538910
Wu Y, 2012, J AM MED INFORM ASSN, V19, P758, DOI 10.1136/amiajnl-2012-000862
Xiao XK, 2011, IEEE T KNOWL DATA EN, V23, P1200, DOI 10.1109/TKDE.2010.247
Xiao Xiaokui, 2007, P 2007 ACM SIGMOD IN
Xu Z, 2011, 6 INT C DIG INF MAN
Zhan J, 2008, IEEE COMPUT INTELL M, V3, P31, DOI 10.1109/MCI.2008.919071
Zhang N, 2011, IEEE T KNOWL DATA EN, V23, P122, DOI 10.1109/TKDE.2010.25
Zhang Q, 2007, 23 INT C DAT ENG ICD
Zhao Y, 2009, 2009 1 INT WORKSH DA
NR 106
TC 13
Z9 13
U1 1
U2 22
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
SN 0025-7079
EI 1537-1948
J9 MED CARE
JI Med. Care
PD AUG
PY 2013
VL 51
IS 8
SU 3
BP S58
EP S65
DI 10.1097/MLR.0b013e31829b1d10
PG 8
WC Health Care Sciences & Services; Health Policy & Services; Public, Environmental & Occupational Health
SC Health Care Sciences & Services; Public, Environmental & Occupational Health
GA AJ7ZQ
UT WOS:000337921600009
PM 23774511
OA Green Accepted
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PT J
AU Sankoh, O

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   Ijsselmuiden, C
AF Sankoh, Osman
   Ijsselmuiden, Carel
CA 25 Others
TI Sharing research data to improve public health: a perspective from the
   global south
SO LANCET
LA English
DT Letter
C1 [Sankoh, Osman] INDEPTH Network, Kanda, Accra, Ghana.
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FU Medical Research Council [G0700837]
CR Council on Health Research for Development (COHRED), AR INT HLTH RES PROG
   Kowal P, 2010, GLOBAL HEALTH ACTION, V3, P11, DOI 10.3402/gha.v3i0.5302
   Sack DA, 2009, B WORLD HEALTH ORGAN, V87, P487, DOI 10.2471/BLT.08.058099
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
NR 4
TC 13
Z9 13
U1 0
U2 4
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0140-6736
J9 LANCET
JI Lancet
PD JUL-AUG
PY 2011
VL 378
IS 9789
BP 401
EP 402
DI 10.1016/S0140-6736(11)61211-7
PG 2
WC Medicine, General & Internal
SC General & Internal Medicine
GA 803XM
UT WOS:000293615900028
PM 21803205
DA 2019-08-06
ER

PT J
AU Murdoch, J
   Poland, F
   Salter, C
AF Murdoch, Jamie
   Poland, Fiona
   Salter, Charlotte
TI Analyzing Interactional Contexts in a Data-Sharing Focus Group
SO QUALITATIVE HEALTH RESEARCH
LA English
DT Article
DE communication; discourse analysis; focus groups; medication;
   triangulation
```

ID CHRONIC ILLNESS; HEALTH; MEDICATION; ASTHMA; MANAGEMENT; ADHERENCE; PSYCHOLOGY; ACCOUNTS; PEOPLE; ADULTS

AB In this article we describe the use of a data-sharing focus group for triangulation with face-to-face interviews. In contrast to member-checking triangulation, this focus group was undertaken to provide a different interactional context to analyze moral discourses in talk about asthma medicine taking. Using principles of discursive psychology to analyze data, participants adopted strategies to manage dilemmas of identification with research findings. Talk about medicine taking was contextualized to the demands of the interaction. Strategies included avoiding direct reference to findings; collectively aligning with medical perspectives; and using stories to carry opinions. Participants also expressed moral discourses around managing asthma in everyday life. These discursive variations strengthened assertions of the role of morality in participants' talk and highlighted advantages in engaging with participants' strategies in focus groups. Different viewpoints identified in this research create problems for member checking, suggesting that researchers need to be sensitive in considering methods of sharing data with participants.

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CR Adams S, 1997, SOC SCI MED, V45, P189, DOI 10.1016/S0277-9536(96)00333-4
Bloor M, 1997, CONTEXT METHOD QUALI, P37
Brondani MA, 2008, QUAL HEALTH RES, V18, P1145, DOI 10.1177/1049732308320114
Burawoy M, 2003, AM SOCIOL REV, V68, P645, DOI 10.2307/1519757
Clavering EK, 2007, QUAL HEALTH RES, V17, P400, DOI 10.1177/1049732306298380
Cornwell J., 1984, HARD EARNED LIVES AC
Crawford R., 1984, ISSUES POLITICAL EC
Crossley ML, 2002, SOC SCI MED, V55, P1471, DOI 10.1016/S0277-9536(01)00265-9
CROSSWAITE C, 1994, HEALTH PROMOT INT, V9, P289, DOI 10.1093/heapro/9.4.289
Edwards D, 1992, DISCURSIVE PSYCHOL
Frank Arthur W., 1995, WOUNDED STORYTELLER
Galvin R, 2002, HEALTH, V6, P107, DOI 10.1177/136345930200600201
Gillies V, 1997, J COMMUNITY APPL SOC, V7, P285, DOI 10.1002/(SICI)1099-1298(199709)7:4<285::AID-CASP407>3.0.CO;2-N
Horne R, 2002, PSYCHOL HEALTH, V17, P17, DOI 10.1080/08870440290001502
Horton-Salway M, 2001, J HEALTH PSYCHOL, V6, P247, DOI 10.1177/135910530100600210
Karnieli-Miller O, 2009, QUAL HEALTH RES, V19, P279, DOI 10.1177/1049732308329306
KITZINGER J, 1994, SOCIOL HEALTH ILL, V16, P103, DOI 10.1111/1467-9566.ep11347023
Lincoln Y., 1985, NATURALISTIC INQUIRY
Lumme-Sandt K, 2002, SOCIOL HEALTH ILL, V24, P285, DOI 10.1111/1467-9566.00295
Lumme-Sandt K, 2000, SOC SCI MED, V50, P1843, DOI 10.1016/S0277-9536(99)00421-9
MURDOCH J, 2010, THESIS U E ANGLIA
Naidoo P, 2009, QUAL HEALTH RES, V19, P55, DOI 10.1177/1049732308327893
Potter Jonathan, 1987, DISCOURSE SOCIAL PSY
Protudjer JLP, 2009, QUAL HEALTH RES, V19, P94, DOI 10.1177/1049732308327348
Prout A, 1999, SOCIOL HEALTH ILL, V21, P137, DOI 10.1111/1467-9566.00147
Puchta C., 2004, FOCUS GROUP PRACTICE
Radley A, 1996, SOCIOL HEALTH ILL, V18, P220, DOI 10.1111/1467-9566.ep10934984
Redmond R, 2008, QUAL HEALTH RES, V18, P1501, DOI 10.1177/1049732308325538

SCHEPERHUGHES N, 2000, ETHNOGRAPHY, V1, P117, DOI DOI 10.1177/14661380022230660
Varenne Herve, 1998, SUCCESSFUL FAILURE
Vermeire E, 2001, J CLIN PHARM THER, V26, P331, DOI 10.1046/j.1365-2710.2001.00363.x
Williams G, 1993, WORLDS ILLNESS BIOGR, P92
Willig C, 2000, THEOR PSYCHOL, V10, P547, DOI 10.1177/0959354300104006
Wong WKT, 2008, QUAL HEALTH RES, V18, P458, DOI 10.1177/1049732308314852
NR 34
TC 13
Z9 14
U1 1
U2 13
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1049-7323
J9 QUAL HEALTH RES
JI Qual. Health Res.
PD MAY
PY 2010
VL 20
IS 5
BP 582
EP 594
DI 10.1177/1049732310361612
PG 13
WC Information Science & Library Science; Social Sciences, Interdisciplinary; Social Sciences, Biomedical
SC Information Science & Library Science; Social Sciences - Other Topics; Biomedical Social Sciences
GA 585TD
UT WOS:000276851100002
PM 20154297
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ER

PT J
AU Pu, CY
Lan, V
Chou, YJ
Lan, CF
AF Pu, Cheng-yun
Lan, Virginia
Chou, Yiing-Jenq
Lan, Chung-fu
TI The crowding-out effects of tobacco and alcohol where expenditure shares are low: Analyzing expenditure data for Taiwan
SO SOCIAL SCIENCE & MEDICINE
LA English
DT Article
DE smoking; alcohol; household expenditure; household budget; crowding-out; Taiwan
ID INSTRUMENTAL VARIABLES; CIGARETTE PRICES; ECONOMIC BURDEN; SMOKING; CONSUMPTION; INCREASES; IMPACT; CHINA; WEAK
AB In this paper, we used data from the 2004 Survey of Family Income & Expenditure of Taiwan to show that the problem of the crowding-out effects of tobacco and alcohol in a country with low expenditure can still be serious. Most

studies that have investigated this issue have focused on developing countries with a high expenditure share on tobacco or alcohol, and have often overlooked the effects in countries with a low expenditure on such goods. After controlling for the endogencity of tobacco and alcohol expenditure, and the possibility that households with a zero expenditure on tobacco and alcohol may result from a corner solution rather than abstention, we found that the lowest income households are still most vulnerable to tobacco and alcohol expenditures despite an overall low expenditure in Taiwan. Even higher income households may suffer a lower standard of living due to such expenditure. In addition, some goods and services may be perceived differently by households with different levels of income and this may be caused by the difference in composition across broad expenditure categories. Our results suggest that the government ought to tackle the problem of smoking and drinking outside the realm of health, since these expenditures may burnt the country's standard of living even when there is high income. (c) 2008 Elsevier Ltd. All rights reserved.

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CR Banks J, 1997, REV ECON STAT, V79, P527, DOI 10.1162/003465397557015
BERIK G, 2005, 200505 U UTAH US DEP
Bonu S, 2005, HEALTH POLICY PLANN, V20, P41, DOI 10.1093/heapol/czi005
BOUND J, 1995, J AM STAT ASSOC, V90, P443, DOI 10.2307/2291055
BUSCH S, 2004, 1094 NBER
CRUZ L, 2005, J HUM RESOUR, V4, P393
Decker SL, 2000, 7535 NAT BUR EC RES
Efroymson D, 2001, TOB CONTROL, V10, P212, DOI 10.1136/tc.10.3.212
Emery S, 2000, AM J PUBLIC HEALTH, V90, P387, DOI 10.2105/AJPH.90.3.387
Guindon GE, 2002, TOB CONTROL, V11, P35, DOI 10.1136/tc.11.1.35
Hu SC, 2005, EUR J PUBLIC HEALTH, V15, P270, DOI 10.1093/eurpub/cki057
Hu TW, 2006, TOB CONTROL S1, V15, P37
JOHN R, 2006, CROWDING OUT EFFECT
Kang HY, 2003, TOB CONTROL, V12, P37, DOI 10.1136/tc.12.1.37
Liu YL, 2006, SOC SCI MED, V63, P2784, DOI 10.1016/j.socscimed.2006.06.019
Max W, 2004, TOB CONTROL, V13, P264, DOI 10.1136/tc.2003.006023
MCCLELLAN M, 1994, JAMA-J AM MED ASSOC, V272, P859, DOI 10.1001/jama.272.11.859
McGhee SM, 2006, TOB CONTROL, V15, P125, DOI 10.1136/tc.2005.013292
Papke LE, 1996, J APPL ECONOM, V11, P619, DOI 10.1002/(SICI)1099-1255(199611)11:6<619::AID-JAE418>3.0.CO;2-1
PIERANI P, 2006, ANN C EUR SOC POP EC
Siahpush M, 2004, TOB CONTROL, V13, P409, DOI 10.1136/tc.2003.004770
Siahpush M, 2003, J EPIDEMIOL COMMUN H, V57, P798, DOI 10.1136/jech.57.10.798
Staiger D, 1997, ECONOMETRICA, V65, P557, DOI 10.2307/2171753
SUNG HY, 2006, TOB CONTROL S1, V15, P5
Tsai YW, 2005, HEALTH ECON, V14, P627, DOI 10.1002/hec.972
Vermeulen F., 2003, EC B, V4, P1
Wang H, 2006, SOC SCI MED, V62, P1414, DOI 10.1016/j.socscimed.2005.07.032
Yang MC, 2005, TOB CONTROL S1, V14, pi62

NR 28
TC 13
Z9 14
U1 0
U2 0

PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0277-9536
J9 SOC SCI MED
JI Soc. Sci. Med.
PD MAY
PY 2008
VL 66
IS 9
BP 1979
EP 1989
DI 10.1016/j.socscimed.2008.01.007
PG 11
WC Public, Environmental & Occupational Health; Social Sciences, Biomedical
SC Public, Environmental & Occupational Health; Biomedical Social Sciences
GA 296XY
UT WOS:000255580400012
PM 18313191
DA 2019-08-06
ER

PT J
AU Zhang, AQ
   Lin, XD
AF Zhang, Aiqing
   Lin, Xiaodong
TI Towards Secure and Privacy-Preserving Data Sharing in e-Health Systems
   via Consortium Blockchain
SO JOURNAL OF MEDICAL SYSTEMS
LA English
DT Article
DE Blockchain; Security; Privacy preservation; e-Health; Personal Health
   Information (PHI)
ID PROXY RE-ENCRYPTION; KEYWORD SEARCH; CLOUDS
AB Electronic health record sharing can help to improve the accuracy of
diagnosis, where security and privacy preservation are critical issues in the
systems. In recent years, blockchain has been proposed to be a promising
solution to achieve personal health information (PHI) sharing with security and
privacy preservation due to its advantages of immutability. This work proposes a
blockchain-based secure and privacy-preserving PHI sharing (BSPP) scheme for
diagnosis improvements in e-Health systems. Firstly, two kinds of blockchains,
private blockchain and consortium blockchain, are constructed by devising their
data structures, and consensus mechanisms. The private blockchain is responsible
for storing the PHI while the consortium blockchain keeps records of the secure
indexes of the PHI. In order to achieve data security, access control, privacy
preservation and secure search, all the data including the PHI, keywords and the
patients' identity are public key encrypted with keyword search. Furthermore,
the block generators are required to provide proof of conformance for adding new
blocks to the blockchains, which guarantees the system availability. Security
analysis demonstrates that the proposed protocol can meet with the security
goals. Furthermor, we implement the proposed scheme on JUICE to evaluate the
performance.
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1808085MF164]; Anhui Provincial Key Laboratory of Network and
Information Security [AHNIS2018003]; Scientific Research Staring
Foundation of Anhui Normal University [2014bsqdjj38]
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Provincial Key Laboratory of Network and Information Security (Grant No.
AHNIS2018003), and Scientific Research Staring Foundation of Anhui
Normal University (Grant No. 2014bsqdjj38).

CR Abbas A, 2014, IEEE J BIOMED HEALTH, V18, P1431, DOI
10.1109/JBHI.2014.2300846
Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG
DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11
Baek J., 2008, INT C COMP SCI ITS A
Bethencourt J., 2006, IEEE S SEC PRIV BERK, P21
Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P506
Boneh D, 2007, LECT NOTES COMPUT SC, V4392, P535
Castro M., 1999, 3 S OP SYST DES IMPL
Chang S, 2016, IEEE T VEH TECHNOL, V65, P4900, DOI 10.1109/TVT.2015.2466651
Dorri A, 2017, IEEE COMMUN MAG, V55, P119, DOI 10.1109/MCOM.2017.1700879
Esposito C, 2018, IEEE CLOUD COMPUT, V5, P31
HL7, HL7 FAST HEALTHC INT
Hu CY, 2012, J COMPUT, V7, P716, DOI 10.4304/jcp.7.3.716-723
Kuo TT, 2017, J AM MED INFORM ASSN, V24, P1211, DOI 10.1093/jamia/ocx068
Leftwich R., PATH DERIVING CLIN V
Novo O, 2018, IEEE INTERNET THINGS, V5, P1184, DOI 10.1109/JIOT.2018.2812239
Ogata W, 2004, J COMPLEXITY, V20, P356, DOI 10.1016/j.jco.2003.08.023
Peterson K., BLOCKCHAIN BASED APP
Ryu E., 2007, IEEE 21 INT C ADV IN, P21
Shae Z., 2017, INT C DISTR COMP SYS
Shao J, 2010, INFORM SCIENCES, V180, P2576, DOI 10.1016/j.ins.2010.03.026
Shen QH, 2014, IEEE J BIOMED HEALTH, V18, P430, DOI 10.1109/JBHI.2013.2292829
Wang JZ, 2018, IEEE ACCESS, V6, P17545, DOI 10.1109/ACCESS.2018.2805837
Wang XA, 2012, J SYST SOFTWARE, V85, P643, DOI 10.1016/j.jss.2011.09.035
Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843
Xia Q, 2017, INFORMATION, V8, DOI 10.3390/info8020044
Yang Y, 2016, IEEE T INF FOREN SEC, V11, P746, DOI 10.1109/TIFS.2015.2509912
Yau W., 2010, INT C SECTECH DRBC J, P13
Yue X, 2016, J MED SYST, V40, DOI 10.1007/s10916-016-0574-6
Zhang J, 2016, IEEE ACCESS, V4, P9239, DOI 10.1109/ACCESS.2016.2645904
Zhang Z., IEEE T CLOUD COMPUT, DOI [10.1109/TCC.2017.2685583, DOI
10.1109/TCC.2017.2685583]
Zhao H., 2017, IEEE INT S AUT DEC S, P22
Zhou J, 2015, IEEE J-STSP, V9, P1332, DOI 10.1109/JSTSP.2015.2427113
Zyskind G., 2015, IEEE SEC PRIV WORKSH, P18

NR 33
TC 12
Z9 13
U1 32
U2 107
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA

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SN 0148-5598
EI 1573-689X
J9 J MED SYST
JI J. Med. Syst.
PD AUG
PY 2018
VL 42
IS 8
AR 140
DI 10.1007/s10916-018-0995-5
PG 18
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA GL1NB
UT WOS:000436868700002
PM 29956061
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ER

PT J
AU Conde-Sala, JL
   Portellano-Ortiz, C
   Calvo-Perxas, L
   Garre-Olmo, J
AF Conde-Sala, Josep L.
   Portellano-Ortiz, Cristina
   Calvo-Perxas, Laia
   Garre-Olmo, Josep
TI Quality of life in people aged 65+in Europe: associated factors and
   models of social welfare-analysis of data from the SHARE project (Wave
   5)
SO QUALITY OF LIFE RESEARCH
LA English
DT Article
DE Ageing; Quality of life; European countries; Health; Socioeconomic
   factors; Models of social welfare
ID OLDER EUROPEANS; SUICIDE; MORTALITY; HEALTH; DEPRESSION; HAPPINESS;
   SYMPTOMS; DECLINE; DISEASE; MARKERS
AB To analyse the clinical, sociodemographic and socioeconomic factors that
influence perceived quality of life (QoL) in a community sample of 33,241 people
aged 65+ and to examine the relationship with models of social welfare in Europe.
   This was a cross-sectional study of data from Wave 5 (2013) of the Survey of
Health, Ageing and Retirement in Europe (SHARE). The instruments used in the
present study were as follows: sociodemographic data, CASP-12 (QoL), EURO-D
(depression), indicators of life expectancy and suicide (WHO), and economic
indicators (World Bank). Statistical analysis included bivariate and multilevel
analyses.
   In the multilevel analysis, greater satisfaction in life, less depression,
sufficient income, better subjective health, physical activity, an absence of
functional impairment, younger age and participation in activities were
associated with better QoL in all countries. More education was only associated
with higher QoL in Eastern European and Mediterranean countries, and only in the
latter was caring for grandchildren also related to better QoL. Socioeconomic
indicators were better and QoL scores higher (mean = 38.5 +/- 5.8) in countries
that had a social democratic (Nordic cluster) or corporatist model (Continental
cluster) of social welfare, as compared to Eastern European and Mediterranean
countries, which were characterized by poorer socioeconomic conditions, more
limited social welfare provision and lower QoL scores (mean = 33.5 +/- 6.4).
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Perceived quality-of-life scores are consistent with the sociodemographic and clinical characteristics of participants, as well as with the socioeconomic indicators and models of social welfare of the countries in which they live.

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RI Calvo-Perxas, Laia/K-9557-2016; Garre-Olmo, Josep/D-8460-2011; Conde-Sala, Josep Lluis/C-5995-2011
OI Calvo-Perxas, Laia/0000-0001-8618-504X; Garre-Olmo, Josep/0000-0002-7817-0814; Conde-Sala, Josep Lluis/0000-0003-4139-0458; Portellano-Ortiz, Cristina/0000-0003-1069-4803; Portellano-Ortiz, Cristina/0000-0001-8477-4684

FU European Commission 7th Framework Programme (SHARE M4) [261982]
FX The study received funding from European Commission 7th Framework Programme (SHARE M4, No 261982). Project: SHARE (Survey of Health, Ageing and Retirement in Europe).

CR Blane D, 2008, SOC SCI MED, V66, P1579, DOI 10.1016/j.socscimed.2007.12.021
Bray I, 2006, SOC PSYCH PSYCH EPID, V41, P333, DOI 10.1007/s00127-006-0049-z
COHEN J, 1973, EDUC PSYCHOL MEAS, V33, P107, DOI 10.1177/001316447303300111
Cohen J., 1988, STAT POWER ANAL BEHA
European Commission, 2013, QUAL LIF EUR SUBJ WE, P5
Hooghe M, 2011, SUICIDE LIFE-THREAT, V41, P453, DOI 10.1111/j.1943-278X.2011.00047.x
Hyde M, 2003, AGING MENT HEALTH, V7, P186, DOI 10.1080/1360786031000101157
Khazaee-Pool M, 2015, J PSYCHIATR MENT HLT, V22, P47, DOI 10.1111/jpm.12168
Knoops KTB, 2004, JAMA-J AM MED ASSOC, V292, P1433, DOI 10.1001/jama.292.12.1433
KUYKEN W, 1995, SOC SCI MED, V41, P1403
Layte R, 2013, J AM GERIATR SOC, V61, pS299, DOI 10.1111/jgs.12198
Malter F, 2015, SHARE WAVE 5 INNOVAT, DOI 10.1002/wdev.204
Mathers CD, 2015, LANCET, V385, P540, DOI 10.1016/S0140-6736(14)60569-9
Morin J, 2013, AM J GERIAT PSYCHIAT, V21, P196, DOI 10.1016/j.jagp.2012.10.020
Motel-Klingebiel A, 2009, EUR J AGEING, V6, P67, DOI 10.1007/s10433-009-0112-1
Murray CJL, 2013, LANCET, V381, P997, DOI 10.1016/S0140-6736(13)60355-4
Netuveli G, 2006, J EPIDEMIOL COMMUN H, V60, P357, DOI 10.1136/jech.2005.040071
Neuberger FS, 2014, EUR J AGEING, V11, P171, DOI 10.1007/s10433-013-0294-4
Niedzwiedz CL, 2014, EUR J PUBLIC HEALTH, V24, P364, DOI 10.1093/eurpub/cku017
Nimrod G, 2016, J GERONTOL B-PSYCHOL, V71, P106, DOI 10.1093/geronb/gbu143
Palgi Y, 2015, QUAL LIFE RES, V24, P1835, DOI 10.1007/s11136-015-0918-6
Pardo A, 2007, PSICOTHEMA, V19, P308
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Sapir A, 2006, JCMS-J COMMON MARK S, V44, P369, DOI 10.1111/j.1468-5965.2006.00627.x
Schaan B, 2013, J GERONTOL B-PSYCHOL, V68, P431, DOI 10.1093/geronb/gbt015
Sexton E, 2015, AGING MENT HEALTH, V19, P622, DOI 10.1080/13607863.2014.955457
Shrira A, 2014, AGING MENT HEALTH, V18, P610, DOI 10.1080/13607863.2013.860951
Shrira A, 2012, INT PSYCHOGERIATR, V24, P1988, DOI 10.1017/S1041610212001123

```
   Siegrist J, 2009, J EUR SOC POLICY, V19, P317, DOI 10.1177/1350506809341513
   Spoerri A, 2010, INT J EPIDEMIOL, V39, P1486, DOI 10.1093/ije/dyq141
   Titelman D, 2013, NORD J PSYCHIAT, V67, P414, DOI
10.3109/08039488.2012.752036
   Von dem Knesebeck O., 2005, HLTH AGEING RETIREME, P199
   Knesebeck OV, 2007, AGEING SOC, V27, P269, DOI 10.1017/S0144686X06005484
   Watzka C, 2012, NEUROPSYCHIATRIE, V26, P95, DOI 10.1007/s40211-012-0039-1
   Whelan CT, 2010, J EUR SOC POLICY, V20, P316, DOI 10.1177/0958928710374378
   Wikman A, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018952
   World Bank, 2013, GDP PER CAP PPP CURR
   World Health Organization, 2014, PREV SUIC GLOB IMP, P80
   World Health Organization (WHO), 2013, LIF EXP BIRTH HLTH L
   Wu J, 2014, EUR J AGEING, V11, P131, DOI 10.1007/s10433-013-0297-1
NR 40
TC 12
Z9 13
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U2 48
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PI DORDRECHT
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AU Tomini, F
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TI Understanding the value of social networks in life satisfaction of
   elderly people: a comparative study of 16 European countries using SHARE
   data
SO BMC GERIATRICS
LA English
DT Article
DE Life satisfaction; Size of social networks; Composition of social
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networks; Older adults; Europe; Survey of health; Aging and retirement

ID QUALITY-OF-LIFE; LONG-TERM-CARE; NATIONAL SAMPLE; HEALTH-STATUS; SURVIVAL; SUPPORT; OLDEST; TIES; MORTALITY; DISEASE

AB Background: Networks of family and friends are a source of support and are generally associated with higher life satisfaction values among older adults. On the other hand, older adults who are satisfied with their life may be more able to develop and maintain a wider social network. For this reason, the causal link between size and composition of the social networks and satisfaction with life is yet to be explored. This paper investigates the effect of the 'size', (number of family and friends, and network) and the 'composition' (the proportion of friends over total number of persons) of the social network on life satisfaction among older adults (50+). Moreover, we also investigate the patterns of this relation between different European countries.

Method: Data from the 4th wave of Survey of Health, Ageing and Retirement in Europe and an instrumental variable approach are used to estimate the extent of the relation between life satisfaction and size and composition of social networks.

Results: Respondents in Western and Northern European (WNE) countries report larger networks than respondents in Eastern and Southern European (ESE) countries. However, the positive relationship between network size and life satisfaction is consistent across countries. On the other hand, the share of friends in the network appears to be generally negatively related to satisfaction with life, though results are not statistically significant for all countries.

Conclusions: Apparently, a larger personal network is important for older adults (50+) to be more satisfied with life. Our results suggest that this relation is particularly positive if the network is comprised of family members.

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FU European Commission [QLK6-CT-2001-00360, SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812, 211909, 227822, 261982]; German Ministry of Education and Research; U.S. National Institute on Aging [U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064]

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CR Achat H, 1998, QUAL LIFE RES, V7, P735, DOI 10.1023/A:1008837002431
Angelini V, 2012, SOC INDIC RES, V105, P293, DOI 10.1007/s11205-011-9882-x
Angrist JD, 1996, J AM STAT ASSOC, V91, P444, DOI 10.2307/2291629
Auer P, 2000, INT LABOUR REV, V139, P379, DOI 10.1111/j.1564-913X.2000.tb00525.x
BALDASSARE M, 1984, RES AGING, V6, P549, DOI 10.1177/0164027584006004006
Baum C.F., 2003, STATA J, V3, P1, DOI DOI 10.1177/1536867X0300300101
Baxter J, 1998, J AGING HEALTH, V10, P287, DOI 10.1177/089826439801000302
Beckie TM, 1997, SOC INDIC RES, V42, P21, DOI 10.1023/A:1006881931793
Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
Bonsang E, 2009, J HEALTH ECON, V28, P143, DOI 10.1016/j.jhealeco.2008.09.002
BOUND J, 1995, J AM STAT ASSOC, V90, P443, DOI 10.2307/2291055
BOWLING A, 1991, J GERONTOL, V46, pS20, DOI 10.1093/geronj/46.1.S20
BURT RS, 1987, SOC NETWORKS, V9, P311, DOI 10.1016/0378-8733(87)90002-5
Choi NG, 1996, SOC WORK RES, V20, P52
Damiani G, 2011, BMC HEALTH SERV RES, V11, DOI 10.1186/1472-6963-11-316
Diener E, 1997, SOC INDIC RES, V40, P189, DOI 10.1023/A:1006859511756
Diener E, 2002, PSYCHOL SCI, V13, P81, DOI 10.1111/1467-9280.00415
Flori KL, 2006, J GERONTOL B-PSYCHOL, V61, pP25
George LK., 1992, EC STATUS SUBJECTIVE
Giles LC, 2005, J EPIDEMIOL COMMUN H, V59, P574, DOI 10.1136/jech.2004.025429
Gonzalez L, 2009, EUR ECON REV, V53, P127, DOI 10.1016/j.euroecorev.2008.05.005
Groot W, 2007, SOC INDIC RES, V82, P189, DOI 10.1007/s11205-006-9035-9
Guilley E, 2005, AGING CLIN EXP RES, V17, P419
HAUSMAN JA, 1978, ECONOMETRICA, V46, P1251, DOI 10.2307/1913827
Haythornthwaite C., 2005, Information Communication & Society, V8, P125, DOI 10.1080/13691180500146185
Haythornthwaite C, 2002, INFORM SOC, V18, P385, DOI 10.1080/01972240290108195
Helliwell JF, 2004, PHILOS T R SOC B, V359, P1435, DOI 10.1098/rstb.2004.1522
Holt-Lunstad J, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000316
Santini ZI, 2015, SOC SCI MED, V147, P134, DOI 10.1016/j.socscimed.2015.10.061
Kawachi I, 2001, J URBAN HEALTH, V78, P458, DOI 10.1093/jurban/78.3.458
Kawachi I, 1996, J EPIDEMIOL COMMUN H, V50, P245, DOI 10.1136/jech.50.3.245
Keller-Cohen D, 2006, AGEING SOC, V26, P585, DOI 10.1017/S0144686X06004910
Landau R, 2001, INT J AGING HUM DEV, V52, P265, DOI 10.2190/RUMT-YCDX-X5HP-P2VH
LARSON R, 1978, J GERONTOL, V33, P109, DOI 10.1093/geronj/33.1.109
Lee R., 2006, J HAPPINESS STUD, V7, P87, DOI DOI 10.1007/S10902-005-1915-1
Lim C, 2010, AM SOCIOL REV, V75, P914, DOI 10.1177/0003122410386686
Litwin H, 1998, SOC SCI MED, V46, P599, DOI 10.1016/S0277-9536(97)00207-4
Litwin H., 2013, SHARE WAVE 4 INNOVAT, P18
Litwin H, 2015, EUR J AGEING, V12, P299, DOI 10.1007/s10433-015-0347-y
Litwin H, 2013, AGEING SOC, V33, P1263, DOI 10.1017/S0144686X12000645
Litwin H, 2011, GERONTOLOGIST, V51, P379, DOI 10.1093/geront/gnq094
Malter F, 2013, SHARE WAVE 4 INNOVAT
Martikainen L, 2009, J HAPPINESS STUD, V10, P721, DOI 10.1007/s10902-008-9117-2
McIntosh CN, 2001, SOC INDIC RES, V54, P37, DOI 10.1023/A:1007264829700
Neves BB, 2015, INT REV SOCIOL, V25, P415, DOI 10.1080/03906701.2015.1050307
Osterle A, 2010, SOC POLICY ADMIN, V44, P461, DOI 10.1111/j.1467-9515.2010.00723.x
Pavot W, 2009, SOC INDIC RES SER, V39, P101, DOI 10.1007/978-90-481-2354-4_5
PERRY CM, 1994, INT J AGING HUM DEV, V38, P41, DOI 10.2190/UQKB-EL57-TN8R-3W1A
Pinquart M, 2000, PSYCHOL AGING, V15, P187, DOI 10.1037//0882-7974.15.2.187

```
   Rafnsson SB, 2015, J AGING HEALTH, V27, P919, DOI 10.1177/0898264315572111
   Reher DS, 1998, POPUL DEV REV, V24, P203, DOI 10.2307/2807972
   Reher DS, 2005, STRONG FAMILY LOW FE, P45
   Rodriguez-Laso A, 2007, BMC GERIATR, V7, P1
   Rozer J, 2016, SOC INDIC RES, V127, P809, DOI 10.1007/s11205-015-0987-5
   SEEMAN TE, 1988, SOC SCI MED, V26, P737, DOI 10.1016/0277-9536(88)90065-2
   Silverman P, 2000, J Cross Cult Gerontol, V15, P289, DOI
10.1023/A:1006793304508
   SPREITZER E, 1974, J GERONTOL, V29, P454, DOI 10.1093/geronj/29.4.454
   Staiger D, 1997, ECONOMETRICA, V65, P557, DOI 10.2307/2171753
   Stock J.H., 2005, TESTING WEAK INSTRUM
   SUGISAWA H, 1994, J GERONTOL, V49, pS3, DOI 10.1093/geronj/49.1.S3
   Thrane Gyrd, 2007, BMC Geriatr, V7, P1, DOI 10.1186/1471-2318-7-1
   Urry J., 2006, MOBILITIES, V1, P261, DOI DOI 10.1080/17450100600726654
   USUI WM, 1985, J GERONTOL, V40, P110, DOI 10.1093/geronj/40.1.110
   van der Horst M, 2012, SOC INDIC RES, V107, P509, DOI 10.1007/s11205-011-
9861-2
   VOGT TM, 1992, J CLIN EPIDEMIOL, V45, P659, DOI 10.1016/0895-4356(92)90138-D
   Wooldridge J., 2012, INTRO ECONOMETRICS M
   WU DM, 1973, ECONOMETRICA, V41, P733, DOI 10.2307/1914093
   ZELLNER A, 1962, ECONOMETRICA, V30, P54, DOI 10.2307/1911287
   Zou X, 2015, MOTIV EMOTION, V39, P693, DOI 10.1007/s11031-015-9490-1
NR 69
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Z9 13
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PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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   Helinski, M
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   Littler, K
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   Littler, Katherine
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   Serafini, Micaela
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OI Pisani, Elizabeth/0000-0002-3674-631X; Merson,
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   Trish/0000-0001-7915-6419; Aaby, Peter/0000-0001-8331-1389; Carr,
   David/0000-0003-1435-307X
FU Wellcome Trust
CR Aaby P, 2014, PLOS MED, V11
   Achan J, 2013, PLOS MED, V10, DOI 10.1371/journal.pmed.1001564
   [Anonymous], 2016, CLIN STUDY DATA REQU
```

Arthur SS, 2015, GLOBAL HEALTH ACTION, V8, P1, DOI 10.3402/gha.v8.28298
Binka F, 2005, TROP MED INT HEALTH, V10, P207, DOI 10.1111/j.1365-3156.2004.01373.x
Carter P, 2015, J MED ETHICS, V41, P404, DOI 10.1136/medethics-2014-102374
Chatham House Data Sharing Advisory Group, 2016, PUBL HLTH SURV CALL
Devereaux PJ, 2016, NEW ENGL J MED, V375, P405, DOI 10.1056/NEJMp1605654
Diouara AAM, 2014, J INT AIDS SOC, V17, DOI 10.7448/IAS.17.1.19315
Ekouevi DK, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0066135
European Medicines Agency, 2015, EUR MED AG POL PUBL
Haug CJ, 2016, NEW ENGL J MED, V374, P2409, DOI 10.1056/NEJMp1605378
Jao I, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135545
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Jumbe NL, 2016, NEW ENGL J MED, V374, P2415, DOI 10.1056/NEJMp1605441
Klein SL, 2016, MBIO, V7, DOI 10.1128/mBio.00514-16
Kok MO, 2016, HEALTH RES POLICY SY, V14, DOI 10.1186/s12961-016-0107-2
Krumholz HM, 2014, CIRC-CARDIOVASC QUAL, V7, P499, DOI 10.1161/CIRCOUTCOMES.114.001166
Le Noury J, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h4320
Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
Merson L, 2016, NEW ENGL J MED, V374, P2414, DOI 10.1056/NEJMp1605148
Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374
Phrma, 2013, PRINC RESP CLIN TRIA
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Poespoprodjo JR, 2015, MALARIA J, V14, DOI 10.1186/s12936-015-0794-0
Republic of Indonesia Ministry of Health Statistics Indonesia Family Health International, 2010, BEH DRUG TAK RISK BE
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Sharing Clinical Trial Data, 2015, SHARING CLIN TRIAL D
Taichman DB, 2016, JAMA-J AM MED ASSOC, V315, P467, DOI 10.1001/jama.2015.18164
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Wellcome Trust, 2008, SHAR PUBL HLTH DAT C
World Health Organization, 2015, GUID TREATM MAL
Yozwiak NL, 2015, NATURE, V518, P477, DOI 10.1038/518477a
NR 35
TC 12
Z9 12
U1 1
U2 13
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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TI A Study to Determine the Most Popular Lifestyle Smartphone Applications and Willingness of the Public to Share Their Personal Data for Health Research
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DT Article
DE data access; data sharing; m-health; smartphone; apps; public health
ID WEIGHT-LOSS; MOBILE; INFORMATION; APPS; OBESITY; MANAGEMENT; PRIVACY
AB Introduction: Smartphone lifestyle applications (apps) and wearable fitness-tracking devices collect a wealth of data that could provide research insights to support prevention and treatment of obesity and chronic diseases. The aim of this study was to pilot a survey to explore patterns of behavioral tracking using smartphone lifestyle apps and individuals' willingness to share their app-generated data. Methods: A cross-sectional Web-based survey was conducted within a university setting. The 35-item survey asked participants about their self-tracking patterns; use of lifestyle apps and wearable devices; how their self-tracked health data could be useful to them; and any restrictions they would impose on sharing personal data. Responses were tabulated and analyzed for trends. Results: The survey was completed by 101 participants. On average, 3.1 (standard deviation [SD] +/- 1.9) health and fitness apps were installed by current app users (n = 85), with MyFitnessPal, MapMyRun, Nike+, and Fitbit being most popular. Most participants were willing to share their personal health data for research (77%). Those who did not normally share their health-tracking data were more likely than sharers to be concerned about privacy (odds ratio [OR] = 5.93; 95% confidence interval [95% CI] = 2.09-16.78), as were those not identifying with the quantified-self movement compared with those who were (OR = 5.04; 95% CI = 1.64-15.50). Discussion: Participants were generally willing to share personal data, thus increasing the potential for these data to inform public health research and for use in targeted personalized program and intervention development. Conclusions: Opportunities for partnerships between researchers and commercial app developers or industry could improve public health research and practice.
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CR Acquisti A, 2013, J LEGAL STUD, V42, P249, DOI 10.1086/671754
   Aguilar-Martinez A, 2014, J TELEMED TELECARE, V20, P339, DOI 10.1177/1357633X14537777

Australian Communications and Media Authority, 2013, MOB APPS PUTT SMART
Australian Communications Consumer Action Network, 2013, APP PURCHASES BY AUS
Azar KMJ, 2013, AM J PREV MED, V45, P583, DOI 10.1016/j.amepre.2013.07.005
Boyles JL, 2012, PRIVACY DATA MANAGEM
Breton ER, 2011, TRANSL BEHAV MED, V1, P523, DOI 10.1007/s13142-011-0076-5
Brouwer Y, EXPLORING DIFFERENCE
Carter MC, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2283
Chen Juliana, 2015, JMIR Mhealth Uhealth, V3, pe104, DOI 10.2196/mhealth.4334
Cho J, 2014, J MED INTERNET RES, V16, P206, DOI 10.2196/jmir.3283
Choe Eun Kyoung, 2014, P 32 ANN ACM C HUM F, P1143, DOI [10.1145/2556288.2557372, DOI 10.1145/2556288.2557372]
Dehling T, 2015, JMIR MHEALTH UHEALTH, V3, DOI 10.2196/mhealth.3672
Dennison L, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2583
Direito A, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-646
Farago P, 2012, APP ENGAGEMENT MATRI
Fox S, 2013, TRACKING FOR HLTH
Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
Gan KO, 2011, AUST NZ J PUBL HEAL, V35, P293, DOI 10.1111/j.1753-6405.2011.00707.x
IBM-United States. Chicago, 2013, IBM SPSS STAT VERS 2
Jeon E, 2014, HEALTHC INFORM RES, V20, P23, DOI 10.4258/hir.2014.20.1.23
Khalaf S, 2014, HLTH FITNESS APPS FI
Kotz D, 2011, P 3 INT C COMM SYST, P1
Kutz D, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2124
Li I, 2010, CHI2010: PROCEEDINGS OF THE 28TH ANNUAL CHI CONFERENCE ON HUMAN FACTORS IN COMPUTING SYSTEMS, VOLS 1-4, P557
Lieffers JRL, 2014, CAN J DIET PRACT RES, V75, P41, DOI 10.3148/75.1.2014.41
Newman MW, 2011, P ACM 2011 C COMP SU, P341, DOI DOI 10.1145/1958824.1958876
Pagoto S, 2013, AM J PREV MED, V45, P576, DOI [10.1016/j.amepre.2013.04.025, 10.1016/j.amepre.2013.04.006]
Patrick K, 2014, PERSONAL DATA PUBLIC
Pew Research Center, 2014, FUT PRIV
PRWeb, 2011, MOT PAT US SMARTPH H
Roberto CA, 2015, LANCET, V385, P2400, DOI 10.1016/S0140-6736(14)61744-X
Sama PR, 2014, JMIR MHEALTH UHEALTH, V2, DOI 10.2196/mhealth.3088
Sano A, 2015, HEALTHAWARE ADVICE S
Sassi F, 2010, OBESITY EC PREVENTIO
Thomas SL, 2008, NUTR J, V7, DOI 10.1186/1475-2891-7-34
Tilenius S, 2013, WILL APP DAY KEEP DO
Wang YC, 2011, LANCET, V378, P815, DOI 10.1016/S0140-6736(11)60814-3
West JH, 2012, J MED INTERNET RES, V14, P184, DOI 10.2196/jmir.1977
WHO, 2014, GLOBAL STATUS REPORT ON VIOLENCE PREVENTION 2014, P1

NR 40
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AU Jao, I
   Kombe, F
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AF Jao, Irene
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   Marsh, Vicki
TI Research Stakeholders' Views on Benefits and Challenges for Public
   Health Research Data Sharing in Kenya: The Importance of Trust and
   Social Relations
SO PLOS ONE
LA English
DT Article
ID EXPERIENCES; PERSPECTIVE; ISSUES
AB Background There is increasing recognition of the importance of sharing
research data within the international scientific community, but also of the
ethical and social challenges this presents, particularly in the context of
structural inequities and varied capacity in international research. Public
involvement is essential to building locally responsive research policies,
including on data sharing, but little research has involved stakeholders from
low-to-middle income countries.
   Methods Between January and June 2014, a qualitative study was conducted in
Kenya involving sixty stakeholders with varying experiences of research in a
deliberative process to explore views on benefits and challenges in research
data sharing. In-depth interviews and extended small group discussions based on
information sharing and facilitated debate were used to collect data. Data were
analysed using Framework Analysis, and charting flow and dynamics in debates.
   Findings The findings highlight both the opportunities and challenges of
communicating about this complex and relatively novel topic for many
stakeholders. For more and less research-experienced stakeholders, ethical
research data sharing is likely to rest on the development and implementation of
appropriate trust-building processes, linked to local perceptions of benefits
and challenges. The central nature of trust is underpinned by uncertainties
around who might request what data, for what purpose and when. Key benefits
perceived in this consultation were concerned with the promotion of public
health through science, with legitimate beneficiaries defined differently by
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different groups. Important challenges were risks to the interests of study participants, communities and originating researchers through stigmatisation, loss of privacy, impacting autonomy and unfair competition, including through forms of intentional and unintentional 'misuse' of data. Risks were also seen for science.

Discussion Given background structural inequities in much international research, building trust in this low-to-middle income setting includes ensuring that the interests of study participants, primary communities and originating researchers will be promoted as far as possible, as well as protected. Important ways of building trust in data sharing include involving the public in policy development and implementation, promoting scientific collaborations around data sharing and building close partnerships between researchers and government health authorities to provide checks and balances on data sharing, and promote near and long-term translational benefits.

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CR Abelson J, 2003, SOC SCI MED, V57, P239, DOI 10.1016/S0277-9536(02)00343-X
[Anonymous], 2014, PLOS J
[Anonymous], SCIENCE
Benatar SR, 2010, J MED ETHICS, V36, P194, DOI 10.1136/jme.2009.032672
Bull S, 2015, JERHRE IN PRESS, V10
Bull S, 2015, J EMPIRICAL IN PRESS, V10
Burgess Michael M, 2004, J Bioeth Inq, V1, P4, DOI 10.1007/BF02448901
Cheah P, 2015, JERHRE IN PRESS, V10
Cheah P, 2015, J EMPIRICAL IN PRESS, V10
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201
Cowgill KD, 2006, JAMA-J AM MED ASSOC, V296, P671, DOI 10.1001/jama.296.6.671
Denny S, 2015, JERHRE IN PRESS, V10
Denny SG, 2015, J EMPIRICAL IN PRESS, V10
ESRC, 2010, RES DAT POL 2010
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
Gilson L, 2003, SOC SCI MED, V56, P1453, DOI 10.1016/S0277-9536(02)00142-9
Green J, 2007, QUALITATIVE METHODS
Hate K, 2015, J EMPIRICAL IN PRESS, V10

Hate K, 2015, JERHRE IN PRESS, V10
Hawkins AK, 2010, NEW GENET SOC, V29, P311, DOI 10.1080/14636778.2010.507487
IJsselmuiden CB, 2010, GLOB PUBLIC HEALTH, V5, P154, DOI 10.1080/17441690903436599
Jao I, 2015, J EMPIRICAL IN PRESS, V10
Kamuya DM, 2013, DEV WORLD BIOETH, V13, P10, DOI 10.1111/dewb.12014
Kamuya DM, 2013, DEV WORLD BIOETH, V13, P1, DOI 10.1111/dewb.12009
Marsh V, 2013, BMC MED ETHICS, V14, DOI 10.1186/1472-6939-14-41
Marsh VM, 2010, BMC MED ETHICS, V11, DOI 10.1186/1472-6939-11-13
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merson L, 2015, J EMPIRICAL IN PRESS, V10
Merson L, 2015, JERHRE IN PRESS, V10
Molster C, 2013, HEALTH EXPECT, V16, P211, DOI 10.1111/j.1369-7625.2011.00701.x
Molyneux S, 2012, BMC MED ETHICS, V13, DOI 10.1186/1472-6939-13-13
MRC, 2014, MRC DAT SHAR 2014
National Institutes of Health, 2014, NIH DAT SHAR POL 201
Nature, 2014, NATURE
Njue M, 2015, PLOS ONE
Parker M, 2007, PRINCIPLES HLTH CARE
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Parkin D, 1991, SACRED VOID SPATIAL
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129
Tindana P, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-76
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
Virtual Kenya, VIRT KEN 2011
Wellcome Trust, 2010, POL DAT MAN SHAR 201
NR 50
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PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
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TI Sharing Public Health Research Data: Toward the Development of Ethical
   Data-Sharing Practice in Low- and Middle-Income Settings
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE biomedical research ethics; data sharing; data release; research data;
   research governance; low-income countries
ID INDIVIDUAL PATIENT DATA; LEVEL DATA; CLINICAL-TRIALS; VIEWS;
   EXPERIENCES; ACCESS; BENEFITS; GENOME; TRUST
AB It is increasingly recognized that effective and appropriate data sharing
requires the development of models of good data-sharing practice capable of
taking seriously both the potential benefits to be gained and the importance of
ensuring that the rights and interests of participants are respected and that
risk of harms is minimized. Calls for the greater sharing of individual-level
data from biomedical and public health research are receiving support among
researchers and research funders. Despite its potential importance, data sharing
presents important ethical, social, and institutional challenges in low-income
settings. In this article, we report on qualitative research conducted in five
low- and middle-income countries exploring the experiences of key research
stakeholders and their views about what constitutes good data-sharing practice.
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   increasing the availability of health research data in ways that are
   equitable, ethical, and efficient, and will accelerate improvements in
   public health. (See www.wellcome.ac.uk/publichealthdata)
CR Abbott A, 2014, NATURE, V505, DOI 10.1038/nature.2014.15410
   [Anonymous], 2009, NATURE, V461, P168
   Antman E, 2014, BRIT MED J, P348
   Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
   Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
   Castellani J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f1881
   Caulfield T, 2008, PLOS BIOL, V6, P430, DOI 10.1371/journal.pbio.0060073
   Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
   Cooper M, 2007, J EMPIR RES HUM RES, V2, P3, DOI 10.1525/JERHRE.2007.2.1.3
   de Vries J, 2012, J MED ETHICS, V38, P474, DOI 10.1136/medethics-2011-100448
   de Vries J, 2011, BMC MED ETHICS, V12, DOI 10.1186/1472-6939-12-5
   de Wolf Virginia A, 2006, IRB, V28, P6
   Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
```

Doshi P, 2013, TRENDS PHARMACOL SCI, V34, P645, DOI 10.1016/j.tips.2013.10.006
Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
European Medicines Agency, 2014, EUR MED AG POL PUBL
Exeter DJ, 2014, HEALTH POLICY, V114, P88, DOI 10.1016/j.healthpol.2013.07.012
Expert Advisory Group on Data Access, 2013, STAT EAGDA FUND REID
Expert Advisory Group on Data Access, 2014, EST INC CHANG CULT S
Ezzy D., 2002, QUALITATIVE ANAL PRA
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
Godlee F., 2012, BRIT MED J, P345
Goldacre B., 2014, BRIT MED J, P348
Goldacre B., 2013, BRIT MED J, P347
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Green J, 2007, QUALITATIVE METHODS
Greenhalgh T., 2009, BRIT MED J, V338
Haga SB, 2011, PUBLIC HEALTH GENOM, V14, P319, DOI 10.1159/000324705
Harris DJ, 2011, LANCET, V378, P1994, DOI 10.1016/S0140-6736(11)61869-2
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Hawkes N., 2013, BRIT MED J, P346
Herriott R., 1983, ED RES, V12, P14, DOI DOI 10.3102/0013189X012002014
Hughes S, 2014, PHARM STAT, V13, P179, DOI 10.1002/pst.1615
Human Genome Organisation, 1996, 1 INT STRAT M HUM GE
Human Genome Organisation, 1997, 2 INT STRAT M HUM GE
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Kim SYH, 2009, J EMPIR RES HUM RES, V4, P3, DOI 10.1525/jer.2009.4.4.3
Kirwan JR, 1997, J RHEUMATOL, V24, P822
Kuehn B. M., 2014, J AM MED ASS, V311
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Lowrance WW, 2007, SCIENCE, V317, P600, DOI 10.1126/science.1147699
Marsh V, 2008, SOC SCI MED, V67, P721, DOI 10.1016/j.socscimed.2008.02.007
Medical Research Council, 2011, MRC POL RES DAT SHAR
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Molster C, 2013, HEALTH EXPECT, V16, P211, DOI 10.1111/j.1369-7625.2011.00701.x
National Institutes of Health, 2003, FIN NIH STAT SHAR RE
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Office of Civil Rights, 2012, GUID REG METH DEID P
Parker M., 2007, PRINCIPLES HLTH CARE, P185
Parker M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000143
Pearce N., 2011, ENVIRON HEALTH-GLOB, P10
Pharmaceutical Research and Manufacturers of America European Federation of Pharmaceutical Industries and Associations, 2013, PRINC RESP CLIN TRIA
Pisani E., 2010, LANCET, V375
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
Rabesandratana T, 2013, SCIENCE, V339, P1369, DOI 10.1126/science.339.6126.1369
Rani Manju, 2011, J Evid Based Med, V4, P204, DOI 10.1111/j.1756-5391.2011.01161.x
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Rathi V., 2012, BRIT MED J, P345
Research Information Network, 2008, SHAR NOT SHAR RES DA
Sankoh O, 2011, LANCET, V378, P401, DOI 10.1016/S0140-6736(11)61211-7
Sherman JE, 2007, STUD FAMILY PLANN, V38, P309, DOI 10.1111/j.1728-4465.2007.00143.x

```
   Sieber Joan E, 1989, IRB, V11, P4, DOI 10.2307/3564184
   Smith Joanna, 2011, Nurse Res, V18, P52
   Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI
10.2471/BLT.10.079129
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   The Wellcome Trust, 2003, M ORG WELLC TRUST FO
   Tindana P, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-76
   UK Data Archive, 2011, ESS UK TOR INT DAT R
   Vallance P, 2013, LANCET, V382, P1073, DOI 10.1016/S0140-6736(13)62001-2
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wellcome Trust, 2009, POL DAT MAN SHAR
   White PD, 2013, BMJ-BRIT MED J, V346, DOI 10.1136/bmj.f3379
   Whitworth J, 2010, B WORLD HEALTH ORGAN, V88, P467, DOI 10.2471/BLT.10.079202
   Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
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Nguyen Van Kinh
Parker, Michael
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TI Trust, Respect, and Reciprocity: Informing Culturally Appropriate
Data-Sharing Practice in Vietnam
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Article
DE data sharing; clinical data; ethics; biomedical data; Vietnam;
qualitative methods; information dissemination; access to information
ID PUBLIC-HEALTH RESEARCH; VIEWS; EXPERIENCES; CONSENT; ACCESS

AB International science funders and publishers are driving a growing trend in data sharing. There is mounting pressure on researchers in low- and middle-income settings to conform to new sharing policies, despite minimal empirically grounded accounts of the ethical challenges of implementing the policies in these settings. This study used in-depth interviews and focus group discussions with 48 stakeholders in Vietnam to explore the experiences, attitudes, and expectations that inform ethical and effective approaches to sharing clinical research data. Distinct views on the role of trust, respect, and reciprocity were among those that emerged to inform culturally appropriate best practices. We conclude by discussing the challenges that authors of data-sharing policies should consider in this unique context.

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CR [Anonymous], 2015, NATURE J
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Council for International Organizations of Medical Sciences World Health Organization, 2002, INT ETH GUID BIOM RE
Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
Donnelly TT, 2006, CAN J NURS RES, V38, P83
European Federation of Pharmaceutical Industries and Associations & The Pharmaceutical Research and Manufacturers of America, 2014, JOINT PRINC RESP CLI
Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7888
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249

Ha Noi School of Public Health, 2014, PHD PUBL HLTH DEGR
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Ho Chi Minh City Department of Health, 2011, OFF INSTR MAN SCI RE
Human Genome Organisation, 1997, INT STRAT M HUM GEN
Human Genome Organisation, 1996, 2 INT STRAT M HUM GE
International Committee of Medical Journal Editors, 2013, DEF ROL AUTH CONTR
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Lairumbi GM, 2011, BMC MED ETHICS, V12, DOI 10.1186/1472-6939-12-22
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Mascalzoni D, 2008, PLOS MED, V5, P1302, DOI 10.1371/journal.pmed.0050192
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Murphy J, 2009, AM J PUBLIC HEALTH, V99, P2128, DOI 10.2105/AJPH.2008.157099
NIH, 2015, NIH SHAR POL REL GUI
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Public Library of Science, 2015, PLOS ED PUBL POL SHA
Rani M, 2012, B WORLD HEALTH ORGAN, V90, P932, DOI 10.2471/BLT.12.105908
Rising K, 2008, PLOS MED, V5, P1561, DOI 10.1371/journal.pmed.0050217
Rohlfing T, 2012, NEUROIMAGE, V59, P4189, DOI 10.1016/j.neuroimage.2011.09.080
Sahoo U, 2012, WOODH PUB SER BIOMED, P1
Science Magazine, 2015, SCI MAGAZINE
Smith Joanna, 2011, Nurse Res, V18, P52
Smith R, 2006, PLOS CLIN TRIALS, V1, DOI 10.1371/journal.pctr.0010006
Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI 10.2471/BLT.10.079129
The Association of Learned & Professional Society Publishers, 2014, ALPSP STM BEL DAT S
The Interacademy Medical Panel, 2013, CALL ACT STRENGTH HL
The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
Thomas DR, 2006, AM J EVAL, V27, P237, DOI 10.1177/1098214005283748
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
Vietnam Ministry of Health & General Statistics Office of Vietnam, 2003, ICPSR24387V1 VIETN M, DOI [10.3886/ICPSR24387.v1, DOI 10.3886/ICPSR24387.V1]
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
Wellcome Trust, 2010, POL DAT MAN SHAR
Wertheim H., 2014, INT PRESENCE RES ASI, P33

NR 43
TC 12
Z9 12
U1 0
U2 9
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1556-2646
EI 1556-2654
J9 J EMPIR RES HUM RES
JI J. Empir. Res. Hum. Res. Ethics
PD JUL
PY 2015
VL 10
IS 3
SI SI
BP 251
EP 263
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PG 13
WC Ethics; Medical Ethics
SC Social Sciences - Other Topics; Medical Ethics
GA CQ0LF
UT WOS:000360286700005
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OA Other Gold, Green Published
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ER

PT J
AU Felix, B
   Danan, C
   Van Walle, I
   Lailler, R
   Texier, T
   Lombard, B
   Brisabois, A
   Roussel, S
AF Felix, Benjamin
   Danan, Corinne
   Van Walle, Ivo
   Lailler, Renaud
   Texier, Thomas
   Lombard, Bertrand
   Brisabois, Anne
   Roussel, Sophie
TI Building a molecular Listeria monocytogenes database to centralize and
   share PFGE typing data from food, environmental and animal strains
   throughout Europe
SO JOURNAL OF MICROBIOLOGICAL METHODS
LA English
DT Article
DE European Union Reference Laboratory; Food chain; Listeria monocytogenes;
   PFGE; Surveillance; Typing database
ID FIELD GEL-ELECTROPHORESIS; PROFICIENCY TESTING TRIALS; PULSENET;
   HARMONIZATION
AB The European Union Reference Laboratory (EURL) for Listeria monocytogenes (Lm)
collaborates with a network of 35 National Reference Laboratories (NRLs)
throughout Europe. Most of these NRLs are in charge of detecting and typing Lm
strains from food, environment and animals, which are isolated nationally. The
past few years EURL activities have enabled NRLs to reinforce typing
capabilities according to standardised protocols. Consequently the need to
exchange typing data within the NRL network has emerged. That is why the EURL
has recently set up a EURL Lm Database (EURL Lm DB). Each NRL contributes data,
which is then shared within the network. Data include strain-typing-results
(PFGE and serotyping) and epidemiological information on the strains.
   This article describes (1) the EURL typing activities that led to the
creation of the EURL Lm DB, (2) the different steps involved in developing the
EURL Lm DB, and (3) the usefulness of this database for public health.
   The combined use of this database, with databases on human strains, is being
integrated into the European surveillance system of Lm strains circulating
throughout Europe. It should improve the detection of this pathogen and provide
support for outbreak investigations. (C) 2014 Elsevier B.V. All rights reserved.
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FU European Commission's Directorate General for Health and Consumer
Protection (DG SANCO) [C(2010)8344 - 2010-12-01, C(2011) 9521 -
2011-12-21, C(2013) 1628 - 2013-03-22, C(2014)27 - 2014-01-24]
FX This work was conducted as part of the activities of the European Union
Reference Laboratory for Listeria monocytogenes and was supported by a
grant from the European Commission's Directorate General for Health and
Consumer Protection (DG SANCO), grant numbers, for 2011 C(2010)8344 -
2010-12-01, for 2012 C(2011) 9521 - 2011-12-21, for 2013 C(2013) 1628 -
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manuscript
CR Cdc U, 2010, MMWR-MORBID MORTAL W, V60, P401
ECDC (European Centre for Disease Prevention and Control), 2014, EXT QUAL ASS SCHEM L
EFSA, 2012, EFSA J, V10, P2597, DOI DOI 10.2903/J.EFSA.2012.2597
European Food Safety Authority (EFSA) BIOHAZ Panel, 2013, EFSA J, V11
Felix B, 2012, GEL ELECTROPHORESIS, V1, P241
Felix B, 2013, FOODBORNE PATHOG DIS, V10, P873, DOI 10.1089/fpd.2013.1494
Felix B, 2012, FOODBORNE PATHOG DIS, V9, P719, DOI 10.1089/fpd.2011.1124
Gerner-Smidt P, 2006, FOODBORNE PATHOG DIS, V3, P9, DOI 10.1089/fpd.2006.3.9
Gilmour MW, 2010, BMC GENOMICS, V11, DOI 10.1186/1471-2164-11-120
Graves LM, 2001, INT J FOOD MICROBIOL, V65, P55, DOI 10.1016/S0168-1605(00)00501-8
Laksanalamai P, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0042448
Li Wei, 2012, Front Med, V6, P366, DOI 10.1007/s11684-012-0214-6
Lombard B., 2012, Accreditation and Quality Assurance, V17, P223, DOI 10.1007/s00769-012-0879-1
Martin P, 2006, FOODBORNE PATHOG DIS, V3, P303, DOI 10.1089/fpd.2006.3.303
Pagotto F, 2006, FOODBORNE PATHOG DIS, V3, P132, DOI 10.1089/fpd.2006.3.132
Quested TE, 2010, INT J FOOD MICROBIOL, V139, pS29, DOI 10.1016/j.ijfoodmicro.2010.01.043
Swaminathan B, 2001, EMERG INFECT DIS, V7, P382
Swaminathan B, 2006, FOODBORNE PATHOG DIS, V3, P36, DOI 10.1089/fpd.2006.3.36
van Walle I., 2013, EUR SURVEILL, V18
NR 19
TC 12
Z9 12
U1 1
U2 10
PU ELSEVIER SCIENCE BV
PI AMSTERDAM

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PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0167-7012
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J9 J MICROBIOL METH
JI J. Microbiol. Methods
PD SEP
PY 2014
VL 104
BP 1
EP 8
DI 10.1016/j.mimet.2014.06.001
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WC Biochemical Research Methods; Microbiology
SC Biochemistry & Molecular Biology; Microbiology
GA AO0GJ
UT WOS:000340986800001
PM 24918990
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ER

PT J
AU de Carvalho, ECA
   Batilana, AP
   Simkins, J
   Martins, H
   Shah, J
   Rajgor, D
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   Pietrobon, R
AF de Carvalho, Elias Cesar Araujo
   Batilana, Adelia Portero
   Simkins, Julie
   Martins, Henrique
   Shah, Jatin
   Rajgor, Dimple
   Shah, Anand
   Rockart, Scott
   Pietrobon, Ricardo
TI Application Description and Policy Model in Collaborative Environment
   for Sharing of Information on Epidemiological and Clinical Research Data
   Sets
SO PLOS ONE
LA English
DT Article
ID BIOMEDICAL-RESEARCH; HEALTH
AB Background: Sharing of epidemiological and clinical data sets among
researchers is poor at best, in detriment of science and community at large. The
purpose of this paper is therefore to (1) describe a novel Web application
designed to share information on study data sets focusing on epidemiological
clinical research in a collaborative environment and (2) create a policy model
placing this collaborative environment into the current scientific social
context.
   Methodology: The Database of Databases application was developed based on
feedback from epidemiologists and clinical researchers requiring a Web-based
platform that would allow for sharing of information about epidemiological and
clinical study data sets in a collaborative environment. This platform should
ensure that researchers can modify the information. A Model-based predictions of
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number of publications and funding resulting from combinations of different policy implementation strategies (for metadata and data sharing) were generated using System Dynamics modeling.

Principal Findings: The application allows researchers to easily upload information about clinical study data sets, which is searchable and modifiable by other users in a wiki environment. All modifications are filtered by the database principal investigator in order to maintain quality control. The application has been extensively tested and currently contains 130 clinical study data sets from the United States, Australia, China and Singapore. Model results indicated that any policy implementation would be better than the current strategy, that metadata sharing is better than data-sharing, and that combined policies achieve the best results in terms of publications.

Conclusions: Based on our empirical observations and resulting model, the social network environment surrounding the application can assist epidemiologists and clinical researchers contribute and search for metadata in a collaborative environment, thus potentially facilitating collaboration efforts among research communities distributed around the globe.

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FU Claude D. Pepper Older Americans Independence Centers (OAICs); National Institute on Aging (NIA) Older Americans Independence Centers; Department of Health and Human Services Public Health Services

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CR Anderson NR, 2007, J AM MED INFORM ASSN, V14, P478, DOI 10.1197/jamia.M2114
BAYER S, 2007, P 2007 INT C SYST DY
Bayer S, 2007, SYST DYNAM REV, V23, P61, DOI 10.1002/sdr.361
Bogue MA, 2007, NUCLEIC ACIDS RES, V35, pD643, DOI 10.1093/nar/gkl1049
BORSHCHEV A, 2007, P 2007 INT C SYST DY
Bossel H., 2004, SYSTEME DYNAMIK SIMU
*CABIG, CABIG
Dolin RH, 2001, ST HEAL T, V84, P319
*ESDI GROUP, 2006, LEV CDISC STAND FAC
FABER J, 2004, INNOVATION CAPABILIT
FAIN E, 1999, BUSINESS MAGAZINE IN, V16, P69
FAIN E, 1999, BUSINESS MAGAZINE IN, V16, P72
Fong Christine, 2006, AMIA Annu Symp Proc, P922
Gostin LO, 1998, ANN INTERN MED, V129, P833, DOI 10.7326/0003-4819-129-10-199811150-00017
Jakobovits RM, 2002, J AM MED INFORM ASSN, V9, P557, DOI 10.1197/jamia.M1138
Jakobovits RM, 1997, J AM MED INFORM ASSN, P454

```
   KERR K, 2008, HLTH CARE INFORM REV, V12, P1174
   KERR K, 2008, HLTH CARE INFORM REV, V12, P37
   Lee ES, 2009, INT J MED INFORM, V78, P10, DOI 10.1016/j.ijmedinf.2008.06.011
   McConnell P, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-60
   MCGREGOR M, 2007, P 2007 INT C SYST DY
   MOFFAT M, 2006, MARKETING METADATA I
   National Institute of Health, NIH DAT SHAR POL
   NILAND JC, 2001, P SEOUL 53 SESS INT
   Niland JC, 2006, J AM MED INFORM ASSN, V13, P402, DOI 10.1197/jamia.M2050
   Patridge J, 2008, J PUBLIC HEALTH MAN, V14, P515, DOI
10.1097/01.PHH.0000338363.20962.f5
   Pietrobon Ricardo, 2004, BMC Med Res Methodol, V4, P29, DOI 10.1186/1471-
2288-4-29
   RWASHANA AS, 2008, INT J COMPUTING ICT, V1, P85
   *SCI COMM, SCI COMM
   Shah J, 2009, ACAD MED, V84, P511, DOI 10.1097/ACM.0b013e31819a8c3c
   SMITH D, 2002, SUCCESSFUL APPROACH
   Sterman J, 2000, BUSINESS DYNAMICS SY
   Whittenburg L, 2006, ST HEAL T, V122, P854
   YAGHOOTKAR K, 2007, P 2007 INT C SYST DY
   YAN J, 2004, MSST, P199
   ZAHN E, 2007, P 2007 INT C SYST DY
   ZHANG Q, 2007, P 2007 INT C SYST DY
   Zink A, 2008, ANN RHEUM DIS, V67, P1041, DOI 10.1136/ard.2007.080598
   2002, DATA STRATEGIES BENC, V6, P70
NR 39
TC 12
Z9 12
U1 1
U2 1
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD FEB 19
PY 2010
VL 5
IS 2
AR e9314
DI 10.1371/journal.pone.0009314
PG 7
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA 560SS
UT WOS:000274923700018
PM 20174560
OA DOAJ Gold, Green Published
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PT J
AU Korst, LM
   Signer, JMK
   Aydin, CE
   Fink, A
AF Korst, Lisa M.
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   Signer, Jordana M. K.
   Aydin, Carolyn E.
   Fink, Arlene
TI Identifying organizational capacities and incentives for clinical
   data-sharing: The case of a regional perinatal information system
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
AB The development of regional data-sharing among healthcare organizations is
viewed as an important step in the development of health information technology
(HIT), but little is known about this complex task. This is a case study of a
regional perinatal data system that involved four hospitals, together
responsible for over 10,000 births annually. Using standard qualitative methods,
we chronicled project milestones, and identified 31 "critical incidents" that
delayed or prevented their achievement. We then used these critical incidents to
articulate six organizational capacity domains associated with the achievement
of project milestones, and a seventh domain consisting of organizational
incentives. Finally, we analyzed the relationship of milestone achievement to
the presence of these capacities and incentives. This data center case suggests
four requirements for sharing data across organizations: 1) a readiness
assessment; 2) a perceived mandate; 3) a formal governance structure; and 4) a
third party IT component.
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RP Korst, LM (reprint author), Magnolia Blvd 154, N Hollywood, CA 91607 USA.
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CR Braller DJ, 2007, HEALTH AFFAIR, V26, pW581
   *CA PER QUAL CAR C, OV
   *CCS HIGH RISK INF, HRIF PROGR REP REQ
   Chaudhry B, 2006, ANN INTERN MED, V144, P742, DOI 10.7326/0003-4819-144-10-
200605160-00125
   Heeks R, 2006, INT J MED INFORM, V75, P125, DOI
10.1016/j.ijmedinf.2005.07.024
   Kaplan B, 1997, J AM MED INFORM ASSN, V4, P94, DOI 10.1136/jamia.1997.0040094
   O'Connor J, 2003, J ADV NURS, V41, P53, DOI 10.1046/j.1365-2648.2003.02506.x
   *ONC, MISS
   *ONC, BARR AD
   Snyder-Halpern R, 2001, INT J MED INFORM, V63, P179, DOI 10.1016/S1386-
5056(01)00179-4
   Stake R, 1995, ART CASE STUDY RES
   Weiner BJ, 2004, HEALTH CARE MANAGE R, V29, P51, DOI 10.1097/00004010-
200401000-00007
NR 12
TC 12
Z9 12
U1 0
U2 0
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD MAR-APR
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PY 2008
VL 15
IS 2
BP 195
EP 197
DI 10.1197/j.jamia.M2475
PG 3
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA 273UL
UT WOS:000253957100009
PM 18096916
DA 2019-08-06
ER

PT J
AU Verropoulou, G
   Tsimbos, C
AF Verropoulou, Georgia
   Tsimbos, Cleon
TI Socio-demographic and health-related factors affecting depression of the
   Greek population in later life: an analysis using SHARE data
SO EUROPEAN JOURNAL OF AGEING
LA English
DT Article
DE depression; socio-demographic factors; physical functioning; EURO-D;
   SHARE
ID 14 EUROPEAN CENTERS; SOCIAL ORIGINS; MARITAL-STATUS; RISK-FACTORS; D
   SCALE; SYMPTOMS; DISABILITY; COMMUNITY; PREVALENCE; VARIABLES
AB Depression in later life is one of the most prevalent conditions forecasted
to rise to the second most burdensome health condition worldwide by 2020. Using
data from the 2004 Study of Health Ageing and Retirement in Europe (SHARE:
release 1) on 857 Greek males and 1,032 females aged 50 or higher this study
explores, firstly, associations of socio-demographic and health related
indicators with depressive symptoms (EURO-D) and, secondly, attempts to identify
patterns and structures among them. To achieve the first objective, the 12-item
summated EURO-D scale is used in binary form with a cut-off point clinically
validated by the EURODEP. Use of logistic regression pinpoints strong
associations with gender, years of education, co-morbidity, disability,
cognitive function and past depression. Women, less educated persons, those with
poor physical health, declining cognitive function and a history of depression
are significantly more at risk of scoring higher than three at the EURO-D scale.
The role of age is not as clear. To achieve the second objective, multiple
correspondence analysis is used in the first instance and factor analysis for
binary data subsequently; two components are identified within EURO-D and
continuous factor scores are produced. These factors are called "affective
suffering" and "motivation". Linear regression models reveal that the first
component is responsible for the gender while the second for the age
differentials in EURO-D; additionally we find that, apart from physical health
indicators which are strongly related to both factors, other associations differ.
Further exploration of this differentiation seems of interest, particularly as
there is an indication that "motivation" may be an affectively neutral condition.
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FU NIA NIH HHS [P01 AG008291, P30 AG012815, U01 AG009740, P01 AG005842]
CR Austin MP, 2001, BRIT J PSYCHIAT, V178, P200, DOI 10.1192/bjp.178.3.200
Beekman ATF, 1999, BRIT J PSYCHIAT, V174, P307, DOI 10.1192/bjp.174.4.307
Billari FC, 2005, NATL INST ECON REV, V194, P56, DOI 10.1177/0027950105061496
BLAZER D, 1989, NEW ENGL J MED, V320, P164, DOI 10.1056/NEJM198901193200306
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Borsch-Supan A, 2005, SURVEY HLTH AGEING R
Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
Braam Arjan W, 2004, Eur J Ageing, V1, P26, DOI 10.1007/s10433-004-0013-2
Braam AW, 2005, BRIT J PSYCHIAT, V187, P35, DOI 10.1192/bjp.187.1.35
CHRISTOFFERSSON A, 1975, PSYCHOMETRIKA, V40, P5, DOI 10.1007/BF02291477
Coleman D, 2005, NEW DEMOGRAPHIC REGI, P11
Copeland John R M, 2004, World Psychiatry, V3, P45
CRONBACH LJ, 1951, PSYCHOMETRIKA, V16, P297, DOI DOI 10.1007/BF02310555
Dewey ME, 2005, HLTH AGEING RETIREME
DIVGI DR, 1979, PSYCHOMETRIKA, V44, P169, DOI 10.1007/BF02293968
*EUR, 2005, 482005 EUR
Gurland B, 1992, Clin Geriatr Med, V8, P377
Hosmer D. W., 2000, APPL LOGISTIC REGRES
Hosmer DW, 1997, STAT MED, V16, P965
Hudson CG, 2005, AM J ORTHOPSYCHIAT, V75, P3, DOI 10.1037/0002-9432.75.1.3
Hudson CG, 1988, J SOCIOLOGY SOCIAL W, V15, P27
Joreskog K. G., 1996, LISREL 8 USERS REFER
Juster FT, 1995, J HUM RESOUR, V30, pS7, DOI 10.2307/146277
LENZE EJ, 2001, AM J GERIAT PSYCHIAT, V9, P119
Lisiankova K, 2005, NATL INST ECON REV, V194, P74, DOI 10.1177/0027950105061497
Marmot M., 2003, HLTH WEALTH LIFESTYL
MURPHY E, 1982, BRIT J PSYCHIAT, V141, P135, DOI 10.1192/bjp.141.2.135
Murray CJL, 1997, LANCET, V349, P1436, DOI 10.1016/S0140-6736(96)07495-8
MUTHEN B, 1978, PSYCHOMETRIKA, V43, P551, DOI 10.1007/BF02293813
*NAT STAT SERV GRE, 2007, STAT YB GREEC 2006
*NAT STAT SERV GRE, 2006, 2001 POP CENS DAT
NEWMANN JP, 1991, J GERONTOL, V46, P224
Ormel J, 2002, J GERONTOL B-PSYCHOL, V57, pP338, DOI 10.1093/geronb/57.4.P338
Osborn DPJ, 2002, INT J GERIATR PSYCH, V17, P375, DOI 10.1002/gps.613
PAHKALA K, 1995, SOC PSYCH PSYCH EPID, V30, P99, DOI 10.1007/BF00802037
Palacios R, 2002, INT J EPIDEMIOL, V31, P786, DOI 10.1093/ije/31.4.786
Perry M J, 1996, J Prim Prev, V17, P17, DOI 10.1007/BF02262736
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P339, DOI 10.1192/bjp.174.4.339
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Prince MJ, 1998, PSYCHOL MED, V28, P337, DOI 10.1017/S0033291797006478
Reynolds JR, 1998, SOC PROBL, V45, P221, DOI 10.1525/sp.1998.45.2.03x0167k
ROSS CE, 1990, J MARRIAGE FAM, V52, P1059, DOI 10.2307/353319
Schoevers RA, 2000, J AFFECT DISORDERS, V59, P127, DOI 10.1016/S0165-0327(99)00124-X
WARHEIT G J, 1973, Journal of Health and Social Behavior, V14, P291, DOI 10.2307/2136773
WEISSMAN MM, 1988, PSYCHOL MED, V18, P141, DOI 10.1017/S003329170001975
WEISSMAN MM, 1977, ARCH GEN PSYCHIAT, V34, P99

```
   WELLS KB, 1989, JAMA-J AM MED ASSOC, V262, P914, DOI 10.1001/jama.262.7.914
   WYKE S, 1992, SOC SCI MED, V34, P523, DOI 10.1016/0277-9536(92)90208-8
   Yang Y, 2005, J AGING HEALTH, V17, P263, DOI 10.1177/0898264305276295
NR 49
TC 12
Z9 12
U1 1
U2 10
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 1613-9372
EI 1613-9380
J9 EUR J AGEING
JI Eur. J. Ageing
PD SEP
PY 2007
VL 4
IS 3
BP 171
EP 181
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PG 11
WC Gerontology
SC Geriatrics & Gerontology
GA 303CX
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PT J
AU Mojon-Azzi, SM
   Mojon, DS
AF Mojon-Azzi, S. M.
   Mojon, D. S.
TI The rate of outpatient cataract surgery in ten European countries: An
   analysis using data from the SHARE survey
SO GRAEFES ARCHIVE FOR CLINICAL AND EXPERIMENTAL OPHTHALMOLOGY
LA English
DT Article
DE SHARE; inpatient; outpatient; cataract surgery; Europe
ID INPATIENT
AB Bckground The aim of this study was to determine the rates of outpatient
cataract surgery (ROCS) in ten European countries and to find country-specific
health indicators explaining the differences.
   Methods Using data from the Survey of Health, Ageing and Retirement in Europe
(SHARE), 251 eligible respondents were identified for which cataract surgery was
the last surgical procedure. The ROCS of ten countries were compared using
logistic regression. The influence of the public expenditure on health as per
cent of the total expenditure on health, of the number of acute care beds per
1,000 population, and of the number of practicing physicians per 1,000
population, was studied by multiple logistic regression. Additional information
was obtained from country-specific opinion leaders in the field of cataract
surgery.
   Results The ROCS differed significantly between the ten analysed European
countries where Denmark had the highest (100%) and Austria the lowest (0%) rate
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of day care surgery. A decrease in the density of acute care beds (p < 0.0000001)
and in the density of practicing physicians (p < 0.05) and an increase in the
public expenditure on health as per cent of the total health expenditure (p <
0.01) lead to an increase in the ROCS. According to the opinion leaders,
regulations and financial incentives also have a strong influence on the ROCS.
   Conclusion The outpatient rate of cataract surgery in the ten European
countries was mainly influenced by the acute-care beds density, but also by the
density of practicing physicians, and by the public expenditure on health.
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CR Atalla ML, 2000, CLIN EXP OPHTHALMOL, V28, P83, DOI 10.1046/j.1442-
9071.2000.00277.x
   Borsch-Supan A., 2005, SURVEY HLTH AGING RE
   Castells X, 2001, J CLIN EPIDEMIOL, V54, P23, DOI 10.1016/S0895-
4356(00)00271-7
   Fan Y P, 1997, Aust Health Rev, V20, P27
   Fedorowicz Z, 2005, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD004242.pub3
   Haapala TT, 2005, GRAEF ARCH CLIN EXP, V243, P1010, DOI 10.1007/s00417-005-
1190-1
   HAMED WW, 2004, COCHRANE DB SYST REV, P4242
   HOLLAND GN, 1992, OPHTHALMOLOGY, V99, P845
   Kutner MH, 2004, APPL LINEAR REGRESSI
   *OECD, 2005, HLTH SPEND RES 2005
   *SHARE, 2005, SHARE SURV HLTH AG R
NR 11
TC 12
Z9 13
U1 1
U2 2
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0721-832X
EI 1435-702X
J9 GRAEF ARCH CLIN EXP
JI Graefes Arch. Clin. Exp. Ophthalmol.
PD JUL
PY 2007
VL 245
IS 7
BP 1041
EP 1044
DI 10.1007/s00417-007-0550-4
PG 4
WC Ophthalmology
SC Ophthalmology
GA 182KP
UT WOS:000247503800018
PM 17318563
DA 2019-08-06
ER

PT J
AU Saunders, CL
   Gulliford, MC
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AF Saunders, Catherine L.
Gulliford, Martin C.
TI Heritabilities and shared environmental effects were estimated from household clustering in national health survey data
SO JOURNAL OF CLINICAL EPIDEMIOLOGY
LA English
DT Article
DE cardiovascular disease; genetic epidemiology; variance components; heritability; household clustering; Health Survey for England 1998
ID CARDIOVASCULAR RISK-FACTORS; BLOOD-PRESSURE; PRETHROMBOTIC STATE; DISEASE; FAMILIES; TWINS; PEDIGREES; MARKERS; PROTEIN

AB Objectives: The relative contributions of genetic and environmental variables to within-household clustering of quantitative traits in household surveys are poorly characterized. We estimated shared genetic and shared environmental contributions to within-household correlation for anthropometric variables and cardiovascular disease risk factors.

Study Design and Setting: Data were analyzed for the Health Survey for England 1998, a representative national household survey. Two-generation pedigrees were defined using information for relationships within households. After standardizing for age and sex, data were analyzed for 11 quantitative traits. Variance components models were fitted to estimate the proportion of variance due to additive genetic variance or shared environmental effects.

Results: Within-household correlation coefficients for all related and unrelated subjects ranged from 0.10 for C-reactive protein to 0.31 for height. Pairwise correlations between related individuals within households were consistently higher than those between unrelated individuals. Estimated heritability ranged from 6% for diastolic blood pressure to 40% for serum cholesterol. The proportion of variance attributable to shared environmental effects ranged from 8% for cholesterol to 24% for height.

Conclusion: In this large, representative national sample of generally small families, estimates for heritability were generally lower than previously reported, whereas the contribution of shared environment and individual-level variation were greater. (C) 2006 Elsevier Inc. All rights reserved.

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FU NCRR NIH HHS [RR03655]

CR Almasy L, 1998, AM J HUM GENET, V62, P1198, DOI 10.1086/301844
Ariens RAS, 2002, LANCET, V359, P667, DOI 10.1016/S0140-6736(02)07813-3
AUSTIN MA, 1987, AM J EPIDEMIOL, V125, P308, DOI 10.1093/oxfordjournals.aje.a114531
Cui JSS, 2003, HYPERTENSION, V41, P207, DOI 10.1161/01.HYP.0000044938.94050.E3
Eichner JE, 2002, AM J EPIDEMIOL, V155, P487, DOI 10.1093/aje/155.6.487
ERENS B, 1999, CARDIOVASCULAR DIS 9, V2
Fava C, 2004, J HYPERTENS, V22, P1717, DOI 10.1097/00004872-200409000-00015
Freeman MS, 2002, DIABETIC MED, V19, P994, DOI 10.1046/j.1464-5491.2002.00843.x
Freeman MS, 2002, ARTERIOSCL THROM VAS, V22, P506, DOI 10.1161/hq0302.104906
Garner C, 2000, BLOOD, V95, P342
Gulliford MC, 1999, AM J EPIDEMIOL, V149, P876
Gulliford MC, 2005, J HUM HYPERTENS, V19, P111, DOI 10.1038/sj.jhh.1001787
Hippisley-Cox J, 2002, BRIT MED J, V325, P636, DOI 10.1136/bmj.325.7365.636
Hsueh WC, 2000, DIABETES CARE, V23, P595, DOI 10.2337/diacare.23.5.595
Jee SH, 2002, YONSEI MED J, V43, P160, DOI 10.3349/ymj.2002.43.2.160

```
   Keen KJ, 2003, STAT MED, V22, P3229, DOI 10.1002/sim.1559
   Khoury MJ, 1993, FUNDAMENTALS GENETIC
   Knoblauch H, 1997, ARTERIOSCL THROM VAS, V17, P2054, DOI
10.1161/01.ATV.17.10.2054
   Knuiman MW, 1996, ANN EPIDEMIOL, V6, P188, DOI 10.1016/1047-2797(96)00004-X
   MacGregor AJ, 2004, CLIN CHEM, V50, P130, DOI 10.1373/clinchem.2003.028258
   Maes HHM, 1997, BEHAV GENET, V27, P325, DOI 10.1023/A:1025635913927
   Merikangas KR, 2003, SCIENCE, V302, P599, DOI 10.1126/science.1091468
   North KE, 2003, AM J EPIDEMIOL, V157, P303, DOI 10.1093/aje/kwf208
   Pankow JS, 2001, ATHEROSCLEROSIS, V154, P681, DOI 10.1016/S0021-
9150(00)00586-4
   Rotimi CN, 1999, HYPERTENSION, V33, P874, DOI 10.1161/01.HYP.33.3.874
   Snyder EE, 2004, OBES RES, V12, P369, DOI 10.1038/oby.2004.47
   Stephens JW, 2003, J INTERN MED, V253, P120, DOI 10.1046/j.1365-
2796.2003.01104.x
   *U COLL LOND NAT C, 2002, HLTH SURV ENGL
   Vossen CY, 2004, J THROMB HAEMOST, V2, P242, DOI 10.1111/j.1538-
7933.2003.00592.x
   Wu KD, 2002, HYPERTENS RES, V25, P529
   Zeegers MPA, 2004, TWIN RES, V7, P245
NR 31
TC 12
Z9 12
U1 0
U2 3
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0895-4356
J9 J CLIN EPIDEMIOL
JI J. Clin. Epidemiol.
PD NOV
PY 2006
VL 59
IS 11
BP 1191
EP 1198
DI 10.1016/j.jclinepi.2006.02.015
PG 8
WC Health Care Sciences & Services; Public, Environmental & Occupational
   Health
SC Health Care Sciences & Services; Public, Environmental & Occupational
   Health
GA 096IE
UT WOS:000241370000010
PM 17027430
DA 2019-08-06
ER

PT J
AU Jumbe, NL
   Murray, JC
   Kern, S
AF Jumbe, N. L'ntshotshole
   Murray, Jeffrey C.
   Kern, Steven
TI Data Sharing and Inductive Learning - Toward Healthy Birth, Growth, and
   Development
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SO NEW ENGLAND JOURNAL OF MEDICINE
LA English
DT Editorial Material
C1 [Jumbe, N. L'ntshotshole; Murray, Jeffrey C.; Kern, Steven] Bill & Melinda
Gates Fdn, Hlth Birth Growth & Dev Core Team, Seattle, WA 98109 USA.
RP Jumbe, NL (reprint author), Bill & Melinda Gates Fdn, Hlth Birth Growth & Dev
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CR Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
   Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
NR 3
TC 11
Z9 11
U1 0
U2 2
PU MASSACHUSETTS MEDICAL SOC
PI WALTHAM
PA WALTHAM WOODS CENTER, 860 WINTER ST,, WALTHAM, MA 02451-1413 USA
SN 0028-4793
EI 1533-4406
J9 NEW ENGL J MED
JI N. Engl. J. Med.
PD JUN 23
PY 2016
VL 374
IS 25
BP 2415
EP 2417
DI 10.1056/NEJMp1605441
PG 3
WC Medicine, General & Internal
SC General & Internal Medicine
GA DP1TG
UT WOS:000378271700005
PM 27168111
DA 2019-08-06
ER

PT J
AU Murtagh, MJ
   Turner, A
   Minion, JT
   Fay, M
   Burton, PR
AF Murtagh, Madeleine J.
   Turner, Andrew
   Minion, Joel T.
   Fay, Michaela
   Burton, Paul R.
TI International Data Sharing in Practice: New Technologies Meet Old
   Governance
SO BIOPRESERVATION AND BIOBANKING
LA English
DT Article
ID DATASHAPER APPROACH; HEALTH; HARMONIZATION
AB The social structures that govern data/sample release aim to safeguard the
confidentiality and privacy of cohort research participants (without whom there
would be no data or samples) and enable the realization of societal benefit
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through optimizing the scientific use of those cohorts. Within collaborations involving multiple cohorts and biobanks, however, the local, national, and supranational institutional and legal guidelines for research (which produce a multiplicity of data access governance structures and guidelines) risk impeding the very science that is the raison d'etre of these consortia. We present an ethnographic study, which examined the epistemic and nonepistemic values driving decisions about data access and their consequences in the context of the pilot of an integrated approach to co-analysis of data. We demonstrate how the potential analytic flexibility offered by this approach was lost under contemporary data access governance. We identify three dominant values: protecting the research participant, protecting the study, and protecting the researcher. These values were both supported by and juxtaposed against a public good argument, and each was used as a rationale to both promote and inhibit sharing of data. While protection of the research participants was central to access permissions, decisions were also attentive to the desire of researchers to see their efforts in building population biobanks and cohorts realized in the form of scientific outputs. We conclude that systems for governing and enabling data access in large consortia need to (1) protect disclosure of research participant information or identity, (2) ensure the specific expectations of research participants are met, (3) embody systems of review that are transparent and not compromised by the specific interests of one particular group of stakeholders, and (4) facilitate data access procedures that are timely and efficient. Practical solutions are urgently needed. New approaches to data access governance should be trialed (and formally evaluated) with input from and discussion with stakeholders.
C1 [Murtagh, Madeleine J.; Turner, Andrew; Minion, Joel T.; Fay, Michaela; Burton, Paul R.] Univ Bristol, Data Knowledge Res Grp, Sch Social & Community Med, Bristol BS8 1TH, Avon, England.
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OI Turner, Andrew/0000-0002-7121-3121
FU Biobank Standardisation and Harmonisation for Research Excellence in the European Union (BioSHaRE-EU) program - European Union Seventh Framework Programme [261433]; METADAC - Medical Research Council; Economic and Social Research Council; Wellcome Trust [MR/N01104X/1]; European Union Seventh Framework Programme BBMRI-LPC [313010]; Medical Research Council; 58READIE project [G1001799/2]; ALSPAC project [102215/Z/13/Z]; Welsh Farr Institute; MRC [MR/K006525/1, MR/K007017/1]; Scottish Farr Institute; Economic and Social Research Council [ES/L007444/1]; Medical Research Council [MR/K023233/1, MR/N01104X/1, MR/M024881/1, MR/K006525/1, G1001799, MR/K007017/1, MC_PC_13043]
FX We would like to thank all participants in the BioSHaRE-EU ethnography and evaluation for their generosity in enabling us to work alongside them and for giving of their time in interviews. The research and analysis leading to these results were supported by the Biobank Standardisation and Harmonisation for Research Excellence in the European Union (BioSHaRE-EU) program, which received funding from the European Union Seventh Framework Programme (FP7/2007-2013) under grant agreement no. 261433, and the METADAC, which received funding from the Medical Research Council, Economic and Social Research Council, and Wellcome Trust (MR/N01104X/1). The Data to Knowledge (D2K) Research Group is also supported by funding from the European Union Seventh Framework Programme BBMRI-LPC (313010) (Biobanking and Biomolecular Resources Research Infrastructure-Large Prospective Cohorts), Medical Research Council, Wellcome Trust, 58READIE project (G1001799/2) (Realizing Easy Access to Data and Infrastructural Enhancement for the 1958 Birth Cohort Biomedical Resource), ALSPAC project (102215/Z/13/Z),

the Welsh and Scottish Farr Institutes, and MRC-funded E-Health
Informatics Research Centres (EHIRCs) (MR/K006525/1 and MR/K007017/1).

CR Atkinson P, 2007, ETHNOGRAPHY PRINCIPL
Austin J. L, 1975, DO THINGS WORDS
Burton PR, 2015, BIOINFORMATICS, V31, P3241, DOI 10.1093/bioinformatics/btv279
Butler J., 2002, GENDER TROUBLE
Cambon-Thomsen A, 2011, NAT GENET, V43, P503, DOI 10.1038/ng.831
Carr D, 2015, J EMPIR RES HUM RES, V10, P314, DOI 10.1177/1556264615593485
Denzin N. K., 2011, SAGE HDB QUALITATIVE
Doiron D, 2013, EMERG THEMES EPIDEMI, V10, DOI 10.1186/1742-7622-10-12
Fortier I, 2011, INT J EPIDEMIOL, V40, P1314, DOI 10.1093/ije/dyr106
Fortier I, 2010, INT J EPIDEMIOL, V39, P1383, DOI 10.1093/ije/dyq139
Foucault Michel., 2002, ORDER THINGS ARCHAEO
Gaye A, 2014, INT J EPIDEMIOL, V43, P1929, DOI 10.1093/ije/dyu188
GEERTZ Clifford, 1973, INTERPRETATION CULTU
Gilbert R, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h5897
GLASER BG, 1965, SOC PROBL, V12, P436, DOI 10.1525/sp.1965.12.4.03a00070
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Murtagh M, 2015, REPORT WP3 OBJECTIVE
Murtagh M, 2012, NORSK EPIDEMIOL, V21, P203
Murtagh M, 2015, REPORT DELIVERABLE D
Murtagh M, REPORT DELIVERABLE D
Murtagh MJ, 2011, HUM GENET, V130, P333, DOI 10.1007/s00439-011-1036-3
P 3 G, 2016, INT POL INT DAT ACC
Potter Jonathan, 1987, DISCOURSE SOCIAL PSY
Rahm AK, 2013, J COMMUN GENET, V4, P445, DOI 10.1007/s12687-013-0146-0
Searle John R., 1969, SPEECH ACTS ESSAY PH
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
van Vliet-Ostaptchouk JV, 2014, BMC ENDOCR DISORD, V14, DOI 10.1186/1472-6823-14-9
Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
World Medical Association General Assembly, 2004, J Int Bioethique, V15, P124

NR 30
TC 11
Z9 11
U1 2
U2 7
PU MARY ANN LIEBERT, INC
PI NEW ROCHELLE
PA 140 HUGUENOT STREET, 3RD FL, NEW ROCHELLE, NY 10801 USA
SN 1947-5535
EI 1947-5543
J9 BIOPRESERV BIOBANK
JI Biopreserv. Biobank.
PD JUN
PY 2016
VL 14
IS 3
SI SI
BP 231
EP 240
DI 10.1089/bio.2016.0002
PG 10
WC Cell Biology; Chemistry, Applied; Medical Laboratory Technology
SC Cell Biology; Chemistry; Medical Laboratory Technology
GA DO5KK

UT WOS:000377821800007
PM 27200470
DA 2019-08-06
ER

PT J
AU Lu, CL
   Wang, S
   Ji, ZL
   Wu, Y
   Xiong, L
   Jiang, XQ
   Ohno-Machado, L
AF Lu, Chia-Lun
   Wang, Shuang
   Ji, Zhanglong
   Wu, Yuan
   Xiong, Li
   Jiang, Xiaoqian
   Ohno-Machado, Lucila
TI WebDISCO: a web service for distributed cox model learning without
   patient-level data sharing
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
DE clinical information systems; decision support systems; distributed
   modeling; cox model
ID SURVIVAL; CANCER
AB Objective The Cox proportional hazards model is a widely used method for analyzing survival data. To achieve sufficient statistical power in a survival analysis, it usually requires a large amount of data. Data sharing across institutions could be a potential workaround for providing this added power.

   Methods and materials The authors develop a web service for distributed Cox model learning (WebDISCO), which focuses on the proof-of-concept and algorithm development for federated survival analysis. The sensitive patient-level data can be processed locally and only the less-sensitive intermediate statistics are exchanged to build a global Cox model. Mathematical derivation shows that the proposed distributed algorithm is identical to the centralized Cox model.

   Results The authors evaluated the proposed framework at the University of California, San Diego (UCSD), Emory, and Duke. The experimental results show that both distributed and centralized models result in near-identical model coefficients with differences in the range <mml:math display in the range 10(-15) to 10(-12). The results confirm the mathematical derivation and show that the implementation of the distributed model can achieve the same results as the centralized implementation.

   Limitation The proposed method serves as a proof of concept, in which a publicly available dataset was used to evaluate the performance. The authors do not intend to suggest that this method can resolve policy and engineering issues related to the federated use of institutional data, but they should serve as evidence of the technical feasibility of the proposed approach.

   Conclusions WebDISCO (Web-based Distributed Cox Regression Model; https://webdisco.ucsd-dbmi.org:8443/cox/) provides a proof-of-concept web service that implements a distributed algorithm to conduct distributed survival analysis without sharing patient level data.
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FU NIH [R00LM011392, K99HG008175, R21LM012060, U54 HL108460];
Patient-Centered Outcomes Research Institute (PCORI) [CDRN-1306-04819]
FX This work was funded in part by NIH grants R00LM011392, K99HG008175,
R21LM012060, U54 HL108460 and Patient-Centered Outcomes Research
Institute (PCORI) contract CDRN-1306-04819.
CR Albers DJ, 2012, CHAOS, V22, DOI 10.1063/1.3675621
ALTMAN DG, 1995, BRIT J CANCER, V72, P511, DOI 10.1038/bjc.1995.364
BRESLOW NE, 1975, INT STAT REV, V43, P45, DOI 10.2307/1402659
Cai T, 2009, BIOMETRICS, V65, P394, DOI 10.1111/j.1541-0420.2008.01074.x
Chambless LE, 2006, STAT MED, V25, P3474, DOI 10.1002/sim.2299
COX DR, 1972, J R STAT SOC B, V34, P187
Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1
El Emam K, 2013, J AM MED INFORM ASSN, V20, P453, DOI 10.1136/amiajnl-2011-000735
Gupta R, 2008, CORNELL STAT CONSULT, V72, P1
Hagar Y, MRH MULTIRESOLUTION
Hagar Y, 2014, STAT ANAL DATA MIN, V7, P385, DOI 10.1002/sam.11236
Hartmann O, 2012, INT J CARDIOL, V161, P166, DOI 10.1016/j.ijcard.2012.09.014
Hosmer DW, 2008, APPL SURVIVAL ANAL R
Hripcsak G, 2015, MEDINFO 15
Jensen PB, 2012, NAT REV GENET, V13, P395, DOI 10.1038/nrg3208
Kalbfleisch J. D, 2011, STAT ANAL FAILURE TI
KARR AF, 2009, J PRIVACY CONFIDENTI, V1, P197
Lundin J, 2003, BRIT MED J, V326, P29, DOI 10.1136/bmj.326.7379.29
Lundin J, 2006, EUR J CANCER, V42, P3228, DOI 10.1016/j.ejca.2006.06.028
Madigan D, 2013, AM J EPIDEMIOL, V178, P645, DOI 10.1093/aje/kwt010
O'Keefe CM, 2012, J PRIV CONFIDENTIALI, V4, P6
Ohno-Machado L, 2014, J AM MED INFORM ASSN, V21, P621, DOI 10.1136/amiajnl-2014-002751
Ohno-Machado L, 2012, J AM MED INFORM ASSN, V19, P196, DOI 10.1136/amiajnl-2011-000538
PARMAR MKB, 1995, SURVIVAL ANAL PRACTI
Wang S, 2013, J BIOMED INFORM, V46, P480, DOI 10.1016/j.jbi.2013.03.008
Wang Y, 2006, BIOINFORMATICS, V22, P2413, DOI 10.1093/bioinformatics/btl396
Wiksten JP, 2008, ANTICANCER RES, V28, P2279
Wolfson M, 2010, INT J EPIDEMIOL, V39, P1372, DOI 10.1093/ije/dyq111
Wu Y, 2012, J AM MED INFORM ASSN, V19, P758, DOI 10.1136/amiajnl-2012-000862
Yu S, 2008, P 14 ACM SIGKDD INT, P1034
Zhang F, 2010, CLIN MED RES, V8, P54
NR 31
TC 11
Z9 11
U1 1
U2 3
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD NOV

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PY 2015
VL 22
IS 6
BP 1212
EP 1219
DI 10.1093/jamia/ocv083
PG 8
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA DI8AF
UT WOS:000373722400019
PM 26159465
OA Green Published, Bronze
DA 2019-08-06
ER

PT J
AU Stephenson, D
   Hu, MT
   Romero, K
   Breen, K
   Burn, D
   Ben-Shlomo, Y
   Bhattaram, A
   Isaac, M
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   Williams-Gray, C
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   Aviles, E
   Marek, K
   Toga, AW
   Stark, Y
   Gordon, MF
   Ford, S
AF Stephenson, Diane
   Hu, Michele T.
   Romero, Klaus
   Breen, Kieran
   Burn, David
   Ben-Shlomo, Yoav
   Bhattaram, Atul
   Isaac, Maria
   Venuto, Charles
   Kubota, Ken
   Little, Max A.
   Friend, Stephen
   Lovestone, Simon
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Morris, Huw R.
Grosset, Donald
Sutherland, Margaret
Gallacher, John
Williams-Gray, Caroline
Bain, Lisa J.
Aviles, Enrique
Marek, Ken
Toga, Arthur W.
Stark, Yafit
Gordon, Mark Forrest
Ford, Steve

TI Precompetitive Data Sharing as a Catalyst to Address Unmet Needs in Parkinson's Disease
SO JOURNAL OF PARKINSONS DISEASE
LA English
DT Article
DE Data standards; privacy; data integration; collaboration; quantitative disease progression; regulatory science
ID MILD COGNITIVE IMPAIRMENT; NONMOTOR FEATURES; CRITICAL PATH; DISORDER; RECOMMENDATIONS; SYMPTOMS; GENDER; COHORT; TRIAL; MOTOR

AB Parkinson's disease is a complex heterogeneous disorder with urgent need for disease-modifying therapies. Progress in successful therapeutic approaches for PD will require an unprecedented level of collaboration. At a workshop hosted by Parkinson's UK and co-organized by Critical Path Institute's (C-Path) Coalition Against Major Diseases (CAMD) Consortiums, investigators from industry, academia, government and regulatory agencies agreed on the need for sharing of data to enable future success. Government agencies included EMA, FDA, NINDS/NIH and IMI (Innovative Medicines Initiative). Emerging discoveries in new biomarkers and genetic endophenotypes are contributing to our understanding of the underlying pathophysiology of PD. In parallel there is growing recognition that early intervention will be key for successful treatments aimed at disease modification. At present, there is a lack of a comprehensive understanding of disease progression and the many factors that contribute to disease progression heterogeneity. Novel therapeutic targets and trial designs that incorporate existing and new biomarkers to evaluate drug effects independently and in combination are required. The integration of robust clinical data sets is viewed as a powerful approach to hasten medical discovery and therapies, as is being realized across diverse disease conditions employing big data analytics for healthcare. The application of lessons learned from parallel efforts is critical to identify barriers and enable a viable path forward. A roadmap is presented for a regulatory, academic, industry and advocacy driven integrated initiative that aims to facilitate and streamline new drug trials and registrations in Parkinson's disease.

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FU Parkinson's UK [J-1301]; NIBIB NIH HHS [P41 EB015922]; NINDS NIH HHS
[T32 NS007338]; National Institute for Health Research
[NF-SI-0512-10053]
CR Arora S, 2013, MOVEMENT DISORD, V28, pE11
Atassi N, 2014, NEUROLOGY, V83, P1719, DOI 10.1212/WNL.0000000000000951
Berardelli A, 2013, EUR J NEUROL, V20, P16, DOI 10.1111/ene.12022
Bhattaram VA, 2009, AAPS J, V11, P456, DOI 10.1208/s12248-009-9123-2
Breen KC, 2013, J NEURAL TRANSM, V120, P531, DOI 10.1007/s00702-012-0928-2
Dorsey ER, 2007, NEUROLOGY, V68, P384, DOI 10.1212/01.wnl.0000247740.47667.03
European Medicine Agency, EMACHMPSAWP102001201
European Medicines Agency, QUAL OP NOV IN PRESS
Foltynie T, 2004, BRAIN, V127, P550, DOI 10.1093/brain/awh067
Gelber RP, 2012, CURR ALZHEIMER RES, V9, P664
Goetz CG, 2008, MOVEMENT DISORD, V23, P2129, DOI 10.1002/mds.22340
Goldman M, 2012, CLIN PHARMACOL THER, V91, P418, DOI 10.1038/clpt.2011.321
Goldman M, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3007990
Goldman M, 2013, CLIN TRANSL MED, V2, DOI 10.1186/2001-1326-2-2
Institute of Medicine, 2013, SHAR CLIN RES DAT WO
Jack CR, 2010, LANCET NEUROL, V9, P119, DOI 10.1016/S1474-4422(09)70299-6
Jankovic J, 2005, MOVEMENT DISORD, V20, pS11, DOI 10.1002/mds.20458
Kasten M, 2013, INT J EPIDEMIOL, V42, P128, DOI 10.1093/ije/dys202
Kuffner R, 2015, NAT BIOTECHNOL, V33, P51, DOI 10.1038/nbt.3051
Litvan I, 2012, MOVEMENT DISORD, V27, P349, DOI 10.1002/mds.24893
Marek K, 2014, NEUROLOGY
Mioshi E, 2006, INT J GERIATR PSYCH, V21, P1078, DOI 10.1002/gps.1610
Neville J, 2015, ALZHEIMERS DEMENT, P1
Noyce AJ, 2014, J NEUROL NEUROSUR PS, V85, P31, DOI 10.1136/jnnp-2013-305420
Olanow CW, 2009, NEW ENGL J MED, V361, P1268, DOI 10.1056/NEJMoa0809335
Rogers JA, 2012, J PHARMACOKINET PHAR, V39, P479, DOI 10.1007/s10928-012-9263-3

```
   Rolinski M, 2014, J NEUROL NEUROSUR PS, V85, P560, DOI 10.1136/jnnp-2013-
306104
   Romero K, 2015, CLIN PHARMACOL THER, V97, P210, DOI 10.1002/cpt.16
   Rudick RA, 2014, MULT SCLER J, V20, P12, DOI 10.1177/1352458513503392
   Schneider SA, 2007, MOVEMENT DISORD, V22, P2210, DOI 10.1002/mds.21685
   Shoulson I, 2007, NEUROLOGY, V69, P1480
   Sieber BA, 2014, ANN NEUROL, V76, P469, DOI 10.1002/ana.24261
   Szewczyk-Krolikowski K, 2014, NEUROLOGY, V83, P208, DOI
10.1212/WNL.0000000000000592
   Szewczyk-Krolikowski K, 2014, PARKINSONISM RELAT D, V20, P99, DOI
10.1016/j.parkreldis.2013.09.025
   Van Den Eeden SK, 2003, AM J EPIDEMIOL, V157, P1015, DOI 10.1093/aje/kwg068
   Wilhelm EE, 2014, JAMA-J AM MED ASSOC, V311, P1201, DOI 10.1001/jama.2014.850
   Williams-Gray CH, 2013, J NEUROL NEUROSUR PS, V84, P1258, DOI 10.1136/jnnp-
2013-305277
   Woodcock J, 2014, NAT REV DRUG DISCOV, V13, P781, DOI 10.1038/nrd4462
   Woodcock J, 2014, NAT REV DRUG DISCOV, V13, P783, DOI 10.1038/nrd4435
   Yarnall AJ, 2014, NEUROLOGY, V82, P308, DOI 10.1212/WNL.0000000000000066
NR 40
TC 11
Z9 11
U1 0
U2 12
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 1877-7171
EI 1877-718X
J9 J PARKINSON DIS
JI J. Parkinsons Dis.
PY 2015
VL 5
IS 3
BP 581
EP 594
DI 10.3233/JPD-150570
PG 14
WC Neurosciences
SC Neurosciences & Neurology
GA CR8LE
UT WOS:000361602500018
PM 26406139
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PT J
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TI The geographic and demographic scope of shared sanitation: an analysis
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   of national survey data from low- and middle-income countries
SO TROPICAL MEDICINE & INTERNATIONAL HEALTH
LA English
DT Article
DE sanitation; Demographic and Health Surveys
ID RISK-FACTORS; ASSOCIATIONS; DISEASE; BURDEN; WEALTH
AB OBJECTIVE A large and growing proportion of the world's population rely on shared sanitation facilities that have historically been excluded from international targets due to concerns about acceptability, hygiene and access. In connection with a proposed change in such policy, we undertook this study to describe the prevalence and scope of households that report relying on shared sanitation and to characterise them in terms of selected socio-economic and demographic covariates.

   METHODS We extracted data from the most recent national household surveys of 84 low-and middle-income countries from Demographic and Health Surveys and Multiple Indicator Cluster Surveys. We describe the prevalence of shared sanitation and explore associations between specified covariates and reliance on shared sanitation using log-binomial regression.

   RESULTS While household reliance on any type of shared sanitation is relatively rare in Europe (2.5%) and the Eastern Mediterranean (7.7%), it is not uncommon in the Americas (14.2%), Western Pacific (16.4%) and South-East Asia (31.3%), and it is most prevalent in Africa (44.6%) where many shared facilities do not meet the definition of 'improved' even if they were not shared (17.7%). Overall, shared sanitation is more common in urban (28.6%) than in rural settings (25.9%), even after adjusting for wealth. While results vary geographically, people who rely on shared sanitation tend to be poorer, reside in urban areas and live in households with more young children and headed by people with no formal education. Data from 21 countries suggest that most sharing is with neighbours and other acquaintances (82.0%) rather than the public.

   CONCLUSIONS The determinants of shared sanitation identified from these data suggest potential confounders that may explain the apparent increased health risk from sharing and should be considered in any policy recommendation. Both geographic and demographic heterogeneity indicate the need for further research to support a change in policies.
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CR [Anonymous], 2014, WORLD POP PROSP 2012
   Boerma J T, 1993, World Health Stat Q, V46, P222
   Clasen TF, 2010, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD007180.pub2
   Curtale F., 1998, Parassitologia (Rome), V40, P251
   DHS MEASURE, 2013, DEM HLTH SURV

```
   Filmer D, 2001, DEMOGRAPHY, V38, P115, DOI 10.1353/dem.2001.0003
   Fink G, 2011, INT J EPIDEMIOL, V40, P1196, DOI 10.1093/ije/dyr102
   Fuller JA, 2014, AM J TROP MED HYG, V91, P173, DOI 10.4269/ajtmh.13-0503
   GOLDING J, 1994, PAEDIATR PERINAT EP, V8, P17, DOI 10.1111/j.1365-
3016.1994.tb00489.x
   Heijnen M, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0093300
   Isunju JB, 2011, PUBLIC HEALTH, V125, P368, DOI 10.1016/j.puhe.2011.03.008
   JMP Taskforce, 2010, JOINT MON PROGR TECH
   Joint Monitoring Programme, 2014, PROGR DRINK WAT SAN
   Joint Monitoring Programme, 2012, POST 2015 PROP SAN T
   Joint Monitoring Programme, 2010, PROGR SAN DRINK WAT
   Joint Monitoring Programme, 2012, PROP CONS DRINK WAT
   Joint Monitoring Programme, 2013, PROGR SAN DRINK WAT
   Joint Monitoring Programme, 2012, PROGR DRINK WAT SAN
   KIMFARLEY RJ, 1984, LANCET, V2, P1322
   Lim SS, 2012, LANCET, V380, P2224, DOI 10.1016/S0140-6736(12)61766-8
   MICS3, 2013, MULT IND CLUST SURV
   Nelson KL, 2008, ANNU REV ENV RESOUR, V33, P119, DOI
10.1146/annurev.environ.33.022007.145142
   Norman Rosana, 2010, Reviews on Environmental Health, V25, P87
   Nundy S, 2011, AM J TROP MED HYG, V84, P38, DOI 10.4269/ajtmh.2011.10-0442
   WegelinSchuringa M, 1997, ENVIRON URBAN, V9, P181, DOI
10.1177/095624789700900208
   World Bank, 2014, COUNTR LEND GROUPS
   Ziegelbauer K, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001162
NR 27
TC 11
Z9 11
U1 0
U2 14
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1360-2276
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J9 TROP MED INT HEALTH
JI Trop. Med. Int. Health
PD NOV
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VL 19
IS 11
BP 1334
EP 1345
DI 10.1111/tmi.12375
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WC Public, Environmental & Occupational Health; Tropical Medicine
SC Public, Environmental & Occupational Health; Tropical Medicine
GA AT2TB
UT WOS:000344787800005
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OA Green Published, Bronze
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PT J
AU Middleton, A
   Bragin, E
   Morley, KI
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Parker, M
AF Middleton, A.
Bragin, E.
Morley, K. I.
Parker, M.
CA DDD Study
TI Online questionnaire development: Using film to engage participants and then gather attitudes towards the sharing of genomic data
SO SOCIAL SCIENCE RESEARCH
LA English
DT Article
DE Genome, Ethics; Survey; Incidental finding; Film; Opportunistic
ID INCIDENTAL FINDINGS; RESPONSE RATE; INTERNET; PAPER; COMPLETENESS; PERSPECTIVES; GENETICS; HEALTH; RETURN
AB How can a researcher engage a participant in a survey, when the subject matter may be perceived as 'challenging' or even be totally unfamiliar to the participant? The Genomethics study addressed this via the creation and delivery of a novel online questionnaire containing 10 integrated films. The films documented various ethical dilemmas raised by genomic technologies and the survey ascertained attitudes towards these. Participants were recruited into the research using social media, traditional media and email invitation. The film-survey strategy was successful: 11,336 initial hits on the survey website led to 6944 completed surveys. Participants included from those who knew nothing of the subject matter through to experts in the field of genomics (61% compliance rate), 72% of participants answered every single question. This paper summarises the survey design process and validation methods applied. The recruitment strategy and results from the survey are presented elsewhere. (c) 2013 The Authors. Published by Elsevier Inc. All rights reserved.
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CR Aday LA, 2006, DESIGNING CONDUCTING
Affleck P, 2009, J MED ETHICS, V35, P209, DOI 10.1136/jme.2007.024034
Baiter K.A, 2005, EPIDEMIOLOGY, V16, P577
Bates BR, 2005, PUBLIC UNDERST SCI, V14, P47, DOI 10.1177/0963662505048409
Beskow LM, 2010, SCI, V2, P3
BRENNAN P, 1992, BMJ-BRIT MED J, V304, P1491, DOI 10.1136/bmj.304.6840.1491
Bylund C. L., 2010, FAMILY COMMUNICATION, P34
Condit CM, 2010, CLIN GENET, V77, P1, DOI 10.1111/j.1399-0004.2009.01316.x
Denscombe M., 2005, GOOD RES GUIDE SMALL
Dillman D., 1998, P SURVEY METHODS SEC
Dillman DA, 2000, MAIL INTERNET SURVEY
Evans JP, 2012, GENET MED, V14, P358, DOI 10.1038/gim.2012.8
Farndon Peter A, 2008, J Genet Couns, V17, P161, DOI 10.1007/s10897-007-9144-x

```
   FEINSTEIN AR, 1990, J CLIN EPIDEMIOL, V43, P543, DOI 10.1016/0895-
4356(90)90158-L
   FINK A, 2003, ASK SURVEY QUESTIONS
   Firth HV, 2011, DEV MED CHILD NEUROL, V53, P702, DOI 10.1111/j.1469-
8749.2011.04032.x
   Fleming CM, 2009, J ENVIRON MANAGE, V90, P284, DOI
10.1016/j.jenvman.2007.09.011
   Frankfort-Nachmias C, 2000, RES METHODS SOCIAL S
   Galvin K. M., 2010, FAMILY COMMUNICATION, P102
   Ganassali S., 2008, SURVEY RES METHODS, V2, P21, DOI DOI
10.18148/SRM/2008.V2I1.598
   Human Genetics Commission, 2000, WHOS HANDS YOUR GEN, P53
   Hunter J, 2013, J EVAL CLIN PRACT, V19, P855, DOI 10.1111/j.1365-
2753.2012.01864.x
   Kamo N, 2011, ANN ONCOL, V22, P723, DOI 10.1093/annonc/mdq417
   Knoppers BM, 2006, EUR J HUM GENET, V14, P1170, DOI 10.1038/sj.ejhg.5201690
   Kongsved SM, 2007, J MED INTERNET RES, V9, DOI 10.2196/jmir.9.3.e25
   Lietz P., 2010, INT J MARKET RES, V52
   Lozar Manfreda K., 2002, J COMPUT MEDIATED CO
   MacElroy B., 2000, J ONLINE RES
   Mathieu E, 2012, BMC MED RES METHODOL, V12, DOI 10.1186/1471-2288-12-162
   McAllister M., 2010, FAMILY COMMUNICATION, P152
   Middleton A., 2014, J COMMUNITY IN PRESS, DOI [10.1007/S12687-014.01.84.2,
DOI 10.1007/S12687-014.01.84.2]
   Middleton A, 2013, AM J MED GENET A, V161, P2099, DOI 10.1002/ajmg.a.36067
   Oppenheim A. N., 1992, QUESTIONNAIRE DESIGN
   Ritter P, 2004, J MED INTERNET RES, V6, P19, DOI 10.2196/jmir.6.3.e29
   Saris W.E., 2007, DESIGN EVALUATION AN
   Smerecnik S., 2011, PUBLIC HEALTH GENOM, V14, P259
   Truell AD, 2002, BEHAV RES METH INS C, V34, P46, DOI 10.3758/BF03195422
   Vicente P, 2010, SOC SCI COMPUT REV, V28, P251, DOI 10.1177/0894439309340751
   Wolf SM, 2008, J LAW MED ETHICS, V36, P219, DOI 10.1111/j.1748-
720X.2008.00266.x
   Wolf SM, 2012, GENET MED, V14, P355, DOI 10.1038/gim.2012.26
   World Values Survey, 2009, WORLD VAL SURV 2005
   Wright C., 2011, NEXT STEPS SEQUENCE
NR 42
TC 11
Z9 11
U1 0
U2 6
PU ACADEMIC PRESS INC ELSEVIER SCIENCE
PI SAN DIEGO
PA 525 B ST, STE 1900, SAN DIEGO, CA 92101-4495 USA
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J9 SOC SCI RES
JI Soc. Sci. Res.
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WC Sociology
SC Sociology
GA AA3QI
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PT J
AU Harris, D
   Khan, L
   Paul, R
   Thuraisingham, B
AF Harris, Douglas
   Khan, Latifur
   Paul, Raymond
   Thuraisingham, Bhavani
TI Standards for secure data sharing across organizations
SO COMPUTER STANDARDS & INTERFACES
LA English
DT Article
DE standards-based approaches; data sharing; real-time data management
AB This paper discusses standards-based approaches for secure data sharing
across organizations. in particular, current standards as well as
standardization trends for data integration, multimedia data management, active
real-time data management, data warehousing and mining, expert data management,
semantic web data management, knowledge management, visualization, metadata
extraction and management, and security management for data sharing are
discussed. We will illustrate the ideas with an example from emergency response
and public health awareness application domain. (c) 2006 Published by Elsevier
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CR BENSLEY E, 1996, P IEEE WORDS LAG BEA
   BERTINO E, 2005, IN PRESS IEEE T SYST
   CLIFTON C, 2001, STANDARDS DATA MININ
   Hayes-Roth Frederick, 1983, BUILDING EXPERT SYST
   Lenat D. B., 1990, BUILDING LARGE KNOWL
   MARCO S, 2004, UNIVERSAL META DATA
   MAYBURY M, 1997, BROADCAST NEWS NAVIG
   Morey D., 2001, KNOWLEDGE MANAGEMENT
   ROBERTS M, 2005, SECURE DATA SHARING
   ROBERTS M, 2004, HOLISTIC APPROACH CO
   Thuraisingham B, 2005, J DATABASE MANAGE, V16, P75, DOI
10.4018/jdm.2005010106
   Thuraisingham B., 1998, DATA MINING TECHNOLO
   Thuraisingham B., 2005, DATABASE APPL SECURI
   Thuraisingham B., 2002, XML DATABASES SEMANT
   Thuraisingham B., 2001, MANAGING MINING MULT
   THURAISINGHAM B, 2005, SECURITY STANDARDS S
   Thuraisingham B., 1997, DATA MANAGEMENT SYST
   Thuraisingham B., 2003, WEB DATA MINING TECH
   Thuraisingham B., 2000, WEB DATA MANAGEMENT
   Ware C., 2004, INFORM VISUALIZATION
NR 20
TC 11
Z9 12
U1 0
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PU ELSEVIER SCIENCE BV
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SN 0920-5489
EI 1872-7018
J9 COMPUT STAND INTER
JI Comput. Stand. Interfaces
PD JAN
PY 2007
VL 29
IS 1
BP 86
EP 96
DI 10.1016/j.csi.2006.01.004
PG 11
WC Computer Science, Hardware & Architecture; Computer Science, Software
   Engineering
SC Computer Science
GA 120FC
UT WOS:000243068500010
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PT J
AU Lawler, M
   Haussler, D
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   Knoppers, BM
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   McMurry, Julie A.
   Knoppers, Bartha M.
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   Walia, Guneet
   Banks, Ian
   Yu, Peter P.
   Staudt, Louis M.
   Sawyers, Charles L.
CA Global Alliance Genomics Hlth
TI Sharing Clinical and Genomic Data on Cancer - The Need for Global
   Solutions
SO NEW ENGLAND JOURNAL OF MEDICINE
LA English
DT Editorial Material
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RP Lawler, M (reprint author), Queens Univ Belfast, Ctr Canc Res & Cell Biol,
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CR Casali PG, 2014, ANN ONCOL, V25, P1458, DOI 10.1093/annonc/mdu218
   Dewey FE, 2016, SCIENCE, V354, DOI 10.1126/science.aaf6814
   Dove ES, 2016, LANCET, V387, P1374, DOI 10.1016/S0140-6736(16)30078-2
   Grossman RL, 2016, NEW ENGL J MED, V375, P1109, DOI 10.1056/NEJMp1607591
   Vis DJ, 2017, ANN ONCOL, V28, P1145, DOI 10.1093/annonc/mdx037
NR 5
TC 10
Z9 10
U1 0
U2 8
PU MASSACHUSETTS MEDICAL SOC
PI WALTHAM
PA WALTHAM WOODS CENTER, 860 WINTER ST,, WALTHAM, MA 02451-1413 USA
SN 0028-4793
EI 1533-4406
J9 NEW ENGL J MED
JI N. Engl. J. Med.
PD MAY 25
PY 2017
VL 376
IS 21
BP 2006
EP 2009
DI 10.1056/NEJMp1612254
PG 4
WC Medicine, General & Internal
SC General & Internal Medicine
GA EV7MC
UT WOS:000401959600003
PM 28538124
OA Green Published
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ER

PT J
AU Chretien, JP
   Rivers, CM
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   Johansson, MA
AF Chretien, Jean-Paul
   Rivers, Caitlin M.
   Johansson, Michael A.
TI Make Data Sharing Routine to Prepare for Public Health Emergencies
SO PLOS MEDICINE
LA English
DT Article
ID CLINICAL-TRIAL DATA; JOURNAL EDITORS
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CR Amsen E., WHAT IS OPEN SCI
   Archambault E, 2014, PROPORTION OPEN ACCE
   Barbui C, 2016, BMC MED, V14, DOI 10.1186/s12916-016-0612-8
   Berlin JA, 2014, CLIN TRIALS, V11, P7, DOI 10.1177/1740774513514497
   Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
   Bill and Melinda Gates Foundation, OP ACC POL
   BIRNEY E, 2009, NATURE, V461, P168, DOI DOI 10.1038/461168A
   Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
   Butler D, 2016, NATURE, DOI [10.1038/nature.2016.19438, DOI
10.1038/NATURE.2016.19438]
   Callaway E., 2016, NATURE, DOI [10.1038/nature.2016.19367, DOI
10.1038/NATURE.2016.19367]
   Carr D, 2015, J EMPIR RES HUM RES, V10, P314, DOI 10.1177/1556264615593485
   Centers for Disease Control and Prevention, ADD REQ FUND OPP ANN
   Centers for Disease Control and Prevention/Agency for Toxic Substances and
Disease Registry, 2003, CDC ATSDR POL REL SH
   Chretien JP, 2015, ELIFE, V4, DOI 10.7554/eLife.09186
   Dinsmore A, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1002003
   Federer LM, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0129506
   GovLab, OP DAT IMP
   Hanwell M., WHAT IS OPEN SCI
   Kurata K, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0060925
   McNabb SJN, 2014, LANCET RESP MED, V2, P436, DOI 10.1016/S2213-2600(14)70102-
X
   Merson L, 2016, NEW ENGL J MED, V374, P2414, DOI 10.1056/NEJMp1605148
   Messina J, 2016, SCI DATA
   Modjarrad K, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001935
   Owens B, 2016, SCIENCE, V351, P329, DOI 10.1126/science.351.6271.329
   Pham-Kanter G, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0108451
   PLOS Medicine Editors, 2016, PLOS MED, V13, DOI [10.1371/journal.pmed.1001949,
DOI 10.1371/JOURNAL.PMED.1001949]
   Pomerantz J, 2016, 1 MONDAY, V21, DOI 10.5210/fm.v21i5.6360
   Research Data Alliance, DLI SERV OP ON FOR A
   Smith Richard, 2016, F1000Res, V5, P781, DOI 10.12688/f1000research.8422.1
   Taichman DB, 2016, ANN INTERN MED, V164, P505, DOI 10.7326/M15-2928
   Tenopir C, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0134826
   Vallance P, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001936
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wellcome Trust, 2016, SHAR DAT ZIK OTH GLO
   Whitty CJM, 2015, LANCET, V386, P1797, DOI 10.1016/S0140-6736(15)00758-8
```

```
   Wikipedia, OP NOT SCI
   World Health Organization, 2015, REP EB INT ASS PAN
   World Health Organization, HANDL INFL GEN SEQ D
   World Health Organization, DEV GLOB NORMS SHAR
   Yozwiak NL, 2015, NATURE, V518, P477, DOI 10.1038/518477a
   Zinner DE, 2016, ACAD MED, V91, P433, DOI 10.1097/ACM.0000000000001028
NR 41
TC 10
Z9 10
U1 0
U2 5
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1549-1676
J9 PLOS MED
JI PLos Med.
PD AUG
PY 2016
VL 13
IS 8
AR e1002109
DI 10.1371/journal.pmed.1002109
PG 7
WC Medicine, General & Internal
SC General & Internal Medicine
GA DW0UD
UT WOS:000383357400026
PM 27529422
OA DOAJ Gold, Green Published
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PT J
AU Rezaeibagha, F
   Mu, Y
AF Rezaeibagha, Fatemeh
   Mu, Yi
TI Distributed clinical data sharing via dynamic access-control policy
   transformation
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE EHR; Security; Privacy; Data sharing; Access control; Encryption
ID PRIVACY; EFFICIENT
AB Background: Data sharing in electronic health record (EHR) systems is
important for improving the quality of healthcare delivery. Data sharing,
however, has raised some security and privacy concerns because healthcare data
could be potentially accessible by a variety of users, which could lead to
privacy exposure of patients. Without addressing this issue, large-scale
adoption and sharing of EHR data are impractical. The traditional solution to
the problem is via encryption. Although encryption can be applied to access
control, it is not applicable for complex EHR systems that require multiple
domains (e.g. public and private clouds) with various access requirements.
   Objectives: This study was carried out to address the security and privacy
issues of EHR data sharing with our novel access-control mechanism, which
captures the scenario of the hybrid clouds and need of access-control policy
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transformation, to provide secure and privacy-preserving data sharing among different healthcare enterprises.

Methods: We introduce an access-control mechanism with some cryptographic building blocks and present a novel approach for secure EHR data sharing and access-control policy transformation in EHR systems for hybrid clouds.

Results: We propose a useful data sharing system for healthcare providers to handle various EHR users who have various access privileges in different cloud environments. A systematic study has been conducted on data sharing in EHR systems to provide a solution to the security and privacy issues.

Conclusions: In conclusion, we introduce an access-control method for privacy protection of EHRs and EHR policy transformation that allows an EHR access-control policy to be transformed from a private cloud to a public cloud. This method has never been studied previously in the literature. Furthermore, we provide a protocol to demonstrate policy transformation as an application scenario. (C) 2016 Elsevier Ireland Ltd. All rights reserved.

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CR Ahmed M, 2014, INT COMMUN HEAT MASS, V58, P1, DOI 10.1016/j.icheatmasstransfer.2014.08.008
Basu S., IEEE COMPUT, V45
Boneh D, 2006, LECT NOTES COMPUT SC, V3860, P226
Calvillo J, 2013, INT J MED INFORM, V82, P58, DOI 10.1016/j.ijmedinf.2012.02.006
Chen K, 2010, INT J MED INFORM, V79, P181, DOI 10.1016/j.ijmedinf.2009.12.007
Chen TS, 2012, J MED SYST, V36, P4005, DOI 10.1007/s10916-012-9873-8
Choe J, 2008, INT J MED INFORM, V77, P242, DOI 10.1016/j.ijmedinf.2007.06.001
Chu CK, 2014, IEEE T PARALL DISTR, V25, P468, DOI 10.1109/TPDS.2013.112
Dong X, 2014, COMPUT SECUR, V42, P151, DOI 10.1016/j.cose.2013.12.002
Duftschmid G, 2013, INT J MED INFORM, V82, P1195, DOI 10.1016/j.ijmedinf.2013.08.002
Ermakova Tatiana, 2013, 2013 IEEE 15th Conference on Business Informatics (CBI), P93, DOI 10.1109/CBI.2013.22
Huang QL, 2013, J COMPUT, V8, P2776, DOI 10.4304/jcp.8.11.2776-2781
Hur J, 2013, IEEE T KNOWL DATA EN, V25, P2271, DOI 10.1109/TKDE.2011.78
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Liang X., 2009, P 4 INT S INF COMP C, P276, DOI DOI 10.1145/1533057.1533094
Liu JH, 2015, FUTURE GENER COMP SY, V52, P67, DOI 10.1016/j.future.2014.10.014
Mohan A., 2009, PATIENT CENTRIC ATTR
Rezaeibagha F, 2015, HEALTH INF MANAG J, V44, P23, DOI 10.1177/183335831504400304
Sadiku MNO, 2014, IEEE POTENTIALS, V33, P34, DOI 10.1109/MPOT.2013.2279684
SHAMIR A, 1979, COMMUN ACM, V22, P612, DOI 10.1145/359168.359176
Sun JY, 2010, IEEE T PARALL DISTR, V21, P754, DOI 10.1109/TPDS.2009.124
Wei GY, 2014, J COMPUT SYST SCI, V80, P1549, DOI 10.1016/j.jcss.2014.04.021
Wu D, 2010, INT CONF COMP SCI, P268, DOI 10.1109/ICCSIT.2010.5563744
Wu R, 2012, COLLABORATECOM, P711, DOI 10.4108/icst.collaboratecom.2012.250497
Yi X, 2013, IEEE GLOB COMM CONF, P2730, DOI 10.1109/GLOCOM.2013.6831487
Yu S., 2010, INFOCOM, P534
Yu YC, 2014, MED BIOL ENG COMPUT, V52, P449, DOI 10.1007/s11517-014-1147-9
NR 27
TC 10
Z9 11
U1 0
U2 26

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PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
   IRELAND
SN 1386-5056
EI 1872-8243
J9 INT J MED INFORM
JI Int. J. Med. Inform.
PD MAY
PY 2016
VL 89
BP 25
EP 31
DI 10.1016/j.ijmedinf.2016.02.002
PG 7
WC Computer Science, Information Systems; Health Care Sciences & Services;
   Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA DJ2ZL
UT WOS:000374074100004
PM 26980356
DA 2019-08-06
ER

PT J
AU Droste, N
   Miller, P
   Baker, T
AF Droste, Nicolas
   Miller, Peter
   Baker, Tim
TI Review article: Emergency department data sharing to reduce
   alcohol-related violence: A systematic review of the feasibility and
   effectiveness of community-level interventions
SO EMERGENCY MEDICINE AUSTRALASIA
LA English
DT Review
DE alcohol; data sharing; emergency department; injury; violence
ID PREVENTING VIOLENCE; INFORMATION; POLICE; CONSUMPTION; ATTENDANCES;
   STRATEGIES; INJURIES; DRINKERS; HEALTH; CITY
AB The present paper aims to review current evidence for the effectiveness
and/or feasibility of using inter-agency data sharing of ED recorded assault
information to direct interventions reducing alcohol-related or nightlife
assaults, injury or violence. Potential data-sharing partners involve police,
local council, liquor licensing regulators and venue management. A systematic
review of the peer-reviewed literature was conducted. The initial search
discovered 19 506 articles. After removal of duplicates and articles not meeting
review criteria, n = 8 articles were included in quantitative and narrative
synthesis. Seven of eight studies were conducted in UK EDs, with the remaining
study presenting Australian data. All studies included in the review deemed data
sharing a worthwhile pursuit. All studies attempting to measure intervention
effectiveness reported substantial reductions of assaults and ED attendances
post-intervention, with one reporting no change. Negative logistic feasibility
concerns were minimal, with general consensus among authors being that data-
sharing protocols and partnerships could be easily implemented into modern ED
triage systems, with minimal cost, staff workload burden, impact to patient
safety, service and anonymity, or risk of harm displacement to other licensed
venues, or increase to length of patient stay. However, one study reported a
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potential harm displacement effect to streets surrounding intervention venues. In future, data-sharing systems should triangulate ED, police and ambulance data sources, and assess intervention effectiveness using randomised controlled trials that account for variations in venue capacity, fluctuations in ED attendance and population levels, seasonal variations in assault and injury, and control for concurrent interventions.

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OI Droste, Nicolas/0000-0002-3291-331X

CR Bellis MA, 2012, BMC PUBLIC HEALTH, V12, DOI 10.1186/1471-2458-12-746
Benger J, 2008, EMERG MED J, V25, P331, DOI 10.1136/emj.2007.048926
Blow FC, 2006, J STUD ALCOHOL, V67, P568, DOI 10.15288/jsa.2006.67.568
Boyle AA, 2013, EMERG MED J, V30, P1020, DOI 10.1136/emermed-2012-201898
Coomber K, 2013, J RURAL HEALTH, V29, P320, DOI 10.1111/jrh.12014
Delgado MK, 2011, ANN EMERG MED, V57, P104, DOI 10.1016/j.annemergmed.2010.07.015
Dent AW, 2008, EMERG MED AUSTRALAS, V20, P121, DOI 10.1111/j.1742-6723.2008.01067.x
Florence C, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d3313
Havard A, 2008, ADDICTION, V103, P368, DOI 10.1111/j.1360-0443.2007.02072.x
Havard A, 2012, EMERG MED AUSTRALAS, V24, P266, DOI 10.1111/j.1742-6723.2012.01537.x
Holder Y, 2001, INJURY SURVEILLANCE
Laing AJ, 2013, EMERG MED AUSTRALAS, V25, P550, DOI 10.1111/1742-6723.12136
Longabaugh R, 2001, J STUD ALCOHOL, V62, P806, DOI 10.15288/jsa.2001.62.806
Macdonald S, 2005, ADDICT BEHAV, V30, P103, DOI 10.1016/j.addbeh.2004.04.016
Macdonald S, 2006, ACCIDENT ANAL PREV, V38, P1107, DOI 10.1016/j.aap.2006.04.019
Mdege ND, 2013, DRUG ALCOHOL DEPEN, V131, P1, DOI 10.1016/j.drugalcdep.2013.01.023
Miller P, 2012, DRUG ALCOHOL REV, V31, P370, DOI 10.1111/j.1465-3362.2011.00375.x
Miller PG, 2011, DEALING ALCOHOL NIGH
Moore SC, 2011, ALCOHOL ALCOHOLISM, V46, P357, DOI 10.1093/alcalc/agr011
Nordqvist C, 2006, ADDICT BEHAV, V31, P191, DOI 10.1016/j.addbeh.2005.04.021
Pointing S, 2011, EMERG MED AUSTRALAS, V23, P106, DOI 10.1111/j.1742-6723.2010.01382.x
Quigg Z, 2012, INJURY PREV, V18, P315, DOI 10.1136/injuryprev-2011-040159
Shepherd Jonathan, 2007, Crim Behav Ment Health, V17, P250
Sivarajasingam V, 2011, BRIT MED J, V343, DOI 10.1136/bmj.d4453
Sutherland I, 2002, INJ PREV, V8, P246, DOI 10.1136/ip.8.3.246
Warburton AL, 2006, EMERG MED J, V23, P12, DOI 10.1136/emj.2004.023028
Warburton AL, 2004, EMERG MED J, V21, P473, DOI 10.1136/emj.2003.004978

NR 27
TC 10
Z9 10
U1 0
U2 0

PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1742-6731
EI 1742-6723

J9 EMERG MED AUSTRALAS
JI Emerg. Med. Australas.
PD AUG
PY 2014
VL 26
IS 4
BP 326
EP 335
DI 10.1111/1742-6723.12247
PG 10
WC Emergency Medicine
SC Emergency Medicine
GA AN0AH
UT WOS:000340242800002
PM 24931278
DA 2019-08-06
ER

PT J
AU Verropoulou, G
AF Verropoulou, Georgia
TI Specific versus general self-reported health indicators predicting
   mortality among older adults in Europe: disparities by gender employing
   SHARE longitudinal data
SO INTERNATIONAL JOURNAL OF PUBLIC HEALTH
LA English
DT Article
DE SRH; GALI; Specific mortality predictors; General mortality predictors;
   Sex disparities
ID RATED HEALTH; RISK; DISABILITY; IMPACT; SYMPTOMS; SMOKING; INDEX
AB The study aims at assessing the relative importance of specific versus
general self-reported indicators of health and disability in predicting
mortality among older adults and at exploring the potential value of the global
activity limitation indicator (GALI), a recently validated general measure of
activity restrictions, as predictor of death.
   Longitudinal data from two waves (2004 and 2006-2007) of the Survey of Health,
Ageing and Retirement in Europe were employed. The sample comprises 17,941
persons aged 50+ at baseline, representing 11 countries. Associations were
estimated by sex using Cox's proportional hazards regression models.
   Most specific and general indicators of health and disability are strong and
independent predictors. There are disparities by sex; among general measures,
controlling for all indicators under consideration, self-rated health (SRH) only
remains significantly associated with mortality among males and GALI among
females.
   A combination of specific and general measures is more efficient in
predicting mortality than either of these alone. SRH and GALI seem to share some
traits, adding health and disability dimensions over specific measures,
representing though different aspects by gender.
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CR Blomgren J, 2012, J EPIDEMIOL COMMUN H, V66, P30, DOI
10.1136/jech.2010.110635

Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
Cho CY, 1998, J AM GERIATR SOC, V46, P677, DOI 10.1111/j.1532-5415.1998.tb03800.x
Deeg DJH, 2003, GERONTOLOGIST, V43, P369, DOI 10.1093/geront/43.3.369
DeSalvo KB, 2006, J GEN INTERN MED, V21, P267, DOI 10.1111/j.1525-1497.2005.00291.x
Dey DK, 2001, EUR J CLIN NUTR, V55, P482, DOI 10.1038/sj.ejcn.1601208
Dunlop DD, 2002, ARCH PHYS MED REHAB, V83, P964, DOI 10.1053/apmr.2002.32817
Flegal KM, 2005, JAMA-J AM MED ASSOC, V293, P1861, DOI 10.1001/jama.293.15.1861
Fonda S., 2004, DOCUMENTATION PHYS F
French DJ, 2013, INT J PUBLIC HEALTH, V58, P345, DOI 10.1007/s00038-012-0430-5
Fukuda Y, 2005, BMC PUBLIC HEALTH, V5, DOI 10.1186/1471-2458-5-53
Gilmour Heather, 2006, Health Rep, V16 Suppl, P21
IDLER EL, 1991, J GERONTOL, V46, pS55, DOI 10.1093/geronj/46.2.S55
Idler EL, 1997, J HEALTH SOC BEHAV, V38, P21, DOI 10.2307/2955359
Jagger C, 2010, J CLIN EPIDEMIOL, V63, P892, DOI 10.1016/j.jclinepi.2009.11.002
Jensen GL, 2006, OBESITY, V14, P509, DOI 10.1038/oby.2006.66
KATZ S, 1983, J AM GERIATR SOC, V31, P721, DOI 10.1111/j.1532-5415.1983.tb03391.x
KATZ S, 1970, GERONTOLOGIST, V10, P20, DOI 10.1093/geront/10.1_Part_1.20
Kivinen P, 1998, AGE AGEING, V27, P41, DOI 10.1093/ageing/27.1.41
Korten AE, 1999, J EPIDEMIOL COMMUN H, V53, P83, DOI 10.1136/jech.53.2.83
LAWTON MP, 1969, GERONTOLOGIST, V9, P9, DOI 10.1093/geront/9.1.9
Mehta KM, 2003, J GERONTOL A-BIOL, V58, P461
Merrill SS, 1997, J GERONTOL A-BIOL, V52, pM19, DOI 10.1093/gerona/52A.1.M19
O'Reilly D, 2010, SOC SCI MED, V71, P1011, DOI 10.1016/j.socscimed.2010.05.042
Orpana HM, 2010, OBESITY, V18, P214, DOI 10.1038/oby.2009.191
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Puts MTE, 2005, J AM GERIATR SOC, V53, P40, DOI 10.1111/j.1532-5415.2005.53008.x
Reynolds SL, 2003, SOC SCI MED, V57, P1875, DOI 10.1016/S0277-9536(03)00053-4
Robine JM, 2003, EUR J PUBLIC HEALTH, V13, P6, DOI 10.1093/eurpub/13.suppl_1.6
Rolland Y, 2006, EUR J EPIDEMIOL, V21, P113, DOI 10.1007/s10654-005-5458-x
Schroder M, 2008, 1 RESULTS SURVEY HLT
Schulz A, 2011, 28 ROST CTR
SHARE, 2011, REL GUID 2 5 0 WAV 1
Simoes EJ, 2012, INT J PUBLIC HEALTH, V57, P719, DOI 10.1007/s00038-012-0341-5
Simons LA, 2005, MED J AUSTRALIA, V182, P219
Oyen H, 2006, SOZ PRAVENTIV MED, V51, P153, DOI 10.1007/s00038-006-0035-y
Verropoulou G, 2012, EUR J AGEING, V9, P305, DOI 10.1007/s10433-012-0238-4
Verropoulou G, 2009, EUR J AGEING, V6, P213, DOI 10.1007/s10433-009-0125-9
Vuorisalmi M, 2008, EUR J AGEING, V5, P327, DOI 10.1007/s10433-008-0093-5
Woo J, 1998, J GERONTOL A-BIOL, V53, pM102, DOI 10.1093/gerona/53A.2.M102
NR 40
TC 10
Z9 11
U1 1
U2 4
PU SPRINGER BASEL AG
PI BASEL
PA PICASSOPLATZ 4, BASEL, 4052, SWITZERLAND

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EI 1661-8564
J9 INT J PUBLIC HEALTH
JI Int. J. Public Health
PD AUG
PY 2014
VL 59
IS 4
BP 665
EP 678
DI 10.1007/s00038-014-0563-9
PG 14
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA AM5ZT
UT WOS:000339940700011
PM 24846530
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PT J
AU Paricharak, S
Klenka, T
Augustin, M
Patel, UA
Bender, A
AF Paricharak, Shardul
Klenka, Tom
Augustin, Martin
Patel, Umesh A.
Bender, Andreas
TI Are phylogenetic trees suitable for chemogenomics analyses of bioactivity data sets: the importance of shared active compounds and choosing a suitable data embedding method, as exemplified on Kinases
SO JOURNAL OF CHEMINFORMATICS
LA English
DT Article
DE Kinase inhibitor; Selectivity; Phylogenetics; Chemogenomics; Polypharmacology
ID CHRONIC MYELOGENOUS LEUKEMIA; CELL LUNG-CANCER; INHIBITOR SELECTIVITY; DRUG DISCOVERY; THERAPEUTIC STRATEGIES; INTERACTIVE TREE; BREAST-CANCER; SPACE; SIMILARITY; KINOME
AB Background: 'Phylogenetic trees' are commonly used for the analysis of chemogenomics datasets and to relate protein targets to each other, based on the (shared) bioactivities of their ligands. However, no real assessment as to the suitability of this representation has been performed yet in this area. We aimed to address this shortcoming in the current work, as exemplified by a kinase data set, given the importance of kinases in many diseases as well as the availability of large-scale datasets for analysis. In this work, we analyzed a dataset comprising 157 compounds, which have been tested at concentrations of 1 mu M and 10 mu M against a panel of 225 human protein kinases in full-matrix experiments, aiming to explain kinase promiscuity and selectivity against inhibitors. Compounds were described by chemical features, which were used to represent kinases (i.e. each kinase had an active set of features and an inactive set).

Results: Using this representation, a bioactivity-based classification was made of the kinome, which partially resembles previous sequence-based classifications, where particularly kinases from the TK, CDK, CLK and AGC

branches cluster together. However, we were also able to show that in approximately 57% of cases, on average 6 kinase inhibitors exhibit activity against kinases which are located at a large distance in the sequence-based classification (at a relative distance of 0.6 - 0.8 on a scale from 0 to 1), but are correctly located closer to each other in our bioactivity-based tree (distance 0 - 0.4). Despite this improvement on sequence-based classification, also the bioactivity-based classification needed further attention: for approximately 80% of all analyzed kinases, kinases classified as neighbors according to the bioactivity-based classification also show high SAR similarity (i.e. a high fraction of shared active compounds and therefore, interaction with similar inhibitors). However, in the remaining similar to 20% of cases a clear relationship between kinase bioactivity profile similarity and shared active compounds could not be established, which is in agreement with previously published atypical SAR (such as for LCK, FGFR1, AKT2, DAPK1, TGFR1, MK12 and AKT1).

Conclusions: In this work we were hence able to show that (1) targets (here kinases) with few shared activities are difficult to establish neighborhood relationships for, and (2) phylogenetic tree representations make implicit assumptions (i.e. that neighboring kinases exhibit similar interaction profiles with inhibitors) that are not always suitable for analyses of bioactivity space. While both points have been implicitly alluded to before, this is to the information of the authors the first study that explores both points on a comprehensive basis. Excluding kinases with few shared activities improved the situation greatly (the percentage of kinases for which no neighborhood relationship could be established dropped from 20% to only 4%). We can conclude that all of the above findings need to be taken into account when performing chemogenomics analyses, also for other target classes.

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CR Alix B, 2012, NUCLEIC ACIDS RES, V40, pW573, DOI 10.1093/nar/gks485
Anastassiadis T, 2011, NAT BIOTECHNOL, V29, P1039, DOI 10.1038/nbt.2017
[Anonymous], 2018, MOL OP ENV MOE
Arce-Lara C, 2007, UROLOGY, V69
Bamborough P, 2008, J MED CHEM, V51, P7898, DOI 10.1021/jm8011036
Bender A, 2004, J CHEM INF COMP SCI, V44, P1708, DOI 10.1021/ci0498719
Bender A, 2008, CURR OPIN DRUG DISC, V11, P327
Bender A, 2007, COMB CHEM HIGH T SCR, V10, P719, DOI 10.2174/138620707782507313
Bender A, 2009, J CHEM INF MODEL, V49, P108, DOI 10.1021/ci800249s
Bongers ML, 2012, PHARMACOECONOMICS, V30, P17, DOI 10.2165/11595000-000000000-00000
Cheng FX, 2012, MOL BIOSYST, V8, P2373, DOI 10.1039/c2mb25110h
Davis MI, 2011, NAT BIOTECHNOL, V29, P1046, DOI 10.1038/nbt.1990
Dessau Ram Benny, 2008, Ugeskr Laeger, V170, P328
Donner A, 2012, NAT CHEM BIOL, V8, P502
Fabian MA, 2005, NAT BIOTECHNOL, V23, P329, DOI 10.1038/nbt1068

Felsenstein J., 1989, CLADISTICS, V5, P164, DOI DOI 10.1111/J.1096-0031.1989.TB00562.X
Gao YH, 2013, BIOCHEM J, V451, P313, DOI 10.1042/BJ20121418
Garcia-Manero G, 2003, CANCER, V98, P437, DOI 10.1002/cncr.11520
Hanks SK, 2003, GENOME BIOL, V4, DOI 10.1186/gb-2003-4-5-111
HANKS SK, 1995, FASEB J, V9, P576
Hinselmann G, 2011, J CHEMINFORMATICS, V3, DOI 10.1186/1758-2946-3-3
Johnson JR, 2003, CLIN CANCER RES, V9, P1972
Kalliokoski T, 2011, MOL INFORM, V30, P923, DOI 10.1002/minf.201100112
Karaman MW, 2008, NAT BIOTECHNOL, V26, P127, DOI 10.1038/nbt1358
Knight ZA, 2010, NAT REV CANCER, V10, P130, DOI 10.1038/nrc2787
Koskela Hanna, 2012, Duodecim, V128, P579
Krystal GW, 2004, LEUKEMIA RES, V28, pS53, DOI 10.1016/j.leukres.2003.10.003
Kuhn D, 2007, CHEMMEDCHEM, V2, P1432, DOI 10.1002/cmdc.200700075
Letunic I, 2007, BIOINFORMATICS, V23, P127, DOI 10.1093/bioinformatics/btl529
Letunic I, 2011, NUCLEIC ACIDS RES, V39, pW475, DOI 10.1093/nar/gkr201
Levitzki A, 2013, ANNU REV PHARMACOL, V53, P161, DOI 10.1146/annurev-pharmtox-011112-140341
Liao JJL, 2007, J MED CHEM, V50, P409, DOI 10.1021/jm0608107
Lombardo LJ, 2004, J MED CHEM, V47, P6658, DOI 10.1021/jm049486a
Lounkine E, 2012, BIOORGAN MED CHEM, V20, P5416, DOI 10.1016/j.bmc.2012.02.034
Manning G, 2002, SCIENCE, V298, P1912, DOI 10.1126/science.1075762
Martin E, 2012, J CHEM INF MODEL, V52, P156, DOI 10.1021/ci200314j
Metz JT, 2011, NAT CHEM BIOL, V7, P200, DOI 10.1038/NCHEMBIO.530
Milletti F, 2010, J CHEM INF MODEL, V50, P1418, DOI 10.1021/ci1001263
Nagano T, 2011, INTERNAL MED, V50, P3019, DOI 10.2169/internalmedicine.50.5903
Norman RA, 2012, TRENDS PHARMACOL SCI, V33, P273, DOI 10.1016/j.tips.2012.03.005
Paolini GV, 2006, NAT BIOTECHNOL, V24, P805, DOI 10.1038/nbt1228
Rexer Brent N., 2012, Critical Reviews in Oncogenesis, V17, P1
Rogers D, 2010, J CHEM INF MODEL, V50, P742, DOI 10.1021/ci100050t
Sos ML, 2010, CANCER RES, V70, P868, DOI 10.1158/0008-5472.CAN-09-3106
Sutherland JJ, 2008, J MED CHEM, V51, P2689, DOI 10.1021/jm701399f
Tamura K, 2011, MOL BIOL EVOL, V28, P2731, DOI 10.1093/molbev/msr121
Tsang RY, 2012, BRIT J CANCER, V106, P6, DOI 10.1038/bjc.2011.516
van der Horst E, 2011, CURR TOP MED CHEM, V11, P1964, DOI 10.2174/156802611796391230
van der Horst E, 2010, BMC BIOINFORMATICS, V11, DOI 10.1186/1471-2105-11-316
Vieth M, 2005, DRUG DISCOV TODAY, V10, P839, DOI 10.1016/S1359-6446(05)03477-X
Vieth M, 2004, BBA-PROTEINS PROTEOM, V1697, P243, DOI 10.1016/j.bbapap.2003.11.028
Wawer M, 2008, J MED CHEM, V51, P6075, DOI 10.1021/jm800867g
Weinmann H, 2005, CHEMBIOCHEM, V6, P455, DOI 10.1002/cbic.200500034
Zhang ZY, 2002, ANNU REV PHARMACOL, V42, P209, DOI 10.1146/annurev.pharmtox.42.083001.144616
Zmasek CM, ARCHAEOPTERYX VISUAL
Zuccotto F, 2010, J MED CHEM, V53, P2681, DOI 10.1021/jm901443h
NR 56
TC 10
Z9 10
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U2 8
PU BIOMED CENTRAL LTD
PI LONDON
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   Muscatello, D
   Mengersen, K
AF Earnest, Arul
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TI Small area estimation of sparse disease counts using shared component
   models-application to birth defect registry data in New South Wales,
   Australia
SO HEALTH & PLACE
LA English
DT Article
DE CAR; Sparse; Spatial; Defects
ID NEURAL-TUBE DEFECTS; CESAREAN DELIVERY; MATERNAL AGE; RISK-FACTOR;
   SPINA-BIFIDA; JOINT; RATES; WEIGHT; EPIDEMIOLOGY; ANENCEPHALUS
AB In the field of disease mapping, little has been done to address the issue of
analysing sparse health datasets. We hypothesised that by modelling two outcomes
simultaneously, one would be able to better estimate the outcome with a sparse
count. We tested this hypothesis utilising Bayesian models, studying both birth
defects and caesarean sections using data from two large, linked birth
registries in New South Wales from 1990 to 2004. We compared four spatial models
across seven birth defects: spina bifida, ventricular septal defect, OS atrial
septal defect, patent ductus arteriosus, cleft lip and or palate, trisomy 21 and
hypospadias. For three of the birth defects, the shared component model with a
zero-inflated Poisson (ZIP) extension performed better than other simpler models,
having a lower deviance information criteria (DIC). With spina bifida, the ratio
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of relative risk associated with the shared component was 2.82 (95% CI: 1.46-5.67). We found that shared component models are potentially beneficial, but only if there is a reasonably strong spatial correlation in effect for the study and referent outcomes. (C) 2010 Elsevier Ltd. All rights reserved.

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CR Assuncao RM, 2004, INT J EPIDEMIOL, V33, P508, DOI 10.1093/ije/dyh040
BAICKER K, 2006, HEALTH AFFAIR, V25, P355
BESAG J, 1991, ANN I STAT MATH, V43, P1, DOI 10.1007/BF00116466
BEST N, 2005, STAT METHODS MED RES, V14, P48
BORMAN B, 1993, J PAEDIATR CHILD H, V29, P282, DOI 10.1111/j.1440-1754.1993.tb00512.x
Brooks SP, 1998, J COMPUT GRAPH STAT, V7, P434, DOI 10.2307/1390675
Clarke S C, 1996, Stat Bull Metrop Insur Co, V77, P28
*CTR EP RES NSW DE, 2000, NSW PUBL HLTH B S, V9, P97
*CTR EP RES NSW DE, 2007, NEW S WAL PUBL HLTH, V18, P9
Dolk H, 1998, BRIT MED J, V317, P905
Downing A, 2008, INT J HEALTH GEOGR, V7, DOI 10.1186/1476-072X-7-41
Earnest A, 2007, INT J HEALTH GEOGR, V6, DOI 10.1186/1476-072X-6-54
Elliott P, 2001, BRIT MED J, V323, P363, DOI 10.1136/bmj.323.7309.363
ERICSON A, 1988, ENVIRON RES, V45, P38, DOI 10.1016/S0013-9351(88)80005-7
Frey L, 2003, EPILEPSIA, V44, P4, DOI 10.1046/j.1528-1157.44.s3.2.x
GAULDEN ME, 1992, MUTAT RES, V296, P69, DOI 10.1016/0165-1110(92)90033-6
Gelfand AE, 2003, BIOSTATISTICS, V4, P11, DOI 10.1093/biostatistics/4.1.11
GORDON D, 1991, OBSTET GYNECOL, V77, P493
Hsieh T T, 1995, Changgeng Yi Xue Za Zhi, V18, P14
Kazembe LN, 2009, HEALTH PLACE, V15, P165, DOI 10.1016/j.healthplace.2008.03.009
Knorr-Held L, 2001, J R STAT SOC A STAT, V164, P73, DOI 10.1111/1467-985X.00187
Kuehl KS, 2006, PEDIATR CARDIOL, V27, P25, DOI 10.1007/s00246-005-0859-x
LAWSON AB, 2000, STAT MED, V19, P2229
Magadi M, 2001, J BIOSOC SCI, V33, P199, DOI 10.1017/S0021932001001997
Maslow AS, 2000, OBSTET GYNECOL, V95, P917, DOI 10.1016/S0029-7844(00)00794-8
Meyer Robert E, 2002, MMWR Recomm Rep, V51, P12
Nili Firouzeh, 2006, Arch Iran Med, V9, P20
Padmadas SS, 2000, SOC SCI MED, V51, P511, DOI 10.1016/S0277-9536(99)00491-8
PARRISH KM, 1994, JAMA-J AM MED ASSOC, V271, P443, DOI 10.1001/jama.271.6.443
PEIPERT JF, 1993, OBSTET GYNECOL, V81, P200
Poletta FA, 2007, AM J MED GENET A, V143A, P3216, DOI 10.1002/ajmg.a.32076
RANKIN J, 2005, ARCH DIS CHILD-FETAL, V90, P374
Reefhuis J, 1999, Community Genet, V2, P97, DOI 10.1159/000016193

```
   Richardson S, 2006, STAT METHODS MED RES, V15, P385, DOI
10.1191/0962280206sm458oa
   Rushton G, 1996, STAT MED, V15, P717, DOI 10.1002/(SICI)1097-
0258(19960415)15:7/9<717::AID-SIM243>3.0.CO;2-0
   Rushton G, 1996, STAT MED, V15, P1907, DOI 10.1002/(SICI)1097-
0258(19960930)15:18<1907::AID-SIM402>3.0.CO;2-R
   SAXEN I, 1975, BRIT J PREV SOC MED, V29, P103
   Seshadri L, 2005, INT J GYNECOL OBSTET, V89, P94, DOI
10.1016/j.ijgo.2005.01.031
   Sims CJ, 2000, AM J OBSTET GYNECOL, V183, P1198, DOI 10.1067/mob.2000.108891
   Spiegelhalter DJ, 2002, J ROY STAT SOC B, V64, P583, DOI 10.1111/1467-
9868.00353
   STRASSBURG MA, 1983, DEV MED CHILD NEUROL, V25, P632
   Summerhayes Richard, 2006, N S W Public Health Bull, V17, P33
   Taffel S M, 1994, Vital Health Stat 21, P1
   Thompson J, 2006, STATA J, V6, P530, DOI 10.1177/1536867X0600600406
   Tuncbilek E, 1999, TURKISH J PEDIATR, V41, P299
   WITTER FR, 1995, OBSTET GYNECOL, V85, P947, DOI 10.1016/0029-7844(95)00082-3
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PT J
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   Yu, J
   Hao, R
   Hu, JK
AF Shen, Wenting
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   Yu, Jia
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TI Enabling Identity-Based Integrity Auditing and Data Sharing With
   Sensitive Information Hiding for Secure Cloud Storage
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LA English
DT Article
DE Cloud storage; data integrity auditing; data sharing; sensitive information hiding
ID SHARED DATA; PRIVACY; SCHEME

AB With cloud storage services, users can remotely store their data to the cloud and realize the data sharing with others. Remote data integrity auditing is proposed to guarantee the integrity of the data stored in the cloud. In some common cloud storage systems such as the electronic health records system, the cloud file might contain some sensitive information. The sensitive information should not be exposed to others when the cloud file is shared. Encrypting the whole shared file can realize the sensitive information hiding, but will make this shared file unable to be used by others. How to realize data sharing with sensitive information hiding in remote data integrity auditing still has not been explored up to now. In order to address this problem, we propose a remote data integrity auditing scheme that realizes data sharing with sensitive information hiding in this paper. In this scheme, a sanitizer is used to sanitize the data blocks corresponding to the sensitive information of the file and transforms these data blocks' signatures into valid ones for the sanitized file. These signatures are used to verify the integrity of the sanitized file in the phase of integrity auditing. As a result, our scheme makes the file stored in the cloud able to be shared and used by others on the condition that the sensitive information is hidden, while the remote data integrity auditing is still able to be efficiently executed. Meanwhile, the proposed scheme is based on identity-based cryptography, which simplifies the complicated certificate management. The security analysis and the performance evaluation show that the proposed scheme is secure and efficient.

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CR Ateniese G, 2005, LECT NOTES COMPUT SC, V3679, P159
Ateniese G, 2005, LECT NOTES COMPUT SC, V3352, P165
Ateniese G., 2008, P 4 INT C SEC PRIV C, P1, DOI DOI 10.1145/1460877.1460889

Ateniese G, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P598
Erway CC, 2009, CCS'09: PROCEEDINGS OF THE 16TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P213
Fu A., 2017, IEEE T BIG DATA, DOI [10.1109/TBDATA.2017.2701347, DOI 10.1109/TBDATA.2017.2701347]
Guan CW, 2015, LECT NOTES COMPUT SC, V9326, P203, DOI 10.1007/978-3-319-24174-6_11
Hur J, 2016, IEEE T KNOWL DATA EN, V28, P3113, DOI 10.1109/TKDE.2016.2580139
Juels A, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P584
Li JW, 2016, IEEE T COMPUT, V65, P2386, DOI 10.1109/TC.2015.2389960
Li YN, 2019, IEEE T DEPEND SECURE, V16, P72, DOI 10.1109/TDSC.2017.2662216
Luo YC, 2015, 2015 IEEE TRUSTCOM/BIGDATASE/ISPA, VOL 1, P434, DOI 10.1109/Trustcom.2015.404
Lynn B., 2015, PAIRING BASED CRYPTO
Ren K, 2012, IEEE INTERNET COMPUT, V16, P69, DOI 10.1109/MIC.2012.14
Shacham H, 2013, J CRYPTOL, V26, P442, DOI 10.1007/s00145-012-9129-2
Shen J, 2017, IEEE T INF FOREN SEC, V12, P2402, DOI 10.1109/TIFS.2017.2705620
Shen WT, 2017, FUTURE GENER COMP SY, V76, P136, DOI 10.1016/j.future.2017.04.029
Shen WT, 2017, J NETW COMPUT APPL, V82, P56, DOI 10.1016/j.jnca.2017.01.015
Sun JY, 2010, IEEE T PARALL DISTR, V21, P754, DOI 10.1109/TPDS.2009.124
Wang BY, 2015, IEEE T SERV COMPUT, V8, P92, DOI 10.1109/TSC.2013.2295611
Wang BY, 2014, IEEE T CLOUD COMPUT, V2, P43, DOI [10.1109/CLOUD.2012.46, 10.1109/TCC.2014.2299807]
Wang C, 2013, IEEE T COMPUT, V62, P362, DOI 10.1109/TC.2011.245
Wang H., 2016, IEEE T SERV COMPUT, DOI [10.1109/TSC.2016.2633260, DOI 10.1109/TSC.2016.2633260]
Wang HQ, 2016, IEEE T INF FOREN SEC, V11, P1165, DOI 10.1109/TIFS.2016.2520886
Wang HQ, 2015, IEEE T SERV COMPUT, V8, P328, DOI 10.1109/TSC.2014.1
Wang HQ, 2013, IEEE T SERV COMPUT, V6, P551, DOI 10.1109/TSC.2012.35
Wang QA, 2011, IEEE T PARALL DISTR, V22, P847, DOI 10.1109/TPDS.2010.183
Worku SG, 2014, COMPUT ELECTR ENG, V40, P1703, DOI 10.1016/j.compeleceng.2013.10.004
Yang GY, 2016, J SYST SOFTWARE, V113, P130, DOI 10.1016/j.jss.2015.11.044
Yu J, 2018, INFORM SCIENCES, V442, P158, DOI 10.1016/j.ins.2018.02.045
Yu J, 2017, IEEE T INF FOREN SEC, V12, P1931, DOI 10.1109/TIFS.2017.2695449
Yu J, 2016, IEEE T INF FOREN SEC, V11, P1362, DOI 10.1109/TIFS.2016.2528500
Yu J, 2015, IEEE T INF FOREN SEC, V10, P1167, DOI 10.1109/TIFS.2015.2400425
Yu Y, 2017, IEEE T INF FOREN SEC, V12, P767, DOI 10.1109/TIFS.2016.2615853
Zhang Y., 2018, IEEE T DEPEND SECURE, DOI [10.1109/TDSC.2018.2829880, DOI 10.1109/TDSC.2018.2829880]
NR 35
TC 9
Z9 9
U1 1
U2 158
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
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AU Zhang, HT
   Wang, ZH
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   Marxer, C
   Burke, J
   Zhang, LX
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   Scherb, Christopher
   Marxer, Claudio
   Burke, Jeff
   Zhang, Lixia
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SP Assoc Comp Machinery, ACM SIGCOMM
DE mHealth; Security; Named Data Networking
AB This paper introduces NDNFit, a distributed mobile health (irdlealth) application built to use the newly proposed Named Data Networking (NON) architecture instead of TCP/IP. The design is inspired by the Open mHealth ecosystem. Open nillealth uses a traditional cloud-enabled mobile architecture, but aspires to provide users with direct control of how their personal health data is used by applications and shared with other users within the ecosystem. NDNFit names and secures users' health data directly using NON network primitives, a more effective building block towards the ideal of user control than 1P-based solutions. Its design illustrates that NDN's data-centric approach to networking can be a. better lit than current networking approaches for mobile health applications, especially those that foreground individuals' control over their own data and, at the same time, target interoperability. This paper discusses the design and initial implementation of an NDNFit prototype, which offers end-users a mobile fitness tracking application. The paper identifies important differences between NDN and TCP/1P for mllealth, concluding with a discussion of future work and research opportunities.

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CR Burke J, 2006, P WORKSH WORLD SENS
   Eng DS, 2013, PEDIATR DIABETES, V14, P231, DOI 10.1111/pedi.12034
   Estrin D, 2010, SCIENCE, V330, P759, DOI 10.1126/science.1196187
   Kang J, 2012, IOWA LAW REV, V97, P809
   Moiseenko I., 2014, NDN0025
   Sifalakis Manolis, 2014, P 1 INT C INF CENTR, P137, DOI DOI
10.1145/2660129.2660150
   Smetters D., 2009, TECHNICAL REPORT
   Sun YW, 2013, 2013 IEEE WORKSHOP ON MEMETIC COMPUTING (MC), P9, DOI
10.1109/MC.2013.6608201
   Tangmunarunkit H, 2015, ACM T INTEL SYST TEC, V6, DOI 10.1145/2717318
   Yu Y., 2015, P 2 C INF CENTR NETW
   Yu Yingdi, 2015, NDN0034
   Zhang LX, 2014, ACM SIGCOMM COMP COM, V44, P66, DOI 10.1145/2656877.2656887
   Zhang Y., 2016, P 3 WORKSH NAM OR MO
NR 13
TC 9
Z9 9
U1 1
U2 3
PU ASSOC COMPUTING MACHINERY
PI NEW YORK
PA 1515 BROADWAY, NEW YORK, NY 10036-9998 USA
BN 978-1-4503-4467-8
PY 2016
BP 142
EP 147
DI 10.1145/2984356.2984379
PG 6
WC Computer Science, Hardware & Architecture; Computer Science, Information
   Systems; Computer Science, Theory & Methods
SC Computer Science
GA BG6NJ
UT WOS:000390613200017
DA 2019-08-06
ER

PT J
AU Roll, A
   Litwin, H
AF Roll, Anat
   Litwin, Howard
TI Intergenerational financial transfers and mental health: An analysis
   using SHARE-Israel data
SO AGING & MENTAL HEALTH
LA English
DT Article
DE depression; exchange; older Jewish parents; adult children; Israel
ID FAMILY SUPPORT; AGE; EXCHANGE; PATTERNS; DEPRESSION; DISABILITY;
   SYMPTOMS; CHILDREN; PARENTS; PEOPLE
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AB Objectives: The purpose of this study was to examine the association between financial transfers from older parents to their adult children and mental health among the parents. The analysis examined the act of transfer-giving, the extent of transfers given and the purpose of the transfer in relation to depressive symptoms.

Method: This study was a secondary analysis of data gathered in the first wave of the Israeli component of the Survey of Health, Ageing and Retirement in Europe (SHARE). The analysis focused upon persons from the majority Jewish elderly cohort, aged 50 years and older, who had living children (N = 1795). Respondents' scores on the Euro-D Depression Scale were regressed on the three financial transfer measures, controlling for age, gender, marital status, household income, health and functional status.

Results: The findings demonstrate a significant inverse relationship between the giving of financial transfers and the number of depressive symptoms of the giver, above and beyond the effects of gender, marital status, income, health status and functional status. The extent of giving was positively related.

Conclusion: The findings support a positive association between acceptable levels of financial giving in late life and mental health. This association is explained as the result of altruistic motivations for giving. Maintenance of viable levels of income security for the older population and promotion of acceptable intergenerational transfers from them to their adult children will benefit both sides of the generational divide.

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RI Roll, Anat/A-1602-2013

FU US National Institute on Aging [R21 AG2516901]; German-Israeli Foundation for Scientific Research and Development; National Insurance Institute of Israel; Ministry of Science; Ministry of Senior Citizens; Tovali-Elkin Memorial Fund
FX The SHARE data collection in Israel was funded by the US National Institute on Aging (R21 AG2516901), by the German-Israeli Foundation for Scientific Research and Development (G.I.F.) and by the National Insurance Institute of Israel. The Israel Gerontological Data Center was established by a grant from the Ministry of Science and is supported by the Ministry of Senior Citizens. A scholarship given to A. Roll by the Tovali-Elkin Memorial Fund at the Paul Baerwald School of Social Work at the Hebrew University in Jerusalem supported the analysis of the data.

CR Aiyagari SR, 2002, J ECON THEORY, V102, P290, DOI 10.1006/jeth.2001.2852
Albertini M, 2007, J EUR SOC POLICY, V17, P319, DOI 10.1177/0958928707081068
Attias-Donfut C., 2005, HLTH AGEING RETIREME, P179
Attias-Donfut C., 1995, SOLIDARITES ENTRE GE, P5
Attias-Donfut Claudine, 2005, Eur J Ageing, V2, P161, DOI 10.1007/s10433-005-0008-7
Blazer D. G., 2002, DEPRESSION LATE LIFE
Borsch-Supan Axel, 2005, Eur J Ageing, V2, P245, DOI 10.1007/s10433-005-0014-9
Carmel S, 2003, INT J AGING HUM DEV, V56, P113, DOI 10.2190/87YH-45QN-48TY-9HN8
Chang YM, 2005, SOUTH ECON J, V71, P821, DOI 10.2307/20062082
Cole MG, 2003, AM J PSYCHIAT, V160, P1147, DOI 10.1176/appi.ajp.160.6.1147
Copeland John R M, 2004, World Psychiatry, V3, P45
DAVEY A, 1998, J GERONTOL B-PSYCHOL, V53, P86
Dewey M, 2005, HLTH AGEING RETIREME, P108
Fritzell J, 2005, AGEING SOC, V25, P397, DOI 10.1017/S0144686X04003150
Grann J., 2000, ASSESSING OLDER PERS, P129

```
   Grundy E, 2005, BRIT J SOCIOL, V56, P233, DOI 10.1111/j.1468-
4446.2005.00057.x
   Jang YR, 2004, INT J AGING HUM DEV, V59, P125, DOI 10.2190/RT1W-2HD7-KG5X-
K1FB
   Kim IK, 2003, SOC INDIC RES, V62-3, P437, DOI 10.1023/A:1022617822399
   Koh S. K., 2003, J FAMILY EC ISSUES, V24, P73
   Kohli M., 2000, MYTH GENERATIONAL CO, P88
   Lee H. L., 2005, J ETHNIC CULTURAL DI, V13, P1, DOI DOI 10.1300/J051V13N04_
   Liang J, 2001, PSYCHOL AGING, V16, P511, DOI 10.1037//0882-7974.16.3.511
   Litwin H, 2004, RES AGING, V26, P202, DOI 10.1177/0164027503260631
   Litwin H, 2004, AGING MENT HEALTH, V8, P196, DOI 10.1080/13607860410001669723
   Litwin H, 2002, AGING MENT HEALTH, V6, P397, DOI 10.1080/1360786021000007018
   Lowenstein A, 2006, AGEING SOC, V26, P203, DOI 10.1017/S0144686X05004502
   MCGARRY K, 1995, J HUM RESOUR, V30, P184
   Mills TL, 2002, AGEING SOC, V22, P273, DOI 10.1017/S0144686X0200867X
   PLOEG J, 2004, CANADIAN J AGING S1, V23, pS113
   Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
   Schroder-Butterfill E, 2004, AGEING SOC, V24, P497, DOI
10.1017/S0144686X0400234X
   SILVERSTEIN M, 1995, J MARRIAGE FAM, V57, P465, DOI 10.2307/353699
NR 32
TC 9
Z9 9
U1 1
U2 8
PU ROUTLEDGE JOURNALS, TAYLOR & FRANCIS LTD
PI ABINGDON
PA 2-4 PARK SQUARE, MILTON PARK, ABINGDON OX14 4RN, OXON, ENGLAND
SN 1360-7863
EI 1364-6915
J9 AGING MENT HEALTH
JI Aging Ment. Health
PY 2010
VL 14
IS 2
BP 203
EP 210
DI 10.1080/13607860903191366
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WC Geriatrics & Gerontology; Gerontology; Psychiatry
SC Geriatrics & Gerontology; Psychiatry
GA 584XY
UT WOS:000276788900011
PM 20336552
OA Green Accepted
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ER

PT J
AU Wood, FB
   Benson, D
   LaCroix, EM
   Siegel, ER
   Fariss, S
AF Wood, FB
   Benson, D
   LaCroix, EM
   Siegel, ER
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TI Use of Internet audience measurement data to gauge market share for online health information services

SO JOURNAL OF MEDICAL INTERNET RESEARCH

LA English

DT Article

DE Internet; World Wide Web; information services; information dissemination; audience research; evaluation studies

AB Background: The transition to a largely Internet and Web-based environment for dissemination of health information has changed the health information landscape and the framework for evaluation of such activities. A multidimensional evaluative approach is needed.

Objective: This paper discusses one important dimension of Web evaluation-usage data. In particular, we discuss the collection and analysis of external data on website usage in order to develop a better understanding of the health information (and related US government information) market space, and to estimate the market share or relative levels of usage for National Library of Medicine (NLM) and National Institutes of Health (NIH) websites compared to other health information providers.

Methods: The primary method presented is Internet audience measurement based on Web usage by external panels of users and assembled by private vendors-in this case, comScore. A secondary method discussed is Web usage based on Web log software data. The principle metrics for both methods are unique visitors and total pages downloaded per month.

Results: NLM websites (primarily MedlinePlus and PubMed) account for 55% to 80% of total NIH website usage depending on the metric used. In turn, NIH.gov top-level domain usage (inclusive of NLM) ranks second only behind WebMD in the US domestic home health information market and ranks first on a global basis. NIH.gov consistently ranks among the top three or four US government top-level domains based on global Web usage. On a site-specific basis, the top health information websites in terms of global usage appear to be WebMD, MSN Health, PubMed, Yahoo! Health, AOL Health, and MedlinePlus. Based on MedlinePlus Web log data and external Internet audience measurement data, the three most heavily used cancer-centric websites appear to be www.cancer.gov (National Cancer Institute), www.cancer.org (American Cancer Society), and www.breastcancer.org (non-profit organization).

Conclusions: Internet audience measurement has proven useful to NLM, with significant advantages compared to sole reliance on usage data from Web log software. Internet audience data has helped NLM better understand the relative usage of NLM and NIH websites in the intersection of the health information and US government information market sectors, which is the primary market intersector for NLM and NIH. However important, Web usage is only one dimension of a complete Web evaluation framework, and other primary research methods, such as online user surveys, usability tests, and focus groups, are also important for comprehensive evaluation that includes qualitative elements, such as user satisfaction and user friendliness, as well as quantitative indicators of website usage.

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CR CATA J, 2001, USER CENTERED WEB DE
STERNE J, 2002, WEB METRICS PROVEN M
Wood F. B., 2003, IT Professional, V5, P22, DOI 10.1109/MITP.2003.1202231

NR 3

TC 9

Z9 9

U1 0

U2 13
PU JOURNAL OF MEDICAL INTERNET RESEARCH
PI TORONTO
PA TORONTO GENERAL HOSPITAL, R FRASER ELLIOTT BLDG, 4TH FL, R 4S435, 190 ELIZABETH ST, TORONTO, ON M5G 2C4, CANADA
SN 1438-8871
J9 J MED INTERNET RES
JI J. Med. Internet Res.
PY 2005
VL 7
IS 3
DI 10.2196/jmir.7.3.e31
PG 10
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA 970JS
UT WOS:000232304600005
OA DOAJ Gold, Green Published
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ER

PT J
AU Petrova, M
   Riley, J
   Abel, J
   Barclay, S
AF Petrova, Mila
   Riley, Julia
   Abel, Julian
   Barclay, Stephen
TI Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from
SO BMJ SUPPORTIVE & PALLIATIVE CARE
LA English
DT Article
DE electronic palliative care coordination systems; EPaCCS; Registries; Health Information Exchange; Electronic Health Records; Palliative Care
ID OF-LIFE CARE; QUALITY; END; REGISTER; DEATHS; CANCER; ORDERS
AB Background Electronic Palliative Care Coordination Systems (EPaCCS) are England's pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. EPaCCS have been under development for 8 years after being proposed, as Locality Registers, in the 2008 End of Life Care Strategy for England. EPaCCS are electronic registers or tools and processes for sharing data which aim to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of 'Coordinate My Care' patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously 'under development' or folding. They also continue to be suboptimally integrated with other data sharing initiatives. Rigorous research is non-existent. Discussion points We discuss the current EPaCCS landscape and way forward. We summarise key facts concerning the availability, uptake, outcomes and costs of EPaCCS. We outline 5 key challenges (scope of projects, unrealistic expectations set by existing guidance, the discrepancy between IT realities in healthcare and our broader lives, information governance and 'death register' associations) and 6 key drivers (robust concept, striking outcomes, national support and strong clinical leadership, clinician commitment, education and funding). Conclusions The priorities for advancing EPaCCS we propose include

linking to other work streams and reframing the concept, potentially making it less 'end of life', overview of current EPaCCS and lessons learnt, continuing work on information standards, rethinking of national funding and new levels of individual and community involvement.

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FU National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research & Care (CLAHRC) East of England at Cambridgeshire and Peterborough NHS Foundation Trust; Health Innovation and Education Cluster (HIEC)
FX This paper presents independent research funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research & Care (CLAHRC) East of England, at Cambridgeshire and Peterborough NHS Foundation Trust, as well as the Health Innovation and Education Cluster (HIEC) hosted by Cambridge University Health Partners (CUHP).

CR Adler-Milstein J, 2013, HEALTH AFFAIR, V32, P1486, DOI 10.1377/hlthaff.2013.0124
Ali AA, 2013, BMJ SUPPORT PALLIAT, V3, P452, DOI 10.1136/bmjspcare-2012-000371
[Anonymous], 2015, 1 NAT C EL PALL CAR
[Anonymous], 2016, 2 NAT C EL PALL CAR
Barclay S, 2011, BRIT J GEN PRACT, V61, DOI 10.3399/bjgp11X549018
Cawley D, 2014, BMJ SUPPORT PALLIAT, V4, pA89
Chumbley K, 2015, BMJ SUPPORT PALLIAT, V5, pA79
Crawley S, INTERNAL REPORT AMBU
Department of Health, 2008, END LIF CAR STRAT PR
Duncan Jeffrey, 2013, AMIA Annu Symp Proc, V2013, P345
eMOLST, EL MED ORD LIF SUST
Erne P, 2015, BMJ OPEN, V5, DOI 10.1136/bmjopen-2014-006218
Fromme EK, 2012, JAMA-J AM MED ASSOC, V307, P34, DOI 10.1001/jama.2011.1956
Georghiou T, 2014, EXPLORING COST CARE
Goodman DC, 2011, TRENDS VARIATION END
GrOnvold M, 2010, DANSK PALLIATIV DATA
Hall S, 2012, FAM PRACT, V29, P576, DOI 10.1093/fampra/cms011
Henry K, 2014, BMJ SUPPORT PALLI S1, V4, pA65
Henry K, 2014, BMJ SUPPORT PALLIAT, V4, pA66
Ipsos MORI, 2011, END LIF LOC REG EV
Jones G, 2013, LONDON J PRIM CARE, V5, P135, DOI 10.1080/17571472.2013.11493400
Leadership Alliance for the Care of Dying People, 2014, ON CHANC GET IT RIGH
Leathen S for Nottingham CityCare Partnership, 2015, FIN IMP EPACCS NOTT
Lindskog M, 2015, EUR J CANCER, V51, P1331, DOI 10.1016/j.ejca.2015.04.001
Lundstrom S, 2012, PALLIATIVE MED, V26, P313, DOI 10.1177/0269216311414758
McKercher C, 2014, NEPHROLOGY, V19, P610, DOI 10.1111/nep.12317
Millington-Sanders Catherine, 2013, London J Prim Care (Abingdon), V5, P106
Momen N, 2012, THORAX, V67, P777, DOI 10.1136/thoraxjnl-2012-201835

```
   Munday D, 2009, BMJ-BRIT MED J, V339, DOI 10.1136/bmj.b2391
   National End of Life Care Intelligence Network (NEoLCIN), 2014, EL PALL CAR
COORD SY
   National End of Life Care Programme, 2012, MAK CAS CHANG EL PAL
   National Information Board, 2014, PERS HLTH CAR 2020 U
   NHS England, CCG DIR
   NHS Scotland, 2013, KEY INF SUMM FREQ AS
   Office for National Statistics, 2016, NAT SURV BER PEOPL V
   Petrova M, 2014, BMJ SUPPORT PALLIAT, V4, pA43
   Pringle A, 2014, BMJ QUAL IMPROV REP, V3
   Public Health England, EOL PROF PLAC DEATH
   Riley J, 2013, PROG PALLIAT CARE, V21, P214, DOI
10.1179/1743291X13Y.0000000060
   Schmidt TA, 2013, J EMERG MED, V44, P796, DOI 10.1016/j.jemermed.2012.07.081
   Seymour JE, 2013, HEALTH EXPECT, V16, P43, DOI 10.1111/j.1369-
7625.2011.00688.x
   Smith C, 2012, BMJ SUPPORT PALLIAT, V2, P301, DOI 10.1136/bmjspcare-2012-
000265
   Sue Ryder, 2013, PARTN EXC PALL SUPP
   The Economist Intelligence Unit, 2015, 2015 QUAL DEATH IND
   Turton C, 2015, END LIFE J, V5
   Van den Block L, 2013, BMC FAM PRACT, V14, DOI 10.1186/1471-2296-14-73
   Wee B, 2015, 1 NAT C EL PALL CAR
   WHO, 2014, GLOBAL STATUS REPORT ON VIOLENCE PREVENTION 2014, P1
   Whole Systems Partnership for NHS Improving Quality, 2013, EC EV EL PALL CAR
CO
   Whole Systems Partnership for Sustainable Improvement NHS England, 2016, IND
EV PALL CAR COOR
   World Health Organization, 2014, TOP 10 CAUSE DEATH
   Wye L, 2016, J RES NURS, V21, P96, DOI 10.1177/1744987116628922
NR 52
TC 8
Z9 8
U1 0
U2 3
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 2045-435X
EI 2045-4368
J9 BMJ SUPPORT PALLIAT
JI BMJ Support. Palliat. Care
PD DEC
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VL 8
IS 4
BP 447
EP 455
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WC Health Care Sciences & Services
SC Health Care Sciences & Services
GA HD7SZ
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OA Green Published, Other Gold
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ER
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PT J
AU Konig, R
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AF Konig, Ronny
Seifert, Alexander
Doh, Michael
TI Internet use among older Europeans: an analysis based on SHARE data
SO UNIVERSAL ACCESS IN THE INFORMATION SOCIETY
LA English
DT Article
DE ICT; Elderly people; Europe; Digital divide; SHARE
ID DIGITAL DIVIDE; TECHNOLOGY; ADULTS; SKILLS
AB Access to the Internet is becoming increasingly important for all generations. However, a digital gap in Internet use remains between younger and older individuals as well as within the elderly population itself. This study, therefore, aimed to investigate Internet use among elderly Europeans. Representative data across 17 countries from the Survey of Health, Ageing and Retirement in Europe (SHARE) were examined. Analyses were based on the responses of 61,202 Europeans aged >= 50. Results highlight that, on average, 49% of all respondents use the Internet. However, the situation varies widely among European countries. Alongside individual indicators, such as age, gender, and social class, results indicate that previous experience with computers during one's time in the workplace is positively associated with Internet use in old age. Furthermore, use of the Internet among an individual's social network positively influences their use. Wider contextual structures such as area of residence and country-specific wealth and communication technology infrastructure also tend to promote Internet use among elderly Europeans. Data from SHARE indicate that private Internet use among older Europeans is driven by personal resources, prior experiences with technology, social salience as well as contextual influences.
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FU European Commission [QLK6-CT-2001-00360, SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812, 211909, 227822, 261982]; German Ministry of Education and Research; Max Planck Society for the Advancement of Science; US National Institute on Aging [U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, HHSN271201300071C]
FX This paper uses data from SHARE Wave 6 (https://doi.org/10.6103/share.w6.600), see Borsch-Supan et al. [43, 44] for methodological details. The SHARE data collection has been primarily funded by the European Commission through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812) and FP7 (SHARE-PREP: No 211909, SHARE-LEAP: No

227822, SHARE M4: No 261982). Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the US National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, HHSN271201300071C), and from various national funding sources is gratefully acknowledged (see www.share-project.org). The data were adjusted for this investigation, and extensive consistency checks were made.

CR Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
Bonfadelli H, 2002, EUR J COMMUN, V17, P65, DOI 10.1177/0267323102017001607
Borsch-Supan Axel, 2017, SURVEY HLTH AGEING R
Brandtzaeg PB, 2011, INT J HUM-COMPUT ST, V69, P123, DOI 10.1016/j.ijhcs.2010.11.004
Ching CC, 2005, URBAN EDUC, V40, P394, DOI 10.1177/0042085905276389
Compaine B. M., 2001, DIGITAL DIVIDE FACIN
Czaja SJ, 2006, PSYCHOL AGING, V21, P333, DOI 10.1037/0882-7974.21.2.333
Dobransky K., 2006, Information Communication & Society, V9, P313, DOI 10.1080/13691180600751298
Doh M., 2015, HUMAN ASPECTS IT AGE, P177, DOI DOI 10.1007/978-3-319-20892-3
Eurostat, 2017, GDP PER CAP PPS TEC0
Eurostat, 2017, IND INT US
Friemel TN, 2016, NEW MEDIA SOC, V18, P313, DOI 10.1177/1461444814538648
Hargittai E, 2010, SOCIOL INQ, V80, P92, DOI 10.1111/j.1475-682X.2009.00317.x
Harrison A. W., 1992, Journal of Management Information Systems, V9, P93
Helsper EJ, 2010, COMMUN RES, V37, P352, DOI 10.1177/0093650209356439
Hepp A, 2014, MEDIATIZED WORLDS: CULTURE AND SOCIETY IN A MEDIA AGE, P1, DOI 10.1057/9781137300355
Hox J. J., 2002, QUANTITATIVE METHODO
Husing T, 2003, ISI INFORMATIONSDIEN, V30, P1
Jung Y, 2010, EDUC GERONTOL, V36, P193, DOI 10.1080/03601270903183313
Korupp SE, 2005, EUR SOCIOL REV, V21, P409, DOI 10.1093/esr/jci030
Ktoridou Despo, 2011, Campus-Wide Information Systems, V28, P154, DOI 10.1108/10650741111145689
LASLETT P, 1994, AGEING SOC, V14, P436, DOI 10.1017/S0144686X00001677
LAWTON MP, 1983, GERONTOLOGIST, V23, P349, DOI 10.1093/geront/23.4.349
Lengsfeld JHB, 2011, INFORM SOC, V27, P141, DOI 10.1080/01972243.2011.566745
Loges WE, 2001, COMMUN RES, V28, P536, DOI 10.1177/009365001028004007
Maas C. J. M., 2005, METHODOLOGY, V1, P86, DOI DOI 10.1027/1614-2241.1.3.86
Mingo I, 2018, SOC INDIC RES, V135, P629, DOI 10.1007/s11205-016-1511-2
Norris P., 2001, DIGITAL DIVIDE CIVIC
OECD, 2017, INT ACC IND
Olson KE, 2011, AGEING INT, V36, P123, DOI 10.1007/s12126-010-9077-9
Olsson T, 2018, INFORM COMMUN SOC, V22, P55, DOI 10.1080/1369118X.2017.1355007
Perrin A, 2015, AM INTERNET ACCESS 2
Rogers E.M., 2003, DIFFUSION INNOVATION, P551, DOI DOI 10.2307/2573300
Sackmann Reinhold, 2013, Gerontechnology, V11, P493, DOI 10.4017/gt.2013.11.4.002.00
Sackmann R., 1994, TECHNISIERUNG ALLTAG
Schelling H. R., 2015, STUDIE DIGITALE SENI
Seifert A., 2015, GERONTECHNOLOGY, V14, P57, DOI [10.4017/gt.2015.14.1.006.00, DOI 10.4017/GT.2015.14.1.006.00]
Seifert A, 2017, EDUC GERONTOL, V43, P451, DOI 10.1080/03601277.2017.1326224
Skrondal A, 2008, MULTILEVEL LONGITUDI
Snijders Tom, 2012, MULTILEVEL ANAL INTR
Spellerberg A., 2008, PERIPHERISIERUNG NEU, P25
Stenberg P. L., 2002, AGR OUTLOOK, V6, P23

```
   van Deursen AJAM, 2011, NEW MEDIA SOC, V13, P893, DOI
10.1177/1461444810386774
   Venkatesh V, 2000, MANAGE SCI, V46, P186, DOI 10.1287/mnsc.46.2.186.11926
   Warschauer M, 2003, SCI AM, V289, P42, DOI 10.1038/scientificamerican0803-42
NR 45
TC 8
Z9 8
U1 12
U2 23
PU SPRINGER HEIDELBERG
PI HEIDELBERG
PA TIERGARTENSTRASSE 17, D-69121 HEIDELBERG, GERMANY
SN 1615-5289
EI 1615-5297
J9 UNIVERSAL ACCESS INF
JI Univers. Access Inf. Soc.
PD AUG
PY 2018
VL 17
IS 3
SI SI
BP 621
EP 633
DI 10.1007/s10209-018-0609-5
PN 2
PG 13
WC Computer Science, Cybernetics; Ergonomics
SC Computer Science; Engineering
GA GO7WM
UT WOS:000440288500012
DA 2019-08-06
ER

PT J
AU Rodriguez, H
   Pennington, SR
AF Rodriguez, Henry
   Pennington, Stephen R.
TI Revolutionizing Precision Oncology through Collaborative Proteogenomics
   and Data Sharing
SO CELL
LA English
DT Editorial Material
ID REPRODUCIBILITY
AB The integration of proteomics into precision oncology presents opportunities
that may transform the molecular analysis of cancer and accelerate basic and
clinical cancer research. This Commentary discusses the importance of
international collaboration and data sharing inspired by the Cancer Moonshot to
accelerate the progress of multi-omic precision medicine-an approach that
addresses the global diversity of people and of cancers.
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FU NULL [Z99 CA999999]
CR Addona TA, 2009, NAT BIOTECHNOL, V27, P633, DOI 10.1038/nbt.1546
```

```
   Blackhall F, 2006, LANCET ONCOL, V7, P499, DOI 10.1016/S1470-2045(06)70725-2
   Carr SA, 2014, MOL CELL PROTEOMICS, V13, P907, DOI 10.1074/mcp.M113.036095
   Druker BJ, 2006, NEW ENGL J MED, V355, P2408, DOI 10.1056/NEJMoa062867
   Jaffe JD, 2004, PROTEOMICS, V4, P59, DOI 10.1002/pmic.200300511
   Kennedy JJ, 2014, NAT METHODS, V11, P149, DOI [10.1038/NMETH.2763,
10.1038/nmeth.2763]
   Kinsinger CR, 2011, MOL CELL PROTEOMICS, V10, DOI 10.1074/mcp.O111.015446
   MacLean B, 2010, BIOINFORMATICS, V26, P966, DOI 10.1093/bioinformatics/btq054
   Mertins P, 2016, NATURE, V534, P55, DOI 10.1038/nature18003
   Pegram M, 2000, SEMIN ONCOL, V27, P13
   Regnier FE, 2010, CLIN CHEM, V56, P165, DOI 10.1373/clinchem.2009.140087
   Tabb DL, 2010, J PROTEOME RES, V9, P761, DOI 10.1021/pr9006365
   Whiteaker JR, 2014, NAT METHODS, V11, P703, DOI 10.1038/nmeth.3002
   Zhang B, 2014, NATURE, V513, P382, DOI 10.1038/nature13438
   Zhang H, 2016, CELL, V166, P755, DOI 10.1016/j.cell.2016.05.069
NR 15
TC 8
Z9 9
U1 0
U2 9
PU CELL PRESS
PI CAMBRIDGE
PA 50 HAMPSHIRE ST, FLOOR 5, CAMBRIDGE, MA 02139 USA
SN 0092-8674
EI 1097-4172
J9 CELL
JI Cell
PD APR 19
PY 2018
VL 173
IS 3
BP 533
EP 537
DI 10.1016/j.cell.2018.04.008
PG 5
WC Biochemistry & Molecular Biology; Cell Biology
SC Biochemistry & Molecular Biology; Cell Biology
GA GD7GB
UT WOS:000430677400002
PM 29677503
OA Other Gold, Green Accepted
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PT J
AU Hoeyer, K
   Tupasela, A
   Rasmussen, MB
AF Hoeyer, Klaus
   Tupasela, Aaro
   Rasmussen, Malene Bogehus
TI Ethics Policies and Ethics Work in Cross-national Genetic Research and
   Data Sharing: Flows, Nonflows, and Overflows
SO SCIENCE TECHNOLOGY & HUMAN VALUES
LA English
DT Article
DE biobank; collaboration; confidentiality; data sharing; ethics; genetic
   research; open science
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ID COLLABORATIONS INVOLVING BIOBANKS; GLOBAL SAMPLE COLLECTION; ELSI CHALLENGES; DNA; CONSENT

AB In recent years, cross-national collaboration in medical research has gained increased policy attention. Policies are developed to enhance data sharing, ensure open-access, and harmonize international standards and ethics rules in order to promote access to existing resources and increase scientific output. In tandem with this promotion of data sharing, numerous ethics policies are developed to control data flows and protect privacy and confidentiality. Both sets of policy making, however, pay limited attention to the moral decisions and social ties enacted in the everyday routines of scientific work. This paper takes its point of departure in the practices of a Danish laboratory with great experience in international collaboration regarding genetic research. We focus on a simple query, what makes genetic material and health data flow, and which hopes and concerns travel along with them? We explore what we call the flows, the nonflows, and the overflows of material and information, and we document the work producing the flows of health data and biomaterial. We call this work ethics work and argue that it is crucial for data sharing though it is rarely articulated in ethics policies, remains inadequately funded, and lacks acknowledgment in policies promoting international data sharing.

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CR Albert M, 2015, Collaboration across Health Research and Medical Care: Healthy Collaboration, P59

Anderson W., 2008, COLLECTORS LOST SOUL

APPELBAUM PS, 1987, HASTINGS CENT REP, V17, P20, DOI 10.2307/3562038

Arzberger P, 2004, DATA SCI J, V3, P135, DOI DOI 10.2481/DSJ.3.135

Bjugn R, 2015, BIOPRESERV BIOBANK, V13, P70, DOI 10.1089/bio.2015.1323

Blasimme A, 2012, AM J BIOETHICS, V12, P20, DOI 10.1080/15265161.2012.699149

Bosk C., 1979, FORGIVE REMEMBER MAN

Cadigan R Jean, 2013, Life Sci Soc Policy, V9, P1

Cambliss D. F., 1996, CARING HOSP NURSES S

Colledge F, 2013, BIOPRESERV BIOBANK, V11, P339, DOI 10.1089/bio.2013.0039

Cooper M., 2014, CLIN LABOR TISSUE DO

Cunningham H, 1998, CRIT ANTHROPOL, V18, P205, DOI 10.1177/0308275X9801800205

Dove ES, 2014, BIOPRESERV BIOBANK, V12, P363, DOI 10.1089/bio.2014.1263

Evans BJ, 2006, J LEGAL MED, V27, P119, DOI 10.1080/01947640600716366

Friese C, 2013, CURR ANTHROPOL, V54, pS129, DOI 10.1086/670805

Geissler PW, 2013, AM ETHNOL, V40, P13, DOI 10.1111/amet.12002

Geissler PW, 2008, SOC SCI MED, V67, P696, DOI 10.1016/j.socscimed.2008.02.004
General Secretariat of the Council, 2016, 259616 GEN SECR COUN
Hayden C, 2007, SOC STUD SCI, V37, P729, DOI 10.1177/0306312707078012
HOCHSCHILD AR, 1979, AM J SOCIOL, V85, P551, DOI 10.1086/227049
Hoeyer K, 2016, NEW GENET SOC, V35, P351, DOI 10.1080/14636778.2016.1245134
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Keating P., 2003, BIOMEDICAL PLATFORMS
Knoppers BM, 2012, ANNU REV GENOM HUM G, V13, P395, DOI 10.1146/annurev-genom-090711-163834
Kowal E, 2013, SOC STUD SCI, V43, P577, DOI 10.1177/0306312712471739
Kowal E, 2013, SOC STUD SCI, V43, P465, DOI 10.1177/0306312713490843
Lauss G, 2012, TRUST IN BIOBANKING, P219
Leonelli S, 2014, BIG DATA SOC, V1, DOI 10.1177/2053951714534395
MARKS J, 2001, RELATIVE VALUES RECO, P355
Mascalzoni D, 2015, EUR J HUM GENET, V23, P721, DOI 10.1038/ejhg.2014.197
Mayrhofer M. T., 2009, INT J RISK ASSESSMEN, V12, P64, DOI [DOI 10.1504/IJRAM.2009.024130, 10.1504/IJRAM.2009.024130]
McGoey L, 2012, ECON SOC, V41, P1, DOI 10.1080/03085147.2011.637330
Meijer I, 2012, SCI PUBL POLICY, V39, P491, DOI 10.1093/scipol/scs033
Mol A., 2008, LOGIC CARE HLTH PROB
Nielsen J., 1980, TOPICS HUM GENET, V5, P1
OECD, 2009, OECD GUID TEST CHEM, P1, DOI DOI 10.1787/9789264076273-EN
OECD, 2007, OECD PRINC GUID ACC
Patra P. K., 2012, TRUST BIOBANKING, P237
Penders B, 2015, Collaboration across Health Research and Medical Care: Healthy Collaboration, P3
Proctor R. N, 2008, AGNOTOLOGY MAKING UN, P1
Reardon J, 2005, IN-FORMATION, P1
Rose H, 2006, COMMUNITY GENET, V9, P184, DOI 10.1159/000092655
Sheller M, 2006, ENVIRON PLANN A, V38, P207, DOI 10.1068/a37268
Sleeboom-Faulkner M, 2011, SOC STUD SCI, V41, P645, DOI 10.1177/0306312711409792
Star SL, 1996, INFORM SYST RES, V7, P111, DOI 10.1287/isre.7.1.111
Timmermans S, 2015, SOC STUD SCI, V45, P77, DOI 10.1177/0306312714559323
Urry J., 2000, SOCIOLOGY SOC MOBILI
NR 47
TC 8
Z9 8
U1 4
U2 21
PU SAGE PUBLICATIONS INC
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SN 0162-2439
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J9 SCI TECHNOL HUM VAL
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PG 24
WC Social Issues

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SC Social Issues
GA ER5LH
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PT J
AU Pevnick, JM
   Fuller, G
   Duncan, R
   Spiegel, BMR
AF Pevnick, Joshua M.
   Fuller, Garth
   Duncan, Ray
   Spiegel, Brennan M. R.
TI A Large-Scale Initiative Inviting Patients to Share Personal Fitness
   Tracker Data with Their Providers: Initial Results
SO PLOS ONE
LA English
DT Article
AB Background
   Personal fitness trackers (PFT) have substantial potential to improve
healthcare.
   Objective
   To quantify and characterize early adopters who shared their PFT data with
providers.
   Methods
   We used bivariate statistics and logistic regression to compare patients who
shared any PFT data vs. patients who did not.
   Results
   A patient portal was used to invite 79,953 registered portal users to share
their data. Of 66,105 users included in our analysis, 499 (0.8%) uploaded data
during an initial 37-day study period. Bivariate and regression analysis showed
that early adopters were more likely than non-adopters to be younger, male,
white, health system employees, and to have higher BMIs. Neither comorbidities
nor utilization predicted adoption.
   Conclusion
   Our results demonstrate that patients had little intrinsic desire to share
PFT data with their providers, and suggest that patients most at risk for poor
health outcomes are least likely to share PFT data. Marketing, incentives,
and/or cultural change may be needed to induce such data-sharing.
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FU National Institute On Aging; National Center for Advancing Translational
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   KL2TR000122]
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   study design, data collection and analysis, decision to publish, or
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CR Ancker JS, 2011, J GEN INTERN MED, V26, P1117, DOI 10.1007/s11606-011-1749-y
   de Veer AJE, 2015, BMC HEALTH SERV RES, V15, DOI 10.1186/s12913-015-0765-8
   Fox S, 2012, MOBILE HLTH 2012
   Goldzweig CL, 2013, ANN INTERN MED, V159, P677, DOI 10.7326/0003-4819-159-10-
201311190-00006
   Kohnke Anne, 2014, Journal of Technology Management & Innovation, V9, P29,
DOI 10.4067/S0718-27242014000200003
   Lee J, 2013, HEALTHC INFORM RES, V19, P167, DOI 10.4258/hir.2013.19.3.167
   Palen TE, 2012, JAMA-J AM MED ASSOC, V308, P2012, DOI 10.1001/jama.2012.14126
   Patel MS, 2015, JAMA-J AM MED ASSOC, V313, P459, DOI 10.1001/jama.2014.14781
   Pew Research Center, 2015, SMARTPH DIFF
   Shaw RJ, 2016, J AM MED INFORM ASSN, V23, P462, DOI 10.1093/jamia/ocv186
   Venkatesh V, 2012, MIS QUART, V36, P157
NR 11
TC 8
Z9 8
U1 0
U2 7
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD NOV 15
PY 2016
VL 11
IS 11
AR e0165908
DI 10.1371/journal.pone.0165908
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA EC0MG
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PT J
AU Patil, S
   Lu, H
   Saunders, CL
   Potoglou, D
   Robinson, N
AF Patil, Sunil
   Lu, Hui
   Saunders, Catherine L.
   Potoglou, Dimitris
   Robinson, Neil
TI Public preferences for electronic health data storage, access, and
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sharing - evidence from a pan-European survey
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
DE Health records; data privacy; stated preference; personal data; public preferences; attitudes
ID RECORDS; INFORMATION; PRIVACY; PATIENT; PERFORMANCE; MODEL; TRUST

AB Objective To assess the public's preferences regarding potential privacy threats from devices or services storing health-related personal data.

Materials and Methods A pan-European survey based on a stated-preference experiment for assessing preferences for electronic health data storage, access, and sharing.

Results We obtained 20 882 survey responses (94 606 preferences) from 27 EU member countries. Respondents recognized the benefits of storing electronic health information, with 75.5%, 63.9%, and 58.9% agreeing that storage was important for improving treatment quality, preventing epidemics, and reducing delays, respectively. Concerns about different levels of access by third parties were expressed by 48.9% to 60.6% of respondents.

On average, compared to devices or systems that only store basic health status information, respondents preferred devices that also store identification data (coefficient/relative preference 95% CI = 0.04 [0.00-0.08], P = 0.034) and information on lifelong health conditions (coefficient = 0.13 [0.08 to 0.18], P < 0.001), but there was no evidence of this for devices with information on sensitive health conditions such as mental and sexual health and addictions (coefficient = -0.03 [-0.09 to 0.02], P = 0.24). Respondents were averse to their immediate family (coefficient = -0.05 [-0.05 to -0.01], P = 0.011) and home care nurses (coefficient = -0.06 [-0.11 to -0.02], P = 0.004) viewing this data, and strongly averse to health insurance companies (coefficient = -0.43 [-0.52 to 0.34], P < 0.001), private sector pharmaceutical companies (coefficient = -0.82 [-0.99 to -0.64], P < 0.001), and academic researchers (coefficient = -0.53 [-0.66 to -0.40], P < 0.001) viewing the data.

Conclusions Storing more detailed electronic health data was generally preferred, but respondents were averse to wider access to and sharing of this information. When developing frameworks for the use of electronic health data, policy makers should consider approaches that both highlight the benefits to the individual and minimize the perception of privacy risks.

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FU European Commission [285635]
FX This study has received funding from the European Commission's Seventh Framework Programme for research, technological development, and demonstration under grant agreement No. 285635 (Public perception of security and privacy: Assessing knowledge, Collecting evidence, Translating research into action).

CR Adler-Milstein J, 2014, HEALTH AFFAIR, V33, P1271, DOI 10.1377/hlthaff.2014.0023
Allenby GM, 2004, MARKET SCI, V23, P95, DOI 10.1287/mksc.1030.0022
Angst CM, 2009, MIS QUART, V33, P339
[Anonymous], 2007, ALOGIT 4 2
[Anonymous], 2014, NHS 5 YEAR FORWARD V
[Anonymous], 2009, LANCET, V374, P175
BOYLE KJ, 1985, LAND ECON, V61, P188, DOI 10.2307/3145811

ChoiceMetrics, 2012, NGEN 1 1 1 US MAN RE
Department of Health, 2012, INN HLTH WEALTH AD D
EFRON B, 1979, ANN STAT, V7, P1, DOI 10.1214/aos/1176344552
Elliott MN, 2009, HEALTH SERV RES, V44, P501, DOI 10.1111/j.1475-6773.2008.00914.x
Florence C, 2014, INJURY PREV, V20, P108, DOI 10.1136/injuryprev-2012-040622
Gerada C., 2014, 10 HLTH APPS HELP YO
Goldacre B, 2014, CARE DATA IS CHAOS I
Greenhalgh T, 2014, BMJ-BRIT MED J, V349, DOI 10.1136/bmj.g7341
Grossklags J, 2007, 25 CENTS IS TOO MUCH
Hill EM, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-72
Hwang HG, 2012, J MED SYST, V36, P3783, DOI 10.1007/s10916-012-9851-1
IBM Corp, 2012, IBM SPSS STAT WIND V
Ioannidis JPA, 2013, JAMA-J AM MED ASSOC, V309, P1410, DOI 10.1001/jama.2013.3150
KAHNEMAN D, 1979, ECONOMETRICA, V47, P263, DOI 10.2307/1914185
Keen J, 2013, POLICY INTERNET, V5, P228, DOI 10.1002/1944-2866.POI330
Kelsey T, 2009, PROSPECT MAGAZINE, P161
KINGMAN S, 1993, BRIT MED J, V306, P1019
Kumaraguru P., 2005, PRIVACY INDEXES SURV
Louviere J. J., 2000, STATED CHOICE METHOD
Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
Fernandez-Aleman JL, 2013, J BIOMED INFORM, V46, P541, DOI 10.1016/j.jbi.2012.12.003
National Information Board, 2014, PERS HLTH CAR 2020
Nissembaum H, 2010, PRIVACY CONTEXT TECH
Nuffield Council on Bioethics, 2015, COLL LINK US DAT BIO
O'Dowd A, 2014, BMJ-BRIT MED J, V349, DOI 10.1136/bmj.g7537
Oderkirk J, 2013, HEALTH POLICY, V112, P9, DOI 10.1016/j.healthpol.2013.06.006
Pagliari C, 2007, BRIT MED J, V335, P330, DOI 10.1136/bmj.39279.482963.AD
Perera G, 2011, INT J MED INFORM, V80, P94, DOI 10.1016/j.ijmedinf.2010.11.005
Pollock AM, 2014, LANCET, V383, P1523, DOI 10.1016/S0140-6736(14)60727-3
Robinson N, 2010, PRIVACY SECURITY RES, V10
Robinson N., 2010, SECURITY WHAT COST Q
Schindler Helen Rebecca, 2012, EUROPES POLICY OPTIO
Schwartz PH, 2015, J GEN INTERN MED, V30, pS25, DOI 10.1007/s11606-014-3054-z
Shaw C, 1999, SOC SCI MED, V49, P1571, DOI 10.1016/S0277-9536(99)00244-0
Stone MA, 2005, BRIT J GEN PRACT, V55, P783
Sweeney L., 2000, 3 CARN MELL U
Taylor MJ, 2014, LIFE SCI SOC POLICY, V10, P1
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI 10.1016/j.ijmedinf.2005.08.009
NR 46
TC 8
Z9 8
U1 0
U2 21
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD NOV

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PY 2016
VL 23
IS 6
BP 1096
EP 1106
DI 10.1093/jamia/ocw012
PG 11
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA EC3DZ
UT WOS:000388006800009
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OA Green Published, Green Accepted, Bronze
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PT J
AU Wang, HQ
   Li, KQ
   Ota, K
   Shen, J
AF Wang, Huaqun
   Li, Keqiu
   Ota, Kaoru
   Shen, Jian
TI Remote Data Integrity Checking and Sharing in Cloud-Based Health
   Internet of Things
SO IEICE TRANSACTIONS ON INFORMATION AND SYSTEMS
LA English
DT Article
DE remote data integrity checking; public cloud; data sharing
AB In the health IoT (Internet of Things), the specialized sensor devices can be
used to monitor remote health and notify the emergency information, e.g., blood
pressure, heart rate, etc. These data can help the doctors to rescue the
patients. In cloud-based health IoT, patients' medical/health data is managed by
the cloud service providers. Secure storage and privacy preservation are
indispensable for the outsourced medical/health data in cloud computing. In this
paper, we study the integrity checking and sharing of outsourced private
medical/health records for critical patients in public clouds (ICS). The patient
can check his own medical/health data integrity and retrieve them. When a
patient is in coma, some authorized entities and hospital can cooperate to share
the patient's necessary medical/health data in order to rescue the patient. The
paper studies the system model, security model and concrete scheme for ICS in
public clouds. Based on the bilinear pairing technique, we design an efficient
ICS protocol. Through security analysis and performance analysis, the proposed
protocol is provably secure and efficient.
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FX The work of H. Wang was supported in part by the National Natural Science Foundation of China under Grant (61272522), in part by the Natural Science Foundation of Liaoning Province under Grant (2014020147), and in part by the Program for Liaoning Excellent Talents in University under Grant (LR2014021), and in part by the CICAEET fund and the PAPD fund. This work of K. Li was partly supported by the National Science Foundation for Distinguished Young Scholars of China (61225010), and the State Key Program of National Natural Science of China (61432002).

CR Ateniese G, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P598
Boneh D., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P213
Boneh D, 2001, LECT NOTES COMPUTER, V2248, P514, DOI DOI 10.1007/3-540-45682-1_30
Bowers K. D., 2009, P 2009 ACM WORKSH CL, P43, DOI [10.1145/1655008.1655015, DOI 10.1145/1655008.1655015]
Fang Hu, 2013, 2013 IEEE International Conference on Green Computing and Communications (GreenCom) and IEEE Internet of Things (iThings) and IEEE Cyber, Physical and Social Computing (CPSCom), P2053, DOI 10.1109/GreenCom-iThings-CPSCom.2013.384
Fu ZJ, 2015, IEICE T COMMUN, VE98B, P190, DOI 10.1587/transcom.E98.B.190
Guo P, 2014, J INTERNET TECHNOL, V15, P929, DOI 10.6138/JIT.2014.15.6.05
He DB, 2015, MULTIMEDIA SYST, V21, P49, DOI 10.1007/s00530-013-0346-9
He DB, 2015, IEEE INTERNET THINGS, V2, P72, DOI 10.1109/JIOT.2014.2360121
He J, 2016, PEER PEER NETW APPL, V9, P67, DOI 10.1007/s12083-014-0314-y
KUMANDURI R, 1998, NUMBER THEORY COMPUT
Lu RX, 2013, IEEE T PARALL DISTR, V24, P614, DOI 10.1109/TPDS.2012.146
Lynn B., PAIRING BASED CRYPTO
MILLER VS, 1986, LECT NOTES COMPUT SC, V218, P417
Miyaji A, 2001, IEICE T FUND ELECTR, VE84A, P1234
Nabeel M, 2013, IEEE T KNOWL DATA EN, V25, P2602, DOI 10.1109/TKDE.2012.180
Ren YJ, 2015, J INTERNET TECHNOL, V16, P317, DOI 10.6138/JIT.2015.16.2.20140918
Vanstone Scott, 1992, COMMUN ACM, V35, P50
Wang C, 2013, IEEE T COMPUT, V62, P362, DOI 10.1109/TC.2011.245
Wang HQ, 2014, J BIOMED INFORM, V50, P226, DOI 10.1016/j.jbi.2014.02.008
Wang HQ, 2013, IEEE T SERV COMPUT, V6, P551, DOI 10.1109/TSC.2012.35
Wu J, 2015, PEER PEER NETW APPL, V8, P1133, DOI 10.1007/s12083-014-0286-y
Xia ZH, 2016, IEEE T PARALL DISTR, V27, P340, DOI 10.1109/TPDS.2015.2401003
Zhao W, 2011, PROCEEDINGS OF 2011 INTERNATIONAL CONFERENCE ON COMMUNICATION TECHNOLOGY AND APPLICATION, ICCTA2011, P660

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PU IEICE-INST ELECTRONICS INFORMATION COMMUNICATIONS ENG
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PA KIKAI-SHINKO-KAIKAN BLDG, 3-5-8, SHIBA-KOEN, MINATO-KU, TOKYO, 105-0011,
   JAPAN
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J9 IEICE T INF SYST
JI IEICE Trans. Inf. Syst.
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WC Computer Science, Information Systems; Computer Science, Software
   Engineering
SC Computer Science
GA DT5ZW
UT WOS:000381563200002
OA Bronze
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PT J
AU Ross, JS
   Ritchie, JD
   Finn, E
   Desai, NR
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AF Ross, Joseph S.
   Ritchie, Jessica D.
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   Desai, Nihar R.
   Lehman, Richard L.
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   Gross, Cary P.
TI Data sharing through an NIH central database repository: a
   cross-sectional survey of BioLINCC users
SO BMJ OPEN
LA English
DT Article
ID CLINICAL-TRIAL DATA; ACCESS
AB Objective: To characterise experiences using clinical research data shared through the National Institutes of Health (NIH)'s Biologic Specimen and Data Repository Information Coordinating Center (BioLINCC) clinical research data repository, along with data recipients' perceptions of the value, importance and challenges with using BioLINCC data.

   Design and setting: Cross-sectional web-based survey.

   Participants: All investigators who requested and received access to clinical research data from BioLINCC between 2007 and 2014.

   Main outcome measures: Reasons for BioLINCC data request, research project plans, interactions with original study investigators, BioLINCC experience and other project details.

Results: There were 536 investigators who requested and received access to clinical research data from BioLINCC between 2007 and 2014. Of 441 potential respondents, 195 completed the survey (response rate=44%); 89% (n=174) requested data for an independent study, 17% (n=33) for pilot/preliminary analysis. Commonly cited reasons for requesting data through BioLINCC were feasibility of collecting data of similar size and scope (n=122) and insufficient financial resources for primary data collection (n=76). For 95% of respondents (n=186), a primary research objective was to complete new research, as opposed to replicate prior analyses. Prior to requesting data from BioLINCC, 18% (n=36) of respondents had contacted the original study investigators to obtain data, whereas 24% (n=47) had done so to request collaboration. Nearly all (n=176; 90%) respondents found the data to be suitable for their proposed project; among those who found the data unsuitable (n=19; 10%), cited reasons were data too complicated to use (n=5) and data poorly organised (n=5). Half (n=98) of respondents had completed their proposed projects, of which 67% (n=66) have been published.

Conclusions: Investigators were primarily using clinical research data from BioLINCC for independent research, making use of data that would otherwise have not been feasible to collect.

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CR Asch DA, 1997, J CLIN EPIDEMIOL, V50, P1129, DOI 10.1016/S0895-4356(97)00126-1

Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201

Fowler Jr F., 1993, SURVEY RES METHODS

Giffen CA, 2015, BIOPRESERV BIOBANK, V13, P271, DOI 10.1089/bio.2014.0050

Hopkins C, 2016, J CLIN EPIDEMIOL, V70, P17, DOI 10.1016/j.jclinepi.2015.07.002

Hudson KL, 2015, JAMA-J AM MED ASSOC, V313, P355, DOI 10.1001/jama.2014.10716

Institute of Medicine of the National Academies of Science, 2015, SHAR CLIN TRIAL DAT

Keyhani S, 2009, NEW ENGL J MED, V361, DOI 10.1056/NEJMp0908239

Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564

Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374

Oushy MH, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0138239

Phrma, 2013, PRINC RESP CLIN TRIA

Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570

Rathi VK, 2014, TRIALS, V15, DOI 10.1186/1745-6215-15-384

```
   Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
   Shanafelt TD, 2012, ARCH INTERN MED, V172, P1377, DOI
10.1001/archinternmed.2012.3199
   Smith CT, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0532-z
   Smith CT, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0097886
   Strom BL, 2014, NEW ENGL J MED, V371, P2052, DOI 10.1056/NEJMp1411794
   Sudman S., 1982, ASKING QUESTIONS PRA
   Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
   Taichman DB, 2016, ANN INTERN MED, V164, P505, DOI 10.7326/M15-2928
   Tenopir C, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0134826
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   U. S. National Institutes of Health National Heart L and Blood Institute
Biologic Specimen and Data Repository Information Coordinating Center (BioLINCC),
PUBL ASS AV BIOLINCC
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PU BMJ PUBLISHING GROUP
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SC General & Internal Medicine
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PT B
AU Zhang, Q
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AF Zhang, Quan
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GP IEEE
TI Firework: Big Data Sharing and Processing in Collaborative Edge
   Environment
SO PROCEEDINGS OF 2016 FOURTH IEEE WORKSHOP ON HOT TOPICS IN WEB SYSTEMS
   AND TECHNOLOGIES (HOTWEB)
LA English
DT Proceedings Paper
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CT 4th IEEE Workshop on Hot Topics in Web Systems and Technologies (HotWeb)
CY OCT 24-25, 2016
CL Washington, DC
SP IEEE, IEEE Comp Soc, Adobe, Google, IBM

AB Cloud computing, arguably, has become the de facto computing platform for the big data processing by researchers and practitioners for the last decade, and enabled different stakeholders to discover valuable information from large scale data. At the same time, in the decade, we have witnessed the fast growing deployment of billions of sensors and actuators in multiple applications domains, such as transportation, manufacturing, connected/wearable health care, smart city and so on, stimulating the emerging of Edge Computing (a.k.a., fog computing, cloudlet). However, data, as the core of both cloud computing and edge computing, is still owned by each stakeholder and rarely shared due to privacy concern and formidable cost of data transportation, which significantly limits Internet of Things (IoT) applications that need data input from multiple stakeholders (e.g., video analytics collects data from cameras owned by police department, transportation department, retailer stores, etc.).

In this paper, we envision that in the era of IoT the demand of distributed big data sharing and processing applications will dramatically increase since the data producing and consuming are pushed to the edge of the network. Data processing in collaborative edge environment needs to fuse data owned by multiple stakeholders, while keeping the computation within stakeholders' data facilities. To attack this challenge, we propose a new computing paradigm, Firework, which is designed for big data processing in collaborative edge environment (CEE). Firework fuses geographically distributed data by creating virtual shared data views that are exposed to end users via predefined interfaces by data owners. The interfaces are provided in the form of a set of datasets and a set of functions, where the functions are privacy preserved and bound to the datasets. Firework targets to share data while ensuring data privacy and integrity for stakeholders. By pushing the data processing as close as to data sources, Firework also aims to avoid data movement from the edge of the network to the cloud and improve the response latency.

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CR Agrawal R, 2000, SIGMOD RECORD, V29, P439
Akidau T, 2013, PROC VLDB ENDOW, V6, P1033, DOI 10.14778/2536222.2536229
Armbrust M, 2010, COMMUN ACM, V53, P50, DOI 10.1145/1721654.1721672
Bonomi F., 2012, P 1 ED MCC WORKSH MO, P13, DOI DOI 10.1145/2342509.2342513
Dean J, 2004, USENIX Association Proceedings of the Sixth Symposium on Operating Systems Design and Implementation (OSDE '04), P137
Evans D, 2011, WHITE PAPER, P1, DOI DOI 10.1109/IEEESTD.2007.373646
Greenberg A, 2009, ACM SIGCOMM COMP COM, V39, P68, DOI 10.1145/1496091.1496103
Heintz B., 2015, P 24 INT S HIGH PERF, P133
Hintjens Pieter, 2013, ZEROMQ MESSAGING MAN
Hunkeler U, 2008, 2008 3RD INTERNATIONAL CONFERENCE ON COMMUNICATION SYSTEM SOFTWARE AND MIDDLEWARE AND WORKSHOPS, VOLS 1 AND 2, P791, DOI 10.1109/COMSWA.2008.4554519
Isard M, 2007, Operating Systems Review, V41, P59, DOI 10.1145/1272998.1273005

```
   Kreps J., 2011, KAFKA DISTRIBUTED ME
   Kulkarni S, 2015, SIGMOD'15: PROCEEDINGS OF THE 2015 ACM SIGMOD INTERNATIONAL
CONFERENCE ON MANAGEMENT OF DATA, P239, DOI 10.1145/2723372.2742788
   Neumeyer L, 2010, Proceedings 2010 10th IEEE International Conference on Data
Mining Workshops (ICDMW 2010), P170, DOI 10.1109/ICDMW.2010.172
   Pu QF, 2015, ACM SIGCOMM COMP COM, V45, P421, DOI [10.1145/2785956.2787505,
10.1145/2829988.2787505]
   Qian Zhilin, 2013, P 8 ACM EUR C COMP S, P1, DOI DOI 10.1145/2465351.2465353
   Saha B, 2015, SIGMOD'15: PROCEEDINGS OF THE 2015 ACM SIGMOD INTERNATIONAL
CONFERENCE ON MANAGEMENT OF DATA, P1357, DOI 10.1145/2723372.2742790
   Satyanarayanan M, 2009, IEEE PERVAS COMPUT, V8, P14, DOI 10.1109/MPRV.2009.82
   Shi W., 2016, IEEE IN IN PRESS JUN
   Shi WS, 2016, COMPUTER, V49, P78, DOI 10.1109/MC.2016.145
   Shvachko K, 2010, IEEE S MASS STOR SYS
   Vulimiri A., 2015, P 12 USENIX C NETW S, P323
   Vulimiri A, 2015, SIGMOD'15: PROCEEDINGS OF THE 2015 ACM SIGMOD INTERNATIONAL
CONFERENCE ON MANAGEMENT OF DATA, P1087, DOI 10.1145/2723372.2735365
   Zaharia M, 2013, P 24 ACM S OP SYST P, P423, DOI DOI 10.1145/2517349.2522737
   Zaharia Matei, 2010, HOTCLOUD, P10, DOI DOI 10.HTTP://DL.ACM.0RG/CITATI0N.CFM?
NR 25
TC 8
Z9 8
U1 1
U2 7
PU IEEE
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BN 978-1-5090-5409-1
PY 2016
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WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic
SC Computer Science; Engineering
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PT S
AU Hull, R
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AF Hull, Richard
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   Heath, Fenno F. Terry, III
   Vianu, Victor
BE Sheng, QZ
   Stroulia, E
   Tata, S
   Bhiri, S
TI Towards a Shared Ledger Business Collaboration Language Based on
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Data-Aware Processes
SO SERVICE-ORIENTED COMPUTING, (ICSOC 2016)
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
CT 14th International Conference on Service-Oriented Computing (ICSOC)
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ID ARTIFACTS

AB Shared ledger technologies, as exemplified by Blockchain, provide a new framework for supporting business collaborations that is based on having a high-reliability, shared, trusted, privacy-preserving, nonrepudiable data repository that includes programmable logic in the form of "smart contracts". The framework has the potential to dramatically transform business collaboration across numerous industry sectors, including finance, supply chain, food production, pharmaceuticals, and healthcare. Widespread adoption of this technology will be accelerated by the development of business-level languages for specifying smart contracts. This paper proposes that data-aware business processes, and in particular the Business Artifact paradigm, can provide a robust basis for a shared ledger Business Collaboration Language (BCL). The fundamental rationale for adopting data-aware processes is that shared ledgers focus on both data and process in equal measure. The paper examines potential advantages of the artifact-based approach from two perspectives: conceptual modeling, and opportunities for formal reasoning (verification). Broad research challenges for the development, understanding, and usage of a shared ledger BCL are highlighted.

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CR ABITEBOUL S, 1986, J COMPUT SYST SCI, V33, P361, DOI 10.1016/0022-0000(86)90058-9
Abiteboul S., 2013, INT S PRINC DAT SYST
[Anonymous], 2011, BUS PROC MOD NOT BPM
Bhattacharya K, 2007, IBM SYST J, V46, P703, DOI 10.1147/sj.464.0703
Bhattacharya K, 2007, LECT NOTES COMPUT SC, V4714, P288
Boaz D., 2013, BIZARTIFACT ARTIFACT
Boaz D., 2014, P BPM DEM SESS
Brown R.G., INTRO R3 CORDA TM DI
Calvanese D., 2013, INT S PRINC DAT SYST
Chao T, 2009, LECT NOTES COMPUT SC, V5701, P261
Cohn D., 2009, IEEE DATA ENG B, V32, P3
Cohn D, 2008, LECT NOTES COMPUT SC, V5364, P722, DOI 10.1007/978-3-540-89652-4_63
Damaggio E, 2013, INFORM SYST, V38, P561, DOI 10.1016/j.is.2012.09.002
Deutsch A., 2009, INT C DAT THEORY ICD
Deutsch A., 2016, INT S PRINC DAT SYST
Deutsch A., 2008, IEEE DATA ENG B, V31, P35
Deutsch A, 2014, SIGMOD REC, V43, P5
Diaz M., 2009, PETRI NETS FUNDAMENT
Flood M.D., 2015, CONTRACT AUTOMATON C
Holzmann G.J., 2007, INT C VER LARG DAT B
HOLZMANN GJ, 1988, SOFTWARE PRACT EXPER, V18, P137, DOI 10.1002/spe.4380180203
Hulin G., 1990, INT C VER LARG DAT B

Hull R., 2011, ACM INT C DISTR EV S
   Hull R., 2013, INT C MAN DAT SIGMOD
   Hull R., 2012, REP NSF WORKSH DAT C
   Hull R, 2009, LECT NOTES COMPUT SC, V5900, P1, DOI 10.1007/978-3-642-10383-
4_1
   Kunzle V, 2011, J SOFTW MAINT EVOL-R, V23, P205, DOI 10.1002/smr.524
   Kumaran S., 2003, S APPL INT SAINT
   Limonad L., 2012, SRII GLOB C
   Manna Z., 1981, STANCS81836
   Marin M., 2012, BUS PROC MAN WORKSH
   Moffitt V.Z., 2015, ACM INT C MAN DAT SI
   Nakamoto Satoshi, 2009, BITCOIN PEER TO PEER
   Nguyen T., 2011, MATCH PROCESSES BUSI
   Nigam A, 2003, IBM SYST J, V42, P428, DOI 10.1147/sj.423.0428
   Pnueli A., 1977, S FDN COMP SCI FOCUU
   Redding G, 2008, LECT NOTES COMPUT SC, V4928, P132
   Redding G, 2010, SERV ORIENTED COMPUT, V4, P191, DOI 10.1007/s11761-010-0065-
4
   Rong Liu, 2011, Business Process Management. Proceedings of the 9th
International Conference (BPM 2011), P265, DOI 10.1007/978-3-642-23059-2_21
   Strosnider JK, 2008, IBM SYST J, V47, P415, DOI 10.1147/sj.473.0415
   Sun YT, 2016, ACM TRANS MANAG INF, V7, DOI 10.1145/2886104
   van der Aalst WMP, 2005, DATA KNOWL ENG, V53, P129, DOI
10.1016/j.datak.2004.07.003
   Van der Aalst WMP, 2001, INT J COOP INF SYST, V10, P443, DOI
10.1142/S0218843001000412
   Weber I., 2016, INT C BUS PROC MAN B
   Zhang F., 2016, IACR CRYPTOLOGY EPRI, V2016
NR 45
TC 8
Z9 8
U1 6
U2 78
PU SPRINGER INTERNATIONAL PUBLISHING AG
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PA GEWERBESTRASSE 11, CHAM, CH-6330, SWITZERLAND
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CA Undiag Dis Network
TI Data Sharing in the Undiagnosed Diseases Network
SO HUMAN MUTATION
LA English
DT Article
DE big data; genetics; genomics; precision medicine; personalized medicine;
   Matchmaker Exchange
AB The Undiagnosed Diseases Network (UDN) builds on the successes of the
Undiagnosed Diseases Program at the National Institutes of Health (NIH UDP).
Through support from the NIH Common Fund, a coordinating center, six additional
clinical sites, and two sequencing cores comprise the UDN. The objectives of the
UDN are to: (1) improve the level of diagnosis and care for patients with
undiagnosed diseases through the development of common protocols designed by an
enlarged community of investigators across the network; (2) facilitate research
into the etiology of undiagnosed diseases, by collecting and sharing
standardized, high-quality clinical and laboratory data including genotyping,
phenotyping, and environmental exposure data; and (3) create an integrated and
collaborative research community across multiple clinical sites, and among
laboratory and clinical investigators, to investigate the pathophysiology of
these rare diseases and to identify options for patient management. Broad-based
data sharing is at the core of achieving these objectives, and the UDN is
establishing the policies and governance structure to support broad data sharing.
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FU NIH Common Fund (through the Office of Strategic Coordination/Office of
   the NIH Director) [U01 HG007530, HG007690, HG007672]
FX Contract grant sponsor: NIH Common Fund (through the Office of Strategic
   Coordination/Office of the NIH Director and managed by NHGRI U01
   HG007530, HG007690, and HG007672).
CR Brownstein CA, 2014, GENOME BIOL, V15, DOI 10.1186/gb-2014-15-3-r53
   Enns GM, 2014, GENET MED, V16, P751, DOI 10.1038/gim.2014.22
   Might M., 2015, TALK MANY CASES NGLY
   Might M., 2012, HUNTING MY SONS KILL
   Petrovski S, 2013, PLOS GENET, V9, DOI 10.1371/journal.pgen.1003709
   Zhu XL, 2015, GENET MED, V17, P774, DOI 10.1038/gim.2014.191
NR 6
TC 8
Z9 8
U1 0
U2 8
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
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SN 1059-7794
EI 1098-1004
J9 HUM MUTAT
JI Hum. Mutat.
PD OCT
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VL 36
IS 10
SI SI
BP 985
EP 988
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PG 4
WC Genetics & Heredity
SC Genetics & Heredity
GA CT7IX
UT WOS:000362989500010
PM 26220576
OA Green Accepted, Bronze
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ER

PT J
AU Carr, D
   Littler, K
AF Carr, David
   Littler, Katherine
TI Sharing Research Data to Improve Public Health: A Funder Perspective
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Editorial Material
DE biomedical research ethics; data sharing; data release; research data;
   research governance; low income countries; clinical research; health
   policy
AB Through the Public Health Research Data Forum, global health research funders
are working together to increase the availability of public health and
epidemiology research data in ways that are equitable, ethical, and efficient.
The Wellcome Trust funded the research reported in this special edition as a
first step toward building an evidence base on the perspectives of research
stakeholders in low- and middle-income countries on the benefits and challenges
of sharing health research data. We hope this work will make a key contribution
to discussions aimed at creating policy frameworks for data access at local,
national, and regional levels that are sensitive to different contexts and
ensure the benefits to research and health are realized in an equitable manner.
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CR Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   Public Health Research Data Forum, 2014, ENH DISC PUBL HLTH E
   Public Health Research Data Forum, 2015, EN DAT LINK MAX VAL
   Rans J, 2013, ENABLING CITATION DA
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, P14
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wykstra S, 2013, DATA ACCESS POLICIES
NR 7
```

```
TC 8
Z9 8
U1 0
U2 0
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1556-2646
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J9 J EMPIR RES HUM RES
JI J. Empir. Res. Hum. Res. Ethics
PD JUL
PY 2015
VL 10
IS 3
SI SI
BP 314
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DI 10.1177/1556264615593485
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WC Ethics; Medical Ethics
SC Social Sciences - Other Topics; Medical Ethics
GA CQ0LF
UT WOS:000360286700010
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OA Green Published, Other Gold
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PT J
AU Pollack, CE
   Lemke, KW
   Roberts, E
   Weiner, JP
AF Pollack, Craig E.
   Lemke, Klaus W.
   Roberts, Eric
   Weiner, Jonathan P.
TI Patient Sharing and Quality of Care Measuring Outcomes of Care
   Coordination Using Claims Data
SO MEDICAL CARE
LA English
DT Article
DE care coordination; performance measure; provider social networks; care
   density
ID SHARED SAVINGS PROGRAM; HEALTH-CARE; DECISION-MAKING; COSTS; PHYSICIANS;
   SYSTEM; ACOS
AB Background: With the goal of improving clinical efficiency and effectiveness,
programs to enhance care coordination are a major focus of health care reform.
   Objective: To examine whether "care density"-a claims-based measure of
patient sharing by office-based physicians-is associated with measures of
quality. Care density is a proxy measure that may reflect how frequently a
patient's doctors collaborate.
   Research Design: Cohort study using administrative databases from 3 large
commercial insurance plans.
   Subjects: A total of 1.7 million adult patients; 31,675 with congestive heart
failure, 78,530 with chronic obstructive pulmonary disease, and 240,378 with
diabetes.
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Measures: Care density was assessed in 2008. Prevention Quality Indicators (PQIs), 30-day readmissions, and Healthcare Effectiveness Data and Information Set quality indicators were measured in the following year.

Results: Among all patients, we found that patients with the highest care density density-indicating high levels of patient sharing among their office-based physicians-had significantly lower rates of adverse events measured as PQIs compared with patients with low-care density (odds ratio = 0.88; 95% confidence interval, 0.85-0.92). A significant association between care density and PQIs was also observed for patients with diabetes mellitus but not congestive heart failure or chronic obstructive pulmonary disease. Diabetic patients with higher care density scores had significantly lower odds of 30-day read-missions (odds ratio = 0.68, 95% confidence interval, 0.48-0.97). Significant associations were observed between care density and Healthcare Effectiveness Data and Information Set measures although not always in the expected direction.

Conclusion: In some settings, patients whose doctors share more patients had lower odds of adverse events and 30-day readmissions.

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FU NIH National Cancer Institute; Office of Behavioral and Social Sciences Research [1K07CA151910-01A1]
FX C.E.P.'s salary was supported by a career development award from the NIH National Cancer Institute and Office of Behavioral and Social Sciences Research (1K07CA151910-01A1). The remaining authors declare no conflict of interest.

CR Barnett ML, 2011, HEALTH SERV RES, V46, P1592, DOI 10.1111/j.1475-6773.2011.01262.x
Berwick DM, 2011, NEW ENGL J MED, V364, DOI 10.1056/NEJMp1103602
Bodenheimer T, 2008, NEW ENGL J MED, V358, P1064, DOI 10.1056/NEJMhpr0706165
Chen C, 2014, JAMA-J AM MED ASSOC, V311, P673, DOI 10.1001/jama.2014.11
Forrest CB, 2006, MED DECIS MAKING, V26, P76, DOI 10.1177/0272989X05284110
Ginsburg PB, 2011, NEW ENGL J MED, V364, P2085, DOI 10.1056/NEJMp1103604
Hussey PS, 2014, JAMA INTERN MED, V174, P742, DOI 10.1001/jamainternmed.2014.245
Kocher RP, 2011, JAMA-J AM MED ASSOC, V306, P1794, DOI 10.1001/jama.2011.1561
Mathias JS, 2012, J AM MED INFORM ASSN, V19, pE96, DOI 10.1136/amiajnl-2011-000536
McDonald K, 2006, MED CARE RES REV, V63, P158
McWilliams JM, 2013, JAMA-J AM MED ASSOC, V310, P829, DOI 10.1001/jama.2013.276302
Mehrotra A, 2011, MILBANK Q, V89, P39, DOI 10.1111/j.1468-0009.2011.00619.x
Meyers D, 2010, ROLES PATIENT CTR ME
Moyer VA, 2012, ANN INTERN MED, V156, P880, DOI 10.7326/0003-4819-156-12-201206190-00424
Orszag PR, 2010, NEW ENGL J MED, V363, P601, DOI 10.1056/NEJMp1006571
Pollack CE, 2014, J CANCER SURVIV, V8, P156, DOI 10.1007/s11764-014-0349-3
Pollack CE, 2013, J GEN INTERN MED, V28, P459, DOI 10.1007/s11606-012-2104-7
Saultz John W, 2003, Ann Fam Med, V1, P134, DOI 10.1370/afm.23
Sirovich B, 2008, HEALTH AFFAIR, V27, P813, DOI 10.1377/hlthaff.27.3.813
WEINER JP, 1991, MED CARE, V29, P452, DOI 10.1097/00005650-199105000-00006

NR 20
TC 8
Z9 8

```
U1 0
U2 9
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
SN 0025-7079
EI 1537-1948
J9 MED CARE
JI Med. Care
PD APR
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VL 53
IS 4
BP 317
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WC Health Care Sciences & Services; Health Policy & Services; Public,
   Environmental & Occupational Health
SC Health Care Sciences & Services; Public, Environmental & Occupational
   Health
GA CG3EE
UT WOS:000353160100007
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PT J
AU Vest, JR
   Issel, LM
AF Vest, Joshua R.
   Issel, L. Michele
TI Factors Related to Public Health Data Sharing between Local and State
   Health Departments
SO HEALTH SERVICES RESEARCH
LA English
DT Article
ID INFORMATION-SYSTEM; IMMUNIZATION
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FU Robert Wood Johnson's Dissertation Award in PHSSR; Robert Wood Johnson
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   [D11HP14605]; Robert Wood Johnson's Junior Faculty Award in PHSSR;
   Public Health Services and Systems Research Coordinating Center (Vest
   PI)
FX This work was supported by the Robert Wood Johnson's Dissertation and
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CR Arzt N. H., 2011, J HEALTHCARE INFORM, V25, P37
Association of State and Territorial Health Officials, 2010, DAT AN
Association of State and Territorial Health Officials, 2011, ASTHO PROF STAT PUBL, VTwo
Association of State and Territorial Health Officials, 2010, ASTHO PROF STAT PUBL, V1
Bartlett DL, 2007, J PUBLIC HEALTH MAN, V13, P559
Baum NM, 2011, J PUBLIC HEALTH MAN, V17, P265, DOI 10.1097/PHH.0b013e318207599c
Carle AC, 2009, BMC MED RES METHODOL, V9, DOI 10.1186/1471-2288-9-49
Centers for Disease Control and Prevention (CDC), 2013, MMWR Morb Mortal Wkly Rep, V62, P48
Centers for Disease Control and Prevention (CDC), 2005, MMWR Morb Mortal Wkly Rep, V54, P722
Centers for Medicare and Medicaid Services, 2011, EL HOSP CAH MEAN US
Centers for Medicare & Medicaid Services, 2011, EL PROF MEAN US TABL
Charles D, 2013, HOSP ADOPTION ELECT
Choo C. W., 2006, KNOWING ORG ORG USE
Committee on Public Health Strategies to Improve Health Board on Population Health Public Health Institute of Medicine, 2012, PUBL HLTH INV HLTH F
Conte C, 2006, J PUBLIC HEALTH MAN, V12, P6
Hasselbring W, 2000, COMMUN ACM, V43, P33
Klompas Michael, 2012, Am J Public Health, V102 Suppl 3, pS325, DOI 10.2105/AJPH.2012.300811
Lenert Leslie, 2012, Am J Public Health, V102, pe1, DOI 10.2105/AJPH.2011.300542
Lenihan P, 2005, J PUBLIC HEALTH MAN, V11, P381
Libbey P., 2011, CROSS JURISDICTIONAL
Linkins RW, 1998, PEDIATR ANN, V27, P349, DOI 10.3928/0090-4481-19980601-09
Mahon BE, 2008, BMC PUBLIC HEALTH, V8, DOI 10.1186/1471-2458-8-160
NACCHO, 2008, NAT PROF LOC HLTH DE
National Association of County & City Health Officials, 2009, 2008 NAT PROF LOC HL
National Association of County & City Health Officials, 2010, NAT PROF LOC HLTH DE
Papadouka V, 2011, J PUBLIC HEALTH MAN, V17, P565, DOI 10.1097/PHH.0b013e3182214746
Rabe-Hesketh S, 2006, J ROY STAT SOC A STA, V169, P805, DOI 10.1111/j.1467-985X.2006.00426.x
Sambamurthy V, 1999, MIS QUART, V23, P261, DOI 10.2307/249754
Skrondal A, 2008, MULTILEVEL LONGITUDI
Stoto MA, 2008, PUBLIC HEALTH REP, V123, P441, DOI 10.1177/003335490812300405
Trust for America's Health, 2013, INV AM HLTH STAT BY
Turning Point National Excellence Collaborative for Information Technology, 2005, FIN REP COLL
UCLA: Academic Technology Services S. C. G., 2012, SID HOLM ADJ P VAL
Vest J. R., 2012, ONLINE J PUBLIC HLTH, V4, P1
Vest J. R., 2013, PUBL HLTH SERV SYST
Vest JR, 2013, J PUBLIC HEALTH MAN, V19, P357, DOI 10.1097/PHH.0b013e31826d8045
Vest JR, 2012, J PUBLIC HEALTH MAN, V18, P160, DOI 10.1097/PHH.0b013e318226c9ef
Zhu K, 2006, MANAGE SCI, V52, P1557, DOI 10.1287/mnsc.1050.0487

NR 38

```
TC 8
Z9 8
U1 0
U2 4
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0017-9124
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J9 HEALTH SERV RES
JI Health Serv. Res.
PD FEB
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VL 49
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BP 373
EP 391
DI 10.1111/1475-6773.12138
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WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA AA3MA
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PT J
AU Solanas, A
   Martinez-Balleste, A
   Mateo-Sanz, JM
AF Solanas, Agusti
   Martinez-Balleste, Antoni
   Mateo-Sanz, Josep M.
TI Distributed Architecture With Double-Phase Microaggregation for the
   Private Sharing of Biomedical Data in Mobile Health
SO IEEE TRANSACTIONS ON INFORMATION FORENSICS AND SECURITY
LA English
DT Article
DE Privacy protection; distributed environments; microaggregation; mobile
   health
AB In this paper, we present the concept of double-phase microaggregation as an
improvement of classical microaggregation for the protection of privacy in
distributed scenarios without fully trusted parties. We apply this new concept
in the context of mobile health and we show that a distributed architecture
consisting of patients and several intermediate entities can apply it to protect
the privacy of patients, whose data are released to third parties for secondary
use. After recalling some fundamental concepts of statistical disclosure control
and microaggregation, we detail the distributed architecture that allows the
private gathering, storage, and sharing of biomedical data. We show that double-
phase multivariate microaggregation properly fits the needs for privacy
preservation of biomedical data in the distributed context of mobile health.
Moreover, we show that double-phase microaggregation performs similarly to
classical microaggregation in terms of information loss, disclosure risk, and
correlation preservation, while avoiding the limitations of a centralized
approach.
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CR [Anonymous], 2002, LECT NOTES COMPUTER, V2316, P97
Brown CD, 2000, OBES RES, V8, P605, DOI 10.1038/oby.2000.79
DALENIUS T, 1982, J STAT PLAN INFER, V6, P73, DOI 10.1016/0378-3758(82)90058-1
Domingo-Ferrer J, 2004, ANN NY ACAD SCI, V3050, P149
DOMINGOFERRER J, 2006, VLDB J, V15, P355
ELGAMAL T, 1985, IEEE T INFORM THEORY, V31, P469, DOI 10.1109/TIT.1985.1057074
Emam K. E., 2009, J AM MED INFORM ASSN, V16, P670, DOI DOI 10.1197/JAMIA.M3144
Greenberg B., 1987, RANK SWAPPING UNPUB
Matthews GJ, 2011, STAT SURV, V5, P1, DOI 10.1214/11-SS074
Naehrig M., P 3 ACM WORKSH CLOUD, P113
Pagliuca D., 1998, SOME RESULTS INDIVID
RIVEST RL, 1978, COMMUN ACM, V21, P120, DOI 10.1145/359340.359342
Samarati P, 2001, IEEE T KNOWL DATA EN, V13, P1010, DOI 10.1109/69.971193
Solanas A, 2006, P COMP STAT COMPSTAT, P917
Solanas A., 2010, P INT JOINT C NEUR N, P1
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
WILLENBORG L., 2001, LECT NOTES STAT, V155
WILLENBORG LCR, 1996, LECT NOTES STAT, V111
NR 18
TC 8
Z9 8
U1 1
U2 5
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
PI PISCATAWAY
PA 445 HOES LANE, PISCATAWAY, NJ 08855-4141 USA
SN 1556-6013
J9 IEEE T INF FOREN SEC

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PD JUN
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SI SI
BP 901
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WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic
SC Computer Science; Engineering
GA 155CX
UT WOS:000319724100007
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PT J
AU Jurges, H
   Pohl, V
AF Juerges, Hendrik
   Pohl, Vincent
TI Medical guidelines, physician density, and quality of care: evidence
   from German SHARE data
SO EUROPEAN JOURNAL OF HEALTH ECONOMICS
LA English
DT Article
DE Physician quality of care; Physician density; Preventive care; Chronic
   disease management; Medical guidelines
ID HEALTH-CARE; CARDIOVASCULAR-DISEASES; INDUCED DEMAND; OLDER PERSONS;
   UNITED-STATES; POPULATION; MORTALITY; VARIABLES; OBESITY; GENDER
AB We use German SHARE data to study the relationship between district general practitioner density and the quality of preventive care provided to older adults. We measure physician quality of care as the degree of adherence to medical guidelines (for the management of risk factors for cardiovascular disease and the prevention of falls) as reported by patients. Contrary to theoretical expectations, we find only weak and insignificant effects of physician density on quality of care. Our results shed doubt on the notion that increasing physician supply will increase the quality of care provided in Germany's present health care system.
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OI Pohl, R. Vincent/0000-0002-4272-1434
FU PHS HHS [OGHA 04-064]; NIA NIH HHS [P01 AG005842, P01 AG08291, P30
   AG12815, Y1-AG-4553-01, U01 AG09740-13S2]
CR Association of American Medical Colleges, 2006, AAMC STAT PHYS WORKF
   Borsch-Supan A., 2005, SURVEY HLTH AGING RE
   Breyer F, 1984, NACHFR NACH MED LEIS
   Campbell S, 2007, NEW ENGL J MED, V357, P181, DOI 10.1056/NEJMsr065990
   Carlsen F, 2000, J HEALTH ECON, V19, P731, DOI 10.1016/S0167-6296(00)00044-8
   Cassel D., 2001, Z GESUNDHEITSWISSENS, V9, P331
   CHANDRA A, 2003, 9513 NBER
   Chen J, 2001, NEW ENGL J MED, V344, P1443, DOI 10.1056/NEJM200105103441906

CHEN MK, 1985, INT J EPIDEMIOL, V14, P300, DOI 10.1093/ije/14.2.300
Cooper-Patrick L, 1999, JAMA-J AM MED ASSOC, V282, P583, DOI 10.1001/jama.282.6.583
Czypionka T, 2006, CLIN PRACTICE GUIDEL
DRANOVE D, 1994, J HEALTH ECON, V13, P61, DOI 10.1016/0167-6296(94)90004-3
DRANOVE D, 2000, HDB HLTH EC
Garber A. M., 2008, 14257 NBER
Getzen T. E., 2010, HLTH EC FINANCING
Gohlke H, 2003, Z KARDIOL, V92, P522, DOI 10.1007/s00392-003-0963-y
Greenberg JO, 2007, AM J CARDIOL, V99, P1476, DOI 10.1016/j.amjcard.2006.12.084
Gulich M, 2004, DEGAM LEITLINIE ALTE
Hagist Christian, 2005, 11833 NBER
Hussey PS, 2004, HEALTH AFFAIR, V23, P89, DOI 10.1377/hlthaff.23.3.89
Jencks SF, 2000, JAMA-J AM MED ASSOC, V284, P1670, DOI 10.1001/jama.284.13.1670
Jensen MK, 2008, CIRCULATION, V117, P3062, DOI 10.1161/CIRCULATIONAHA.107.759951
Joung I.M.A., 1995, INT J EPIDEMIOL, V24, P575
Jurges H, 2007, HLTH INSURANCE STATU, P119
Karlsson M, 2007, J HEALTH ECON, V26, P699, DOI 10.1016/j.jhealeco.2006.12.001
Katz A, 2006, HEALTH SERV RES, V41, P2238, DOI 10.1111/j.1475-6773.2006.00589.x
Krakauer H, 1996, HEALTH SERV RES, V31, P191
Kramer W, 1981, Z GESAMTE STAATSWISS, V1, P45
Laditka JN, 2005, HEALTH SERV RES, V40, P1148, DOI 10.1111/j.1475-6773.2005.00403.x
Laditka JN, 2004, HEALTH PLACE, V10, P231, DOI 10.1016/j.healthplace.2003.09.004
Lowel H, 2006, MED KLIN, V101, P804, DOI 10.1007/s00063-006-1108-7
McGlynn EA, 1997, HEALTH AFFAIR, V16, P7, DOI 10.1377/hlthaff.16.3.7
McGlynn EA, 2004, HEALTH AFFAIR, V23, P100, DOI 10.1377/hlthaff.23.3.100
McGlynn EA, 2001, HEALTH AFFAIR, V20, P82, DOI 10.1377/hlthaff.20.3.82
McGlynn EA, 2003, NEW ENGL J MED, V348, P2635, DOI 10.1056/NEJMsa022615
McGuire T., 2000, HDB HLTH EC, V1
MCKINSTRY B, 1994, BRIT J GEN PRACT, V44, P349
Morris S, 2008, J HEALTH ECON, V27, P1357, DOI 10.1016/j.jhealeco.2008.02.012
Papke LE, 1996, J APPL ECONOM, V11, P619, DOI 10.1002/(SICI)1099-1255(199611)11:6<619::AID-JAE418>3.0.CO;2-1
Perrin J M, 1986, Health Aff (Millwood), V5, P63, DOI 10.1377/hlthaff.5.4.63
POHLMEIER W, 1995, J HUM RESOUR, V30, P339, DOI 10.2307/146123
Raina P, 2002, HEALTH SERV RES, V37, P751, DOI 10.1111/1475-6773.00047
RIZZO JA, 1992, J HUM RESOUR, V27, P381, DOI 10.2307/146169
Scheffer AC, 2008, AGE AGEING, V37, P19, DOI 10.1093/ageing/afm169
Schindelheim GL, 2004, AM J EMERG MED, V22, P503, DOI 10.1016/j.ajem.2004.07.011
Shi LY, 2001, AM J PUBLIC HEALTH, V91, P1246, DOI 10.2105/AJPH.91.8.1246
Staiger D, 1997, ECONOMETRICA, V65, P557, DOI 10.2307/2171753
Stevens J.A., 2008, JAMA-J AM MED ASSOC, V299, P225
Vellas BJ, 1997, AGE AGEING, V26, P189, DOI 10.1093/ageing/26.3.189
Wennberg John E, 2002, Health Aff (Millwood), VSuppl Web Exclusives, pW96

NR 50
TC 8
Z9 8
U1 0
U2 14
PU SPRINGER

```
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
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J9 EUR J HEALTH ECON
JI Eur. J. Health Econ.
PD OCT
PY 2012
VL 13
IS 5
BP 635
EP 649
DI 10.1007/s10198-011-0372-5
PG 15
WC Economics; Health Policy & Services
SC Business & Economics; Health Care Sciences & Services
GA 995RJ
UT WOS:000308029500011
PM 22203268
DA 2019-08-06
ER

PT J
AU Colditz, GA
AF Colditz, Graham A.
TI Constraints on Data Sharing Experience From the Nurses' Health Study
SO EPIDEMIOLOGY
LA English
DT Editorial Material
ID BREAST-CANCER; WOMEN; REANALYSIS; RISK
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FU NCI NIH HHS [P30 CA091842]
CR Bain C, 2004, JNCI-J NATL CANCER I, V96, P826, DOI 10.1093/jnci/djh143
   Beral V, 1997, LANCET, V350, P1047
   Colditz GA, 2005, NAT REV CANCER, V5, P388, DOI 10.1038/nrc1608
   Colditz GA, 2008, J NATL CANCER I, V100, P918, DOI 10.1093/jnci/djn193
   Dorgan JF, 2002, JNCI-J NATL CANCER I, V94, P606
   Lochner K, 2008, AM J EPIDEMIOL, V168, P336, DOI 10.1093/aje/kwn123
   Meza R, 2008, CANCER CAUSE CONTROL, V19, P317, DOI 10.1007/s10552-007-9094-5
   *OFF EXTR RES, 2003, NOTOD03032 US DEP HL
   Ritz B, 2007, ARCH NEUROL-CHICAGO, V64, P990, DOI 10.1001/archneur.64.7.990
   Rosenberg L, 1995, J Am Med Womens Assoc (1972), V50, P56
   Samet JM, 2009, EPIDEMIOLOGY, V20, P172, DOI 10.1097/EDE.0b013e3181930df3
NR 11
TC 8
Z9 8
U1 0
U2 1
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA 530 WALNUT ST, PHILADELPHIA, PA 19106-3621 USA
SN 1044-3983
J9 EPIDEMIOLOGY
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JI Epidemiology
PD MAR
PY 2009
VL 20
IS 2
BP 169
EP 171
DI 10.1097/EDE.0b013e318196ad0f
PG 3
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 412HH
UT WOS:000263715400004
PM 19234411
OA Green Accepted
DA 2019-08-06
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PT J
AU Prokosch, HU
   Acker, T
   Bernarding, J
   Binder, H
   Boeker, M
   Boerries, M
   Daumke, P
   Ganslandt, T
   Hesser, J
   Honing, G
   Neumaier, M
   Marquardt, K
   Renz, H
   Rothkotter, HJ
   Schade-Brittinger, C
   Schmucker, P
   Schuttler, J
   Sedlmayr, M
   Serve, H
   Sohrabi, K
   Storf, H
AF Prokosch, Hans-Ulrich
   Acker, Till
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   Binder, Harald
   Boeker, Martin
   Boerries, Melanie
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   Ganslandt, Thomas
   Hesser, Juergen
   Hoening, Gunther
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   Marquardt, Kurt
   Renz, Harald
   Rothkoetter, Hermann-Josef
   Schade-Brittinger, Carmen
   Schmuecker, Paul
   Schuettler, Juergen
   Sedlmayr, Martin
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Serve, Hubert
Sohrabi, Keywan
Storf, Holger
TI MIRACUM: Medical Informatics in Research and Care in University Medicine
A Large Data Sharing Network to Enhance Translational Research and
Medical Care
SO METHODS OF INFORMATION IN MEDICINE
LA English
DT Article
DE Data reuse; data sharing; Medical Informatics Initiative; MIRACUM; data integration centres
ID INTEGRATING BIOLOGY; CLINICAL-RESEARCH; SECONDARY USE; HEALTH DATA; RECRUITMENT; BIOBANK; SYSTEMS; IMPLEMENTATION; TRANSMART; PCORNET

AB Introduction: This article is part of the Focus Theme of Methods of Information in Medicine on the German Medical Informatics Initiative. Similar to other large international data sharing networks (e.g. OHDSI, PCORnet, eMerge, RD-Connect) MIRACUM is a consortium of academic and hospital partners as well as one industrial partner in eight German cities which have joined forces to create interoperable data integration centres (DIC) and make data within those DIC available for innovative new IT solutions in patient care and medical research. Objectives: Sharing data shall be supported by common interoperable tools and services, in order to leverage the power of such data for biomedical discovery and moving towards a learning health system. This paper aims at illustrating the major building blocks and concepts which MIRACUM will apply to achieve this goal. Governance and Policies: Besides establishing an efficient governance structure within the MIRACUM consortium (based on the steering board, a central administrative office, the general MIRACUM assembly, six working groups and the international scientific advisory board), defining DIC governance rules and data sharing policies, as well as establishing (at each MIRACUM DIC site, but also for MIRACUM in total) use and access committees are major building blocks for the success of such an endeavor. Architectural Framework and Methodology: The MIRACUM DIC architecture builds on a comprehensive ecosystem of reusable open source tools (MIRACOLIX), which are linkable and interoperable amongst each other, but also with the existing software environment of the MIRACUM hospitals. Efficient data protection measures, considering patient consent, data harmonization and a MIRACUM metadata repository as well as a common data model are major pillars of this framework. The methodological approach for shared data usage relies on a federated querying and analysis concept. Use Cases: MIRACUM aims at proving the value of their DIC with three use cases: IT support for patient recruitment into clinical trials, the development and routine care implementation of a clinico-molecular predictive knowledge tool, and molecular-guided therapy recommendations in molecular tumor boards. Results: Based on the MIRACUM DIC release in the nine months conceptual phase first large scale analysis for stroke and colorectal cancer cohorts have been pursued. Discussion: Beyond all technological challenges successfully applying the MIRACUM tools for the enrichment of our knowledge about diagnostic and therapeutic concepts, thus supporting the concept of a Learning Health System will be crucial for the acceptance and sustainability in the medical community and the MIRACUM university hospitals.

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FU German Federal Ministry of Education and Research (BMBF) within the Medical Informatics Funding Scheme [FKZ 01ZZ1606A-H]
FX MIRACUM is funded by the German Federal Ministry of Education and Research (BMBF) within the Medical Informatics Funding Scheme (FKZ 01ZZ1606A-H).
CR Bialke M, 2015, METHOD INFORM MED, V54, P364, DOI 10.3414/ME14-01-0133
Campbell MK, 2007, HEALTH TECHNOL ASSES, V11
Christoph J, 2017, APPL CLIN INFORM, V8, P1173, DOI 10.4338/ACI-2017-05-RA-0085
Christoph J, 2015, METHOD INFORM MED, V54, P276, DOI 10.3414/ME13-01-0133
Christoph J, 2017, STUD HEALTH TECHNOL, V236, P70, DOI 10.3233/978-1-61499-759-7-70

Collins FS, 2014, J AM MED INFORM ASSN, V21, P576, DOI 10.1136/amiajnl-2014-002864
Cuggia M, 2011, INT J MED INFORM, V80, P371, DOI 10.1016/j.ijmedinf.2011.02.003
De Moor G, 2015, J BIOMED INFORM, V53, P162, DOI 10.1016/j.jbi.2014.10.006
Dilts DM, 2006, J CLIN ONCOL, V24, P4545, DOI 10.1200/JCO.2005.05.0104
Doiron D, 2013, EMERG THEMES EPIDEMI, V10, DOI 10.1186/1742-7622-10-12
Doods J, 2015, STUD HEALTH TECHNOL, V210, P506, DOI 10.3233/978-1-61499-512-8-506
Eijssen Lars, 2015, F1000Res, V4, P33, DOI 10.12688/f1000research.6009.2
Fleurence RL, 2014, J AM MED INFORM ASSN, V21, P578, DOI 10.1136/amiajnl-2014-002747
Fortier I, 2010, INT J EPIDEMIOL, V39, P1383, DOI 10.1093/ije/dyq139
Friedman C, 2015, J AM MED INFORM ASSN, V22, P43, DOI 10.1136/amiajnl-2014-002977
Gainotti S, 2018, EUR J HUM GENET, V26, P631, DOI 10.1038/s41431-017-0085-z
Garza M, 2016, J BIOMED INFORM, V64, P333, DOI 10.1016/j.jbi.2016.10.016
Gaye A, 2014, INT J EPIDEMIOL, V43, P1929, DOI 10.1093/ije/dyu188
Gottesman O, 2013, GENET MED, V15, P761, DOI 10.1038/gim.2013.72
Haverkamp C, 2018, CLIN NEURORADIOL, V28, P225, DOI 10.1007/s00062-017-0656-y
He S, 2016, TRANSMARTXNAT CONNEC
Herrick R, 2016, NEUROIMAGE, V124, P1093, DOI 10.1016/j.neuroimage.2015.06.076
Hinderer M, 2017, PHARMACOGENOMICS, V18, P773, DOI 10.2217/pgs-2017-0027
Hinderer M, 2017, BMC MED INFORM DECIS, V17, DOI 10.1186/s12911-017-0480-y
Hinderer M, 2017, STUD HEALTH TECHNOL, V236, P48, DOI 10.3233/978-1-61499-759-7-48
Howe D, 2008, NATURE, V455, P47, DOI 10.1038/455047a
Hripcsak G, 2015, STUD HEALTH TECHNOL, V216, P574, DOI 10.3233/978-1-61499-564-7-574
Hripcsak G, 2016, P NATL ACAD SCI USA, V113, P7329, DOI 10.1073/pnas.1510502113
Kadioglu D, 2016, HEC 2016 HLTH EXPL C
Khalilia Mohammed, 2015, AMIA Annu Symp Proc, V2015, P717
Klann JG, 2016, J AM MED INFORM ASSN, V23, P909, DOI 10.1093/jamia/ocv188
Kohane IS, 2012, J AM MED INFORM ASSN, V19, P181, DOI 10.1136/amiajnl-2011-000492
KOPCKE F, 2013, BMC MED INFORM DECIS, V13
Lablans M, 2015, METHOD INFORM MED, V54, P346, DOI 10.3414/ME14-01-0137
M-MDR, MIRACUM MET REP
Maier C, 2018, APPL CLIN INFORM, V9, P54, DOI 10.1055/s-0037-1617452
Marcus DS, 2007, J DIGIT IMAGING, V20, P130, DOI 10.1007/s10278-007-9066-z
Mate S, 2017, STUD HEALTH TECHNOL, V243, P100, DOI 10.3233/978-1-61499-808-2-100
Mate S, 2017, STUD HEALTH TECHNOL, V243, P42, DOI 10.3233/978-1-61499-808-2-42
Meystre S M, 2017, Yearb Med Inform, V26, P38, DOI 10.15265/IY-2017-007
Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
Pommerening K, 2014, TMF SCHRIFTENREIHE
Prasser F, 2016, BMC MED INFORM DECIS, V16, DOI 10.1186/s12911-016-0287-2
Prasser Fabian, 2014, AMIA Annu Symp Proc, V2014, P984
Scheufele Elisabeth, 2014, AMIA Jt Summits Transl Sci Proc, V2014, P96
Schreiweis B, 2014, INT J MED INFORM, V83, P860, DOI 10.1016/j.ijmedinf.2014.08.005
Semler SC, 2018, METHOD INFORM MED, V57, pE50, DOI 10.3414/ME18-03-0003
Spjuth O, 2016, EUR J HUM GENET, V24, P521, DOI 10.1038/ejhg.2015.165

```
   Storf H, 2017, REGISTRIES RARE DIS, DOI [10. 1007/s00103-017-2536-7, DOI
10.1007/S00103-017-2536-7]
   Trinczek B, 2014, APPL CLIN INFORM, V5, P264, DOI 10.4338/ACI-2013-07-RA-0047
   Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
NR 51
TC 7
Z9 7
U1 31
U2 41
PU GEORG THIEME VERLAG KG
PI STUTTGART
PA RUDIGERSTR 14, D-70469 STUTTGART, GERMANY
SN 0026-1270
EI 2511-705X
J9 METHOD INFORM MED
JI Methods Inf. Med.
PD JUL
PY 2018
VL 57
SU 1
BP E82
EP E91
DI 10.3414/ME17-02-0025
PG 10
WC Computer Science, Information Systems; Health Care Sciences & Services;
   Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA GN9ON
UT WOS:000439532900008
PM 30016814
OA Other Gold
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PT J
AU Goodman, D
   Johnson, CO
   Bowen, D
   Smith, M
   Wenzel, L
   Edwards, K
AF Goodman, Deborah
   Johnson, Catherine O.
   Bowen, Deborah
   Smith, Megan
   Wenzel, Lari
   Edwards, Karen
TI De-identified genomic data sharing: the research participant perspective
SO JOURNAL OF COMMUNITY GENETICS
LA English
DT Article
DE De-identification; Genomic research; Participant views; Data linkage;
   Precision Medicine
ID GENETIC RESEARCH; CONSENT; COMMUNITY; ATTITUDES; MEDICINE; BIOBANK;
   VIEWS
AB Combining datasets into larger and separate datasets is becoming increasingly
common, and personal identifiers are often removed in order to maintain
participant anonymity. Views of research participants on the use of de-
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identified data in large research datasets are important for future projects, such as the Precision Medicine Initiative and Cancer Moonshot Initiative. This quantitative study set in the USA examines participant preferences and evaluates differences by demographics and cancer history. Study participants were recruited from the Northwest Cancer Genetics Registry and included cancer patients, their relatives, and controls. A secure online survey was administered to 450 participants. While the majority participants were not concerned about personal identification when participating in a genetic study using de-identified data, they expressed their concern that researchers protect their privacy and information. Most participants expressed a desire that their data should be available for as many research studies as possible, and in doing so, they would increase their chance of receiving personal health information. About 20% of participants felt that a link should not be maintained between the participant and their de-identified data. Reasons to maintain a link included an ability to return individual health results and an ability to support further research. Knowledge of participants' attitudes regarding the use of data into a research repository and the maintenance of a link to de-identified data is critical to the success of recruitment into future genomic research projects.

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FU NIH [R01CA149051]
FX This research was supported by NIH grant no. R01CA149051 to Karen Edwards (PI), "Identification of Issues and Expectations of Subjects Participating in Genetic Studies of Cancer".
CR Budimir D, 2011, CROAT MED J, V52, P262, DOI 10.3325/cmj.2011.52.262
Caulfield T, 2014, J LAW BIOSCI, V1, P94, DOI 10.1093/jlb/lst004
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Condit Celeste M, 2015, IRB, V37, P1
DAUGHERTY C, 1995, J CLIN ONCOL, V13, P1062, DOI 10.1200/JCO.1995.13.5.1062
Goodman D, 2016, PUBLIC HEALTH GENOM, V19, P220, DOI 10.1159/000447346
Haddow G, 2007, SOC SCI MED, V64, P272, DOI 10.1016/j.socscimed.2006.08.028
Hoeyer K, 2012, TRUST BIOBANKING DEA, V33, P21
Jamal L, 2014, EUR J HUM GENET, V22, DOI 10.1038/ejhg.2013.276
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
McCarty CA, 2007, COMMUNITY GENET, V10, P2, DOI 10.1159/000096274
McCarty CA, 2011, AM J MED GENET A, V155A, P737, DOI 10.1002/ajmg.a.33896
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
Okun MA, 2003, PSYCHOL AGING, V18, P231, DOI 10.1037/0882-7974.18.2.231
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Ormond KE, 2009, AM J MED GENET A, V149A, P188, DOI 10.1002/ajmg.a.32635
R Core Team, 2015, R LANGUAGE ENV STAT
Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI 10.1586/14737159.2014.961917
Steinsbekk KS, 2013, MED HEALTH CARE PHIL, V16, P151, DOI 10.1007/s11019-011-9353-9
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
NR 21
TC 7
Z9 7

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U1 1
U2 6
PU SPRINGER HEIDELBERG
PI HEIDELBERG
PA TIERGARTENSTRASSE 17, D-69121 HEIDELBERG, GERMANY
SN 1868-310X
EI 1868-6001
J9 J COMMUN GENET
JI J. Commun. Genet.
PD JUL
PY 2017
VL 8
IS 3
BP 173
EP 181
DI 10.1007/s12687-017-0300-1
PG 9
WC Genetics & Heredity
SC Genetics & Heredity
GA EZ7VT
UT WOS:000404934500004
PM 28382417
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DA 2019-08-06
ER

PT J
AU Cook-Deegan, R
   McGuire, AL
AF Cook-Deegan, Robert
   McGuire, Amy L.
TI Moving beyond Bermuda: sharing data to build a medical information
   commons
SO GENOME RESEARCH
LA English
DT Article
AB The ubiquity of DNA sequencing and the advent of medical imaging, electronic
health records, and "omics" technologies have produced a deluge of data. Making
meaning of those data-creating scientific knowledge and useful clinical
information-will vastly exceed the capacity of even the largest institutions.
Data must be shared to achieve the promises of genomic science and precision
medicine.
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FX Research was supported in part by grants from the National Human Genome
   Research Institute (R01 HG008918; P50 HG003391). R.C.-D. is a senior
   fellow at FasterCures, a Center of the Milken Institute.
CR American Medical Association, 2013, D 460 971 GEN AN VAR
   [Anonymous], 2011, PREC MED BUILD KNOWL
   [Anonymous], 2013, IDF DIABETES ATLAS, P1
   Arias JJ, 2015, J LAW BIOSCI, V2, P56, DOI 10.1093/jlb/lsu032
   Biden J., 2016, PENN MED ALMANAC, V62, P1
   BRCA Challenge, 2015, GLOB ALL GEN HLTH
   Cech TR, 2003, PLANT PHYSIOL, V132, P19, DOI 10.1104/pp.900068
```

```
   Cochrane Archie L., 1972, EFFECTIVENESS EFFICI
   Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
   Contreras J. L., 2011, MINN J L SCI TECH, V120, P61
   Curnutte MA, 2014, NAT BIOTECHNOL, V32, P980, DOI 10.1038/nbt.3030
   Eddy David M, 2011, Virtual Mentor, V13, P55, DOI
10.1001/virtualmentor.2011.13.1.mhst1-1101
   Feingold EA, 2004, SCIENCE, V306, P636, DOI 10.1126/science.1105136
   Field MJ, 1992, GUIDELINES CLIN PRAC
   Food and Drug Administration US Department of Health and Human Services
Center for Devices and Radiological Health Office of In Vitro Diagnostics and
Radiological Health and Center for Biologics Evaluation and Research, 2016, US
PUBL HUM GEN VAR
   GarciaSancho M, 2012, SCI TECHNOL MED MOD, P1, DOI 10.1057/9780230370937
   Gibbs RA, 2003, NATURE, V426, P789, DOI 10.1038/nature02168
   Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN T
   Global Alliance for Genomics and Health, 2013, WHIT PAP CREAT GLOB
   Kellis M, 2014, P NATL ACAD SCI USA, V111, P6131, DOI 10.1073/pnas.1318948111
   Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
   Lunshof JE, 2014, SCIENCE, V343, P373, DOI 10.1126/science.1249382
   McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
   Merton Robert, 1942, SOCIOLOGY SCI THEORE, V1, P267
   Micheel Christine M., 2012, EVOLUTION TRANSLATIO
   National Human Genome Research Institute, 2000, ENCODE CONS DAT REL
   National Institutes of Health, 2015, NIH SEC BEST PRACT C
   National Institutes of Health, 2014, FED REGISTER, V79, P51345
   Ostrom E, 2000, J ECON PERSPECT, V14, P137, DOI 10.1257/jep.14.3.137
   Ostrom E, 1990, GOVERNING COMMONS EV
   Popper KR., 1959, GENOMICS, V83, P349
   President's Council of Advisors on Science and Technology, 2014, BETT HLTH
CAR ALOW C
   Ray T., 2015, GENOMEWEB
   Reardon J, 2000, GEN OP WORKSH GROUP
   Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
   Rothstein MA, 2015, J LAW MED ETHICS, V43, P673, DOI 10.1111/jlme.12310
   Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
   Wellcome Trust, 2003, M ORG WELLC TRUST JA
   Wellcome Trust Sanger Institute, 2014, DAT SHAR POL
   Ziman J., 1978, RELIABLE KNOWLEDGE E
NR 40
TC 7
Z9 7
U1 2
U2 8
PU COLD SPRING HARBOR LAB PRESS, PUBLICATIONS DEPT
PI COLD SPRING HARBOR
PA 1 BUNGTOWN RD, COLD SPRING HARBOR, NY 11724 USA
SN 1088-9051
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J9 GENOME RES
JI Genome Res.
PD JUN
PY 2017
VL 27
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BP 897
EP 901
DI 10.1101/gr.216911.116
PG 5
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WC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology; Genetics & Heredity
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology; Genetics & Heredity
GA EW5BY
UT WOS:000402521400001
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OA Green Published, Other Gold
DA 2019-08-06
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PT J
AU Gomez-Cabrero, D
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Vargas, C
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CA Synergy-COPD Consortia
TI From comorbidities of chronic obstructive pulmonary disease to identification of shared molecular mechanisms by data integration
SO BMC BIOINFORMATICS
LA English
DT Article
ID GENE ONTOLOGY; COPD; RISK; EXACERBATIONS; ENRICHMENT; IMPACT; CODES; ICD9
AB Background: Deep mining of healthcare data has provided maps of comorbidity relationships between diseases. In parallel, integrative multi-omics investigations have generated high-resolution molecular maps of putative relevance for understanding disease initiation and progression. Yet, it is unclear how to advance an observation of comorbidity relations (one disease to others) to a molecular understanding of the driver processes and associated biomarkers.

Results: Since Chronic Obstructive Pulmonary disease (COPD) has emerged as a central hub in temporal comorbidity networks, we developed a systematic integrative data-driven framework to identify shared disease-associated genes and pathways, as a proxy for the underlying generative mechanisms inducing comorbidity. We integrated records from approximately 13 M patients from the Medicare database with disease-gene maps that we derived from several resources including a semantic-derived knowledge-base. Using rank-based statistics we not only recovered known comorbidities but also discovered a novel association between COPD and digestive diseases. Furthermore, our analysis provides the first set of COPD co-morbidity candidate biomarkers, including IL15, TNF and JUP, and characterizes their association to aging and life-style conditions, such as smoking and physical activity.

Conclusions: The developed framework provides novel insights in COPD and especially COPD co-morbidity associated mechanisms. The methodology could be used to discover and decipher the molecular underpinning of other comorbidity relationships and furthermore, allow the identification of candidate co-morbidity biomarkers.

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CR Amberger JS, 2015, NUCLEIC ACIDS RES, V43, pD789, DOI 10.1093/nar/gku1205
[Anonymous], 1990, WORLD HLTH STAT Q, V43, P204
Ashburner M, 2000, NAT GENET, V25, P25, DOI 10.1038/75556
Barnes PJ, 2009, EUR RESPIR J, V33, P1165, DOI 10.1183/09031936.00128008
Barreiro E, 2009, THORAX, V64, P13, DOI 10.1136/thx.2008.105163
BENJAMINI Y, 1995, J R STAT SOC B, V57, P289
Betts JC, 2015, PHARMACOL RES PERSPE, V3, DOI 10.1002/prp2.94
Blake JA, 2015, NUCLEIC ACIDS RES, V43, pD1049, DOI 10.1093/nar/gku1179
Bodenreider O, 1998, J AM MED INFORM ASSN, V5, P76, DOI 10.1136/jamia.1998.0050076

Burge AT, 2016, PHYSIOTHERAPY
Burgel PR, 2014, AM J RESP CRIT CARE, V189, P7, DOI 10.1164/rccm.201311-2029ED
Cano I, 2014, J TRANSL MED, V12
Capobianco E, 2013, TRENDS MOL MED, V19, P515, DOI 10.1016/j.molmed.2013.07.004
CARUSO G, 1991, Recenti Progressi in Medicina, V82, P585
Celli BR, 2009, LANCET, V374, P1885, DOI 10.1016/S0140-6736(09)62082-1
Cepek P, 2016, IMMUNOLOGY, V148, P150, DOI 10.1111/imm.12593
Cheng D, 2008, NUCLEIC ACIDS RES, V36, pW399, DOI 10.1093/nar/gkn296
Cobb WS, 2009, HERNIA, V13, P1, DOI 10.1007/s10029-008-0428-3
Cohen J., 2002, APPL MULTIPLE REGRES
Dal Negro RW, 2015, MULTIDISCIP RESP MED, V10
Davis AP, 2013, NUCLEIC ACIDS RES, V41, pD1104, DOI 10.1093/nar/gks994
de Groot DA, 2014, AGE AGEING, V43, P773, DOI 10.1093/ageing/afu075
Decramer M, 2013, LANCET RESP MED, V1, P73, DOI 10.1016/S2213-2600(12)70060-7
Decramer M, 2012, LANCET, V379, P1341, DOI 10.1016/S0140-6736(11)60968-9
Eagan TML, 2012, RESP RES, V13, DOI 10.1186/1465-9921-13-48
Ekbom A, 2008, LUNG, V186, P167, DOI 10.1007/s00408-008-9080-z
Faner R, 2013, COPD, V10, P138, DOI 10.3109/15412555.2012.729621
Freeman CM, 2010, J IMMUNOL, V184, P6504, DOI 10.4049/jimmunol.1000006
Garcia-Olmos L, 2013, BMC FAM PRACT, V14, DOI 10.1186/1471-2296-14-11
Global Initiative for Chronic Obstructive Lung Disease, 2015, GLOB STRAT DIAGN MAN
Goh KI, 2007, P NATL ACAD SCI USA, V104, P8685, DOI 10.1073/pnas.0701361104
Gomez-Cabrero D, 2014, J TRANSL MED BIOMED, V12
Han MK, 2010, AM J RESP CRIT CARE, V182, P598, DOI 10.1164/rccm.200912-1843CC
Hansell AL, 2004, PHARMACOEPIDEM DR S, V13, P547, DOI 10.1002/pds.931
Harmston Nathan, 2010, Human Genomics, V5, P17
Hartel FW, 2005, J BIOMED INFORM, V38, P114, DOI 10.1016/j.jbi.2004.09.001
Hernandez C, 2015, RESP MED, V109, P500, DOI 10.1016/j.rmed.2015.01.005
Hidalgo CA, 2009, PLOS COMPUT BIOL, V5, DOI 10.1371/journal.pcbi.1000353
Hinks A, 2013, NAT GENET, V45, P664, DOI 10.1038/ng.2614
Hollenbach JA, 2015, J AUTOIMMUN, V64, P13, DOI 10.1016/j.jaut.2015.06.010
Houghton AM, 2013, NAT REV CANCER, V13, P233, DOI 10.1038/nrc3477
Husson F., 2010, EXPLORATORY MULTIVAR
Jansson SA, 2015, COPD, V12, P381, DOI 10.3109/15412555.2014.974089
Jensen AB, 2014, NAT COMMUN, V5, DOI 10.1038/ncomms5022
Kannan V, 2016, SCI REP-UK, V6, DOI 10.1038/srep26170
KATZ D, 1978, BIOMETRICS, V34, P469, DOI 10.2307/2530610
Keely S, 2014, CHEST, V46, P65
Lerner A, 2015, AUTOIMMUN REV, V14, P1038, DOI 10.1016/j.autrev.2015.07.007
Liu YF, 2015, NUCLEIC ACIDS RES, V43, pW535, DOI 10.1093/nar/gkv383
Lococo F, 2015, NOVEL THERAPEUTIC ST, P3655
Lozano R, 2012, LANCET, V380, P2095, DOI 10.1016/S0140-6736(12)61728-0
Maglott D, 2004, NUCLEIC ACIDS RES, V33, P54
Maier D, 2011, BMC SYST BIOL, V5, DOI 10.1186/1752-0509-5-38
Marchesi M, 2013, J TRANSL MED, V11, DOI 10.1186/1479-5876-11-247
Mathur S, 2014, FRONT PHYSIOL, V5, DOI 10.3389/fphys.2014.00104
Megiorni F, 2012, J BIOMED SCI, V19, DOI 10.1186/1423-0127-19-88
Menche J, 2015, SCIENCE, V20, P347
Moni MA, 2015, FRONT CELL DEV BIOL, V3
Moni Mohammad Ali, 2014, J Clin Bioinforma, V4, P8, DOI 10.1186/2043-9113-4-8
Mullen MT, 2013, CIRC-CARDIOVASC QUAL, V6, P505, DOI 10.1161/CIRCOUTCOMES.113.000215
Murtagh F, 1985, COMPSTAT LECT, V4
Negewo NA, 2015, RESPIROLOGY, V20, P1160, DOI 10.1111/resp.12642
Park J, 2009, MOL SYST BIOL, V5, DOI 10.1038/msb.2009.16

Patel ARC, 2013, AM J RESP CRIT CARE, V188, P1091, DOI 10.1164/rccm.201306-1170OC
Payne T H, 1992, Proc Annu Symp Comput Appl Med Care, P654
Postma DS, 2013, RESP MED, V107, P1939, DOI 10.1016/j.rmed.2013.07.011
Ramos EM, 2014, EUR J HUM GENET, V22, P144, DOI 10.1038/ejhg.2013.96
Rivals I, 2007, BIOINFORMATICS, V23, P401, DOI 10.1093/bioinformatics/btl633
Roca J, 2016, METHODS MOL BIOL, V1386, P283, DOI 10.1007/978-1-4939-3283-2_13
Rodriguez DA, 2012, FREE RADICAL BIO MED, V52, P88, DOI 10.1016/j.freeradbiomed.2011.09.022
Rolland T, 2014, CELL, V159, P1212, DOI 10.1016/j.cell.2014.10.050
SLEE VN, 1978, ANN INTERN MED, V88, P424, DOI 10.7326/0003-4819-88-3-424
Smith NLD, 2014, CLIN MICROBIOL INFEC, V20, pO480, DOI 10.1111/1469-0691.12473
Snir O, 2014, ARTHRITIS RES THER, V16, DOI 10.1186/s13075-014-0414-3
Subramanian A, 2005, P NATL ACAD SCI USA, V102, P15545, DOI 10.1073/pnas.0506580102
Suh KS, 2010, EXPERT REV MOL DIAGN, V10, P1069, DOI [10.1586/erm.10.87, 10.1586/ERM.10.87]
Van Remoortel H, 2014, AM J RESP CRIT CARE, V189, P30, DOI 10.1164/rccm.201307-1240OC
Vanfleteren LEGW, 2013, AM J RESP CRIT CARE, V187, P728, DOI 10.1164/rccm.201209-1665OC
Vestbo J, 2012, CLIN RESPIR J, V6, P208, DOI 10.1111/crj.12002
Vogelmeier C, 2014, EUR RESPIR J, V43, P949, DOI 10.1183/09031936.00019714
Wang AY, 2001, J AM MED INFORM ASSN, P741
Watz H, 2014, LANCET RESP MED, V2, P63, DOI 10.1016/S2213-2600(13)70200-5
Yang H, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0120515
Zdrenghea MT, 2012, EUR J CLIN INVEST, V42, P1010, DOI 10.1111/j.1365-2362.2012.02672.x
Zi ZK, 2012, FEBS LETT, V586, P1921, DOI 10.1016/j.febslet.2012.03.063
NR 85
TC 7
Z9 7
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TI Improving the informational continuity of care in diabetes mellitus
   treatment with a nationwide Shared EHR system: Estimates from Austrian
   claims data
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Medical records; Medical records systems; Computerized; Continuity of
   patient care; Diabetes mellitus; Austria
ID ELECTRONIC HEALTH RECORD; CLINICAL INFORMATION; DATA EXCHANGE; PATIENT;
   NEEDS; COMMUNICATION; COORDINATION; PHYSICIANS; OUTCOMES; ACCESS

AB Purpose: Shared Electronic Health Record (EHR) systems, which provide a health information exchange (HIE) within a community of care, were found to be a key enabler of informational continuity of diabetes mellitus (DM) care. Quantitative analyses of the actual contribution of Shared EHR systems to informational continuity of care are rare. The goal of this study was to quantitatively analyze (i) the degree of fragmentation of DM care in Austria as an indicator for the need for HIE, and (ii) the quantity of information (i.e. number of documents) from Austrian DM patients that would be made available by a nationwide Shared EHR system for HIE.

Methods: Our analyses are based on social security claims data of 7.9 million Austrians from 2006 and 2007. DM patients were identified through medication data and inpatient diagnoses. The degree of fragmentation was determined by the number of different healthcare providers per patient. The amount of information that would be made available by a nationwide Shared EHR system was estimated by the number of documents that would have been available to a healthcare provider if he had access to information on the patient's visits to any of the other healthcare providers. As a reference value we determined the number of locally available documents that would have originated from the patient's visits to the healthcare provider himself. We performed our analysis for two types of systems: (i) a "comprehensive" Shared EHR system (SEHRS), where each visit of a patient results in a single document (progress note), and (ii) the Austrian ELGA system, which allows four specific document types to be shared.

Results: 391,630 DM patients were identified, corresponding to 4.7% of the Austrian population. More than 90% of the patients received health services from more than one healthcare provider in one year. Both, the SEHRS as well as ELGA would have multiplied the available information during a patient visit in comparison to an isolated local EHR system; the median ratio of external to local medical documents was between 1:1 for a typical visit at a primary care provider (SEHRS as well as ELGA) and 39:1 (SEHRS) respectively 28:1 (ELGA) for a typical visit at a hospital.

Conclusions: Due to the high degree of care fragmentation, there is an obvious need for HIE for Austrian DM patients. Both, the SEHRS as well as ELGA could provide a substantial contribution to informational continuity of care in Austrian DM treatment. Hospitals and specialists would have gained the most amount of external information, primary care providers and pharmacies would have at least doubled their available information. Despite being the most important potential feeders of a national Shared EHR system according to our analysis, primary care providers will not tap their full corresponding potential under the current implementation scenario of ELGA. (C) 2016 The Authors. Published by Elsevier Ireland Ltd.

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CR Accenture, 2013, DIG DOCT IS
Ammenwerth E, 2014, INT J MED INFORM, V83, P655, DOI 10.1016/j.ijmedinf.2014.06.004
[Anonymous], 2013, BENCHM DEPL EHEALTH
Beaser RS, 2011, ENDOCR PRACT, V17, P880, DOI 10.4158/EP10398.OR
Branger PJ, 1999, INT J MED INFORM, V53, P133, DOI 10.1016/S1386-5056(98)00154-3
Cabana MD, 2004, J FAM PRACTICE, V53, P974
Cheng SH, 2011, HEALTH POLICY PLANN, V26, P157, DOI 10.1093/heapol/czq035
Chini F, 2011, BMC PUBLIC HEALTH, V11, DOI 10.1186/1471-2458-11-688
Duftschmid G, 2004, METHOD INFORM MED, V43, P124
Duftschmid G, 2013, INT J MED INFORM, V82, P1195, DOI 10.1016/j.ijmedinf.2013.08.002
Duftschmid G, 2012, STUD HEALTH TECHNOL, V180, P667, DOI 10.3233/978-1-61499-101-4-667
European Commission, 2011, EUR COUNTR THEIR JOU
European Committee for Standardization, 2007, 139401 EN EUR COMM S
Goodwin N, 2012, INTEGRATED CARE PATI
Graham Mark J, 2003, AMIA Annu Symp Proc, P852
Haggerty JL, 2003, BRIT MED J, V327, P1219, DOI 10.1136/bmj.327.7425.1219
Herbek S., 2012, EUR SURG, V15, P5
Hripcsak G, 2007, J AM MED INFORM ASSN, V14, P235, DOI 10.1197/jamia.M2206
Hubner-Bloder G., 2011, MIE 2011 OSL, P369
International Organization for Standardization, 2005, 205142005 ISOTR
Joshy G, 2006, DIABETES TECHNOL THE, V8, P587, DOI 10.1089/dia.2006.8.587
Kripalani S, 2007, JAMA-J AM MED ASSOC, V297, P831, DOI 10.1001/jama.297.8.831
Lehnbom EC, 2013, STUD HEALTH TECHNOL, V192, P3, DOI 10.3233/978-1-61499-289-9-3
Liang H., 2004, INT J INFORM MANAGE, V24, P507

```
   MacPhail LH, 2009, MED CARE, V47, P993, DOI 10.1097/MLR.0b013e31819e1ffe
   Maenpaa T, 2009, INT J MED INFORM, V78, P757, DOI
10.1016/j.ijmedinf.2009.07.001
   Medicare Payment Advisory Commission, 2006, REP C INCR VAL MED
   Mihalynuk TV, 2004, FAM MED, V36, P722
   Nunez-Benjumea F, 2014, STUD HEALTH TECHNOL, V205, P617, DOI 10.3233/978-1-
61499-432-9-617
   O'Malley AS, 2011, NEW ENGL J MED, V364, P1090, DOI 10.1056/NEJMp1011227
   O'Malley KJ, 2005, HEALTH SERV RES, V40, P1620, DOI 10.1111/j.1475-
6773.2005.00444.x
   Parker V., 2013, BR J DIABETES VASC D, V13, P150
   Pham HH, 2007, NEW ENGL J MED, V356, P1130, DOI 10.1056/NEJMsa063979
   Raaijmakers LGM, 2013, BMC FAM PRACT, V14, DOI 10.1186/1471-2296-14-114
   Reid R, 2002, DEFUSING CONFUSION C
   Reuss E, 2004, INT J MED INFORM, V73, P363, DOI
10.1016/j.ijmedinf.2004.02.003
   Rudin RS, 2014, J AM MED INFORM ASSN, V21, P13, DOI 10.1136/amiajnl-2013-
001737
   Rudin RS, 2011, J AM MED INFORM ASSN, V18, P853, DOI 10.1136/amiajnl-2010-
000072
   Schober E, 2009, J PEDIATR-US, V155, P190, DOI 10.1016/j.jpeds.2009.03.010
   Schoen C, 2009, HEALTH AFFAIR, V28, pW1, DOI 10.1377/hlthaff.28.1.w1
   Sinha P.K., 2013, ELECT HLTH RECORD ST
   Smith PC, 2005, JAMA-J AM MED ASSOC, V293, P565, DOI 10.1001/jama.293.5.565
   Statistik Austria, 2007, OST GES 2006 2007
   Statistik Austria, 2015, JAHR SEIT 1981 NACH
   van Walraven C, 2008, CAN MED ASSOC J, V179, P1013, DOI 10.1503/cmaj.080430
NR 45
TC 7
Z9 7
U1 0
U2 14
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
   IRELAND
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AF Rahimzadeh, Vasiliki
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TI An International Framework for Data Sharing: Moving Forward with the Global Alliance for Genomics and Health
SO BIOPRESERVATION AND BIOBANKING
LA English
DT Article
ID POLICY

AB The Global Alliance for Genomics and Health is marshaling expertise in biomedical research and data sharing policy to propel bench-to-bedside translation of genomics in parallel with many of the BioSHaRE-EU initiatives described at length in this Issue. Worldwide representation of institutions, funders, researchers, and patient advocacy groups at the Global Alliance is testament to a shared ideal that sees maximizing the public good as a chief priority of genomic innovation in health. The Global Alliance has made a critical stride in this regard with the development of its Framework for Responsible Sharing of Genomic and Health-related Data.(1) This article first discusses the human rights pillars that underlie the Framework and mission of the Global Alliance. Second, it outlines the Global Alliance's use of data governance policies through a number of demonstration projects. Finally, the authors describe how the Global Alliance envisions international data sharing moving forward in the postgenomic era.

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CR Baker D, 2014, GENOMIC CLIN DATA SH
BRCA Challenge, BRCA CHALL
Burton PR, 2015, BIOINFORMATICS, V31, P3241, DOI 10.1093/bioinformatics/btv279
Drazen JM, 2015, NEW ENGL J MED, V372, P201, DOI 10.1056/NEJMp1415160
Dyke SOM, 2016, PLOS GENET, V12, DOI 10.1371/journal.pgen.1005772
Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
GA4GH, BEAC PROJ
Garrett SB, 2015, CTS-CLIN TRANSL SCI, V8, P362, DOI 10.1111/cts.12259
General Assembly of UN, 1948, UN DECL HUM RIGHTS
Global Alliance for Genomics and Health, FRAM RESP SHAR GEN H
Hayden EC, 2013, NATURE, V498, P16, DOI 10.1038/498017a

```
   Hinterberger A, 2015, PUBLIC CULTURE, V27, P361, DOI 10.1215/08992363-2841904
   Knoppers BM, 2007, TRENDS BIOTECHNOL, V25, P284, DOI
10.1016/j.tibtech.2007.04.006
   Knoppers BM, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-87
   Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
   Kosseim P, 2014, GENOME BIOL, V15, DOI 10.1186/s13059-014-0430-2
   Matchmaker Exchange API, MATCHM EXCH API
   Our Work, OUR WORK
   Paten B, 2015, J AM MED INFORM ASSN, V22, P1143, DOI 10.1093/jamia/ocv047
   Philippakis AA, 2015, HUM MUTAT, V36, P915, DOI 10.1002/humu.22858
   Sansone SA, 2012, NAT GENET, V44, P121, DOI 10.1038/ng.1054
   Shabani M, 2015, EMBO MOL MED, V7, P507, DOI 10.15252/emmm.201405002
   Veltman JA, 2015, GENOME MED, V7, DOI 10.1186/s13073-015-0200-0
NR 23
TC 7
Z9 7
U1 0
U2 6
PU MARY ANN LIEBERT, INC
PI NEW ROCHELLE
PA 140 HUGUENOT STREET, 3RD FL, NEW ROCHELLE, NY 10801 USA
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J9 BIOPRESERV BIOBANK
JI Biopreserv. Biobank.
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WC Cell Biology; Chemistry, Applied; Medical Laboratory Technology
SC Cell Biology; Chemistry; Medical Laboratory Technology
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ER

PT J
AU Stoddart, J
   Chan, B
   Joly, Y
AF Stoddart, Jennifer
   Chan, Benny
   Joly, Yann
TI The European Union's Adequacy Approach to Privacy and International Data
   Sharing in Health Research
SO JOURNAL OF LAW MEDICINE & ETHICS
LA English
DT Article
AB The European Union (EU) approach to data protection consists of assessing the
adequacy of the data protection offered by the laws of a particular jurisdiction
against a set of principles that includes purpose limitation, transparency,
quality, proportionality, security, access, and rectification. The EU's Data
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Protection Directive sets conditions on the transfer of data to third countries by prohibiting Member States from transferring to such countries as have been deemed inadequate in terms of the data protection regimes. In theory, each jurisdiction is evaluated similarly and must be found fully compliant with the EU's data protection principles to be considered adequate. In practice, the inconsistency with which these evaluations are made presents a hurdle to international data-sharing and makes difficult the integration of different data-sharing approaches; in the 20 years since the Directive was first adopted, the laws of only five countries from outside of the EU, Economic Area, or the European Free Trade Agreement have been deemed adequate to engage in data transfers without the need for further administrative safeguards.

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CR [Anonymous], 2009, NATURE, V461, P168
   [Anonymous], 2014, COMMUNICATION
   [Anonymous], 1998, 12 WP
   Asia-Pacific Economic Cooperation, APEC PRIV FRAM
   Bamberger KA, 2011, STANFORD LAW REV, V63, P247
   Blume P, 2015, INT DATA PRIV LAW, V5, P34, DOI 10.1093/idpl/ipu026
   CRID, 2010, AN AD PROT PERS DAT
   Data Guidance, 2015, EU LIFE CONTINUES DE
   European Commission, COMM DEC AD PROT PER
   European Data Protection Supervisor, LEAD EX EDPS STRAT 2
   Global Alliance for Genomics & Health, 2014, FRAM RESP SHAR GEN H
   Gratton E., 2014, COMMUNICATION
   Greenleaf G., 2015, PRIVACY LAWS BUSINES, V133, p[1, 6]
   Greenleaf G., 2011, PRIVACY LAWS BUSINES, V111, P8
   HUGO, 1996, 1 INT STRAT M HUM GE
   Karen McCullagh, 2007, J INT COMMERCIAL LAW, V2, P190
   Kosseim P, 2014, GENOME BIOL, V15, DOI 10.1186/s13059-014-0430-2
   Kuner C, 2013, TRANSBORDER DATA FLO
   Kuner C., 2013, TRANSBORDER DATA FLO, P48
   Kuner C., 2013, TRANSBORDER DATA FLO, P160
   Long WJ, 2002, J EUR PUBLIC POLICY, V9, P325, DOI 10.1080/13501760210138778
   Makulilo AB, 2013, INT DATA PRIV LAW, V3, P42, DOI 10.1093/idpl/ips031
   Mayer-Schonberger Viktor, 2013, BIG DATA REVOLUTION
   Office of the Privacy Commissioner of Canada, PRIV LEG CAN
   Office of the Privacy Commissioner of Canada, LEG INF REL PIPEDA S
   Pijetlovic K., 2014, PROTECTING HUMAN RIG, P183
   Teschke, 2010, CANADIAN J PUBLIC HL, V101, p[159, 163]
   The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
   Wolf C., 2014, WASHINGTON U J LAW P, V43, p[227, 251]
   World Anti-Doping Agency, SUMM COMM WADA EUR W

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Z9 7
U1 0
U2 0
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PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA

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JI J. Law Med. Ethics
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WC Ethics; Law; Medical Ethics; Medicine, Legal
SC Social Sciences - Other Topics; Government & Law; Medical Ethics; Legal
   Medicine
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UT WOS:000374189400013
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PT B
AU Qiu, LF
   Gai, KK
   Qiu, MK
AF Qiu, Longfei
   Gai, Keke
   Qiu, Meikang
BE Qiu, MK
TI Optimal Big Data Sharing Approach for Tele-health in Cloud Computing
SO 2016 IEEE INTERNATIONAL CONFERENCE ON SMART CLOUD (SMARTCLOUD)
LA English
DT Proceedings Paper
CT IEEE International Conference on Smart Cloud (IEEE SmartCloud)
CY NOV 18-20, 2016
CL New York City, NY
SP IEEE, IEEE SmartCloud 2016 Comm, IEEE TCSC, IEEE Comp Soc, Pace Univ, ATE,
Columbia Univ, Longxiang High Tech, N Amer Chinese Talents Assoc, Stony Brook
Univ, Shanghai Jiao Tong Univ, IEEE Transacti Comp, IEEE Transact Cloud Comp,
IEEE Comp Soc Smart Comp
DE Tele-health; big data; cloud computing; data sharing
ID AWARE; SYSTEMS
AB The rapid development of tele-health systems have received driving
engagements from various emerging techniques, such as big data and cloud
computing. Sharing data among multiple tele-health systems is an adaptive
approach for improving service quality via the network-based technologies.
However, current implementations of data sharing in cloud computing is still
facing the restrictions caused by the networking capacities and virtual machine
switches. In this paper, we focus on the problem of data sharing obstacles in
cloud computing and propose an approach that uses dynamic programming to produce
optimal solutions to data sharing mechanisms. The proposed approach is called
Optimal Telehealth Data Sharing Model (OTDSM), which considers transmission
probabilities, maximizing network capacities, and timing constraints. Our
experimental results have proved the flexibility and adoptability of the
proposed method.
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CR Alami H., 2015, J INT SOC TELEMEDICI, V4, pe5
[Anonymous], 2015, SECURITY COMMUNICATI
Baig MM, 2013, MED BIOL ENG COMPUT, V51, P485, DOI 10.1007/s11517-012-1021-6
Baig MM, 2013, J MED SYST, V37, DOI 10.1007/s10916-012-9898-z
Chen M, 2016, MOBILE NETW APPL, V21, P729, DOI 10.1007/s11036-015-0665-5
Chen M, 2016, SENSORS-BASEL, V16, DOI 10.3390/s16070974
Chen M, 2015, IEEE NETWORK, V29, P32, DOI 10.1109/MNET.2015.7064900
Chen M, 2015, IEEE WIREL COMMUN, V22, P20, DOI 10.1109/MWC.2015.7054715
Deutsch JE, 2007, IEEE T NEUR SYS REH, V15, P30, DOI 10.1109/TNSRE.2007.891384
Gai K., 2016, IEEE T CLOUD COMPUT, P1
Gai K., 2014, J INFO SYST APPL RES, V7, P28
Gai KK, 2017, ACM T EMBED COMPUT S, V16, DOI 10.1145/2979677
Gai KK, 2016, 2016 IEEE 3RD INTERNATIONAL CONFERENCE ON CYBER SECURITY AND CLOUD COMPUTING (CSCLOUD), P273, DOI 10.1109/CSCloud.2016.52
Gai KK, 2016, 2016 IEEE 3RD INTERNATIONAL CONFERENCE ON CYBER SECURITY AND CLOUD COMPUTING (CSCLOUD), P198, DOI 10.1109/CSCloud.2016.48
Gai KK, 2016, 2016 IEEE 2ND INTERNATIONAL CONFERENCE ON BIG DATA SECURITY ON CLOUD (BIGDATASECURITY), IEEE INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE AND SMART COMPUTING (HPSC), AND IEEE INTERNATIONAL CONFERENCE ON INTELLIGENT DATA AND SECURITY (IDS), P140, DOI 10.1109/BigDataSecurity-HPSC-IDS.2016.68
Gai KK, 2015, 2015 IEEE 2ND INTERNATIONAL CONFERENCE ON CYBER SECURITY AND CLOUD COMPUTING (CSCLOUD), P98, DOI 10.1109/CSCloud.2015.72
Gai KK, 2015, 2015 IEEE 2ND INTERNATIONAL CONFERENCE ON CYBER SECURITY AND CLOUD COMPUTING (CSCLOUD), P1, DOI 10.1109/CSCloud.2015.73
Gai KK, 2015, 2015 IEEE 2ND INTERNATIONAL CONFERENCE ON CYBER SECURITY AND CLOUD COMPUTING (CSCLOUD), P74, DOI 10.1109/CSCloud.2015.75
Gai KK, 2016, J NETW COMPUT APPL, V59, P46, DOI 10.1016/j.jnca.2015.05.016
Gai KK, 2015, 2015 IEEE 17TH INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE COMPUTING AND COMMUNICATIONS, 2015 IEEE 7TH INTERNATIONAL SYMPOSIUM ON CYBERSPACE SAFETY AND SECURITY, AND 2015 IEEE 12TH INTERNATIONAL CONFERENCE ON EMBEDDED SOFTWARE AND SYSTEMS (ICESS), P1332, DOI 10.1109/HPCC-CSS-ICESS.2015.250
Gai KK, 2015, 2015 IEEE 17TH INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE COMPUTING AND COMMUNICATIONS, 2015 IEEE 7TH INTERNATIONAL SYMPOSIUM ON CYBERSPACE SAFETY AND SECURITY, AND 2015 IEEE 12TH INTERNATIONAL CONFERENCE ON EMBEDDED SOFTWARE AND SYSTEMS (ICESS), P752, DOI 10.1109/HPCC-CSS-ICESS.2015.168
Gai KK, 2012, INT C MULTIMED INFO, P142, DOI 10.1109/MINES.2012.240
Hua YC, 2015, LECT NOTES COMPUT SC, V9085, P123, DOI 10.1007/978-3-319-19156-0_13
Li YX, 2017, IEEE T SYST MAN CY-S, V47, P729, DOI 10.1109/TSMC.2016.2521824
Mamaghanian H, 2011, IEEE T BIO-MED ENG, V58, P2456, DOI 10.1109/TBME.2011.2156795
Naeem M, 2015, IEEE SENS J, V15, P1463, DOI 10.1109/JSEN.2014.2363571
Peddi S., 2016, FUTURE GENERATION CO
Qiu MK, 2018, FUTURE GENER COMP SY, V80, P421, DOI 10.1016/j.future.2016.01.006
Qiu MK, 2014, 2014 IEEE INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE COMPUTING AND COMMUNICATIONS, 2014 IEEE 6TH INTL SYMP ON CYBERSPACE SAFETY AND SECURITY, 2014 IEEE 11TH INTL CONF ON EMBEDDED SOFTWARE AND SYST (HPCC,CSS,ICESS), P574, DOI 10.1109/HPCC.2014.98
Qiu MK, 2015, IEEE T COMPUT, V64, P3528, DOI 10.1109/TC.2015.2409857
Santoso F, 2015, PHYSIOL MEAS, V36, DOI 10.1088/0967-3334/36/10/R53
Wang J., 2016, J SYSTEMS ARCHITECTU

```
   Xiang W, 2016, IEEE NETWORK, V30, P30, DOI 10.1109/MNET.2016.7474341
   Yang CC, 2009, TELEMED J E-HEALTH, V15, P62, DOI 10.1089/tmj.2008.0060
   Yin H, 2016, 2016 IEEE 2ND INTERNATIONAL CONFERENCE ON BIG DATA SECURITY ON
CLOUD (BIGDATASECURITY), IEEE INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE AND
SMART COMPUTING (HPSC), AND IEEE INTERNATIONAL CONFERENCE ON INTELLIGENT DATA
AND SECURITY (IDS), P245, DOI 10.1109/BigDataSecurity-HPSC-IDS.2016.76
   Zhao H, 2016, FUTURE GENER COMP SY, V56, P766, DOI
10.1016/j.future.2015.05.005
NR 36
TC 7
Z9 7
U1 1
U2 4
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-5090-5263-9
PY 2016
BP 184
EP 189
DI 10.1109/SmartCloud.2016.21
PG 6
WC Computer Science, Theory & Methods
SC Computer Science
GA BG7PL
UT WOS:000391560900027
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PT J
AU Min, H
   Ohira, R
   Collins, MA
   Bondy, J
   Avis, NE
   Tchuvatkina, O
   Courtney, PK
   Moser, RP
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   Hesse, BW
   Cooper, M
   Reeves, D
   Lanese, B
   Helba, C
   Miller, SM
   Ross, EA
AF Min, Hua
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   Collins, Michael A.
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   Courtney, Paul K.
   Moser, Richard P.
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   Hesse, Bradford W.
   Cooper, Mary
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   Lanese, Bob
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TI Sharing behavioral data through a grid infrastructure using data
   standards
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
ID ELECTRONIC HEALTH RECORDS; SUBJECTIVE NUMERACY SCALE; MEANINGFUL USE;
   NCI THESAURUS; SCIENCE; PROGRESS; TOOLKIT; SYSTEMS; PHENX
AB Objective In an effort to standardize behavioral measures and their data
representation, the present study develops a methodology for incorporating
measures found in the National Cancer Institute's (NCI) grid-enabled measures
(GEM) portal, a repository for behavioral and social measures, into the cancer
data standards registry and repository (caDSR).
   Methods The methodology consists of four parts for curating GEM measures into
the caDSR: (1) develop unified modeling language (UML) models for behavioral
measures; (2) create common data elements (CDE) for UML components; (3) bind CDE
with concepts from the NCI thesaurus; and (4) register CDE in the caDSR.
   Results UML models have been developed for four GEM measures, which have been
registered in the caDSR as CDE. New behavioral concepts related to these
measures have been created and incorporated into the NCI thesaurus. Best
practices for representing measures using UML models have been utilized in the
practice (eg, caDSR). One dataset based on a GEM-curated measure is available
for use by other systems and users connected to the grid.
   Conclusions Behavioral and population science data can be standardized by
using and extending current standards. A new branch of CDE for behavioral
science was developed for the caDSR. It expands the caDSR domain coverage beyond
the clinical and biological areas. In addition, missing terms and concepts
specific to the behavioral measures addressed in this paper were added to the
NCI thesaurus. A methodology was developed and refined for curation of
behavioral and population science data.
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CR Abernethy AP, 2011, TRANSL BEHAV MED, V1, P45, DOI 10.1007/s13142-011-0024-4
   Abraham C, 2008, HEALTH PSYCHOL, V27, P379, DOI 10.1037/0278-6133.27.3.379
   [Anonymous], 2010, ONC STANDARDS CERTIF
```

Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
Cella D, 2002, QUAL LIFE RES, V11, P207, DOI 10.1023/A:1015276414526
Cella D, 2007, MED CARE, V45, pS3, DOI 10.1097/01.mlr.0000258615.42478.55
Cella D, 2010, J CLIN EPIDEMIOL, V63, P1179, DOI 10.1016/j.jclinepi.2010.04.011
COHEN S, 1983, J HEALTH SOC BEHAV, V24, P385, DOI 10.2307/2136404
Courtney PK, 2011, CANCER J, V17, P219, DOI 10.1097/PPO.0b013e3182270c83
de Coronado S, 2004, ST HEAL T, V107, P33
Fagerlin A, 2007, MED DECIS MAKING, V27, P672, DOI 10.1177/0272989x07304449
Forman MR, 2010, AM J PREV MED, V38, P646, DOI 10.1016/j.amepre.2010.03.002
Fragoso G, 2004, COMP FUNCT GENOM, V5, P648, DOI 10.1002/cfg.445
Fridsma DB, 2008, J AM MED INFORM ASSN, V15, P130, DOI 10.1197/jamia.M2556
Gershon RC, 2010, LANCET NEUROL, V9, P138, DOI 10.1016/S1474-4422(09)70335-7
Hamilton CM, 2011, AM J EPIDEMIOL, V174, P253, DOI 10.1093/aje/kwr193
Hastings Shannon, 2009, Summit Transl Bioinform, V2009, P44
Hendershot T, 2011, CURR PROTOC HUM GENE, P1211
Jha AK, 2010, JAMA-J AM MED ASSOC, V304, P1709, DOI 10.1001/jama.2010.1497
Jha AK, 2010, HEALTH AFFAIR, V29, P1951, DOI 10.1377/hlthaff.2010.0502
McGuinness DL, 2011, ACM WEBSCI 11 KOBL G, P1
McKinnon RA, 2012, AM J PREV MED, V42, P433, DOI 10.1016/j.amepre.2012.01.004
Michie S, 2005, QUAL SAF HEALTH CARE, V14, P26, DOI 10.1136/qshc.2004.011155
Moser RP, 2011, ANN BEHAV MED, V41, pS145
Moser RP, 2011, AM J PREV MED, V40, pS134, DOI 10.1016/j.amepre.2011.01.004
Noar SM, 2005, HEALTH EDUC RES, V20, P275, DOI 10.1093/her/cyg113
Noy Natalya F., 2001, KSL0105 STANF KNOWL
Noy NF, 2004, SIGMOD RECORD, V33, P65
Oster S, 2008, J AM MED INFORM ASSN, V15, P138, DOI 10.1197/jamia.M2522
RADLOFF L S, 1977, Applied Psychological Measurement, V1, P385, DOI 10.1177/014662167700100306
Shaikh AR, 2009, 13 APHA ANN M NOV 7
Stover PJ, 2010, CURR OPIN LIPIDOL, V21, P136, DOI 10.1097/MOL.0b013e3283377395
von Eschenbach AC, 2006, CANCER INFORM, V2, P22
Zikmund-Fisher BJ, 2007, MED DECIS MAKING, V27, P663, DOI 10.1177/0272989x07303824
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TC 7
Z9 7
U1 0
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PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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WC Computer Science, Information Systems; Computer Science, Interdisciplinary Applications; Health Care Sciences & Services;

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   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
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AU Levy, MA
   Freymann, JB
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   Berglund, AE
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   Guo, XT
   Casavant, TL
   Brown, BJ
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   Boada, F
   Laymon, C
   Oborski, M
   Rubin, DL
AF Levy, Mia A.
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   Guo, Xiaotao
   Casavant, Thomas L.
   Brown, Bartley J.
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   Mountz, James M.
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   Laymon, Charles
   Oborski, Matt
   Rubin, Daniel L.
TI Informatics methods to enable sharing of quantitative imaging research
   data
SO MAGNETIC RESONANCE IMAGING
LA English
DT Article
DE Quantitative Imaging Network; Data sharing; Imaging informatics;
   Research informatics; Image repository; Image meta-data repository;
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Clinical data repository; System architecture

AB Introduction: The National Cancer Institute Quantitative Research Network (QIN) is a collaborative research network whose goal is to share data, algorithms and research tools to accelerate quantitative imaging research. A challenge is the variability in tools and analysis platforms used in quantitative imaging. Our goal was to understand the extent of this variation and to develop an approach to enable sharing data and to promote reuse of quantitative imaging data in the community.

Methods: We performed a survey of the current tools in use by the QIN member sites for representation and storage of their QIN research data including images, image meta-data and clinical data. We identified existing systems and standards for data sharing and their gaps for the QIN use case. We then proposed a system architecture to enable data sharing and collaborative experimentation within the QIN.

Results: There are a variety of tools currently used by each QIN institution. We developed a general information system architecture to support the QIN goals. We also describe the remaining architecture gaps we are developing to enable members to share research images and image meta-data across the network.

Conclusions: As a research network, the QIN will stimulate quantitative imaging research by pooling data, algorithms and research tools. However, there are gaps in current functional requirements that will need to be met by future informatics development. Special attention must be given to the technical requirements needed to translate these methods into the clinical research workflow to enable validation and qualification of these novel imaging biomarkers. (C) 2012 Elsevier Inc. All rights reserved.

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FU NIH/NCI [PAR-11-150]; NCI [HHSN261200800001E]; caBIG Imaging Workspace [98411XSB2]

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   Workspace contract no. 98411XSB2.
CR [Anonymous], CLIN TRIALS PROC
   [Anonymous], AIM TEMPL BUILD ATB
   [Anonymous], XNAT OP SOURC INF BI
   [Anonymous], CLEARCANVAS COMMUNIT
   Biomedical Informatics Research Network (BIRN), COND BIOM RES
   Bogaerts J, 2009, EUR J CANCER, V45, P248, DOI 10.1016/j.ejca.2008.10.027
   Boulton G, 2011, LANCET, V377, P1633, DOI 10.1016/S0140-6736(11)60647-8
   Buckler AJ, 2011, RADIOLOGY, V259, P875, DOI 10.1148/radiol.10100800
   Channin DS, 2009, RADIOLOGY, V253, P590, DOI 10.1148/radiol.2533090135
   Clunie DA, 2007, CANCER INFORM, V4, P33
   Korenblum D, 2011, J DIGIT IMAGING, V24, P739, DOI 10.1007/s10278-010-9328-z
   Lambin P, RADIOMICS EXTRACTING
   Moskowitz CS, 2009, EUR J CANCER, V45, P300, DOI 10.1016/j.ejca.2008.11.010
   Rubin Daniel L, 2008, AMIA Annu Symp Proc, P626
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wang FS, 2010, P SOC PHOTO-OPT INS, V7628, DOI 10.1117/12.843606
NR 16
TC 7
Z9 11
U1 0
U2 13
PU ELSEVIER SCIENCE INC
PI NEW YORK
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J9 MAGN RESON IMAGING
JI Magn. Reson. Imaging
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SI SI
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AU Becnel, LB
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TI Minireview: Progress and Challenges in Proteomics Data Management,
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SO MOLECULAR ENDOCRINOLOGY
LA English
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ID TANDEM MASS-SPECTROMETRY; DIFFERENCE GEL-ELECTROPHORESIS; CHICKEN
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PROGESTERONE-RECEPTOR; PROTEIN IDENTIFICATION DATA; HEMATOPOIETIC STEM-CELLS; AFFINITY TAG ICAT; PHOSPHORYLATION SITES; NEXT-GENERATION; GENE-EXPRESSION; BREAST-CANCER

AB The proteome represents the identity, expression levels, interacting partners, and posttranslational modifications of proteins expressed within any given cell. Proteomic studies aim to census the quantitative and qualitative factors regulating the biological relationships of proteins acting in concert as functional cellular networks. In the field of endocrinology, proteomics has been of considerable value in determining the function and mechanism of action of endocrine signaling molecules in the cell membrane, cytoplasm, and nucleus and for the discovery of proteins as candidates for clinical biomarkers. The volume of data that can be generated by proteomics methodologies, up to gigabytes of data within a few hours, brings with it its own logistical hurdles and presents significant challenges to realizing the full potential of these datasets. In this minireview, we describe selected current proteomics methodologies and their application in basic and translational endocrinology before focusing on mass spectrometry as a model for current progress and challenges in data analysis, management, sharing, and integration. (Molecular Endocrinology 26: 1660-1674, 2012)

C1 [Becnel, Lauren B.] Baylor Coll Med, Dept Med Hematol & Oncol, Houston, TX 77030 USA.
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CR Aebersold R, 2003, NATURE, V422, P198, DOI 10.1038/nature01511
Alban A, 2003, PROTEOMICS, V3, P36, DOI 10.1002/pmic.200390006
Apweiler R, 2012, NUCLEIC ACIDS RES, V40, pD71, DOI 10.1093/nar/gkr981
Atsriku C, 2009, MOL CELL PROTEOMICS, V8, P467, DOI 10.1074/mcp.M800282-MCP200
Bansal AD, 2010, J AM SOC NEPHROL, V21, P303, DOI 10.1681/ASN.2009070728
Berg D, 2012, J CELL PHYSIOL, V227, P204, DOI 10.1002/jcp.22718
Bitton DA, 2008, BMC BIOINFORMATICS, V9, DOI 10.1186/1471-2105-9-118
Border MB, 2012, MOL BIOSYST, V8, P1304, DOI 10.1039/c2mb05079j
Bradshaw RA, 2006, MOL CELL PROTEOMICS, V5, P787, DOI 10.1074/mcp.E600005-MCP200
Brody E N, 2000, J Biotechnol, V74, P5, DOI 10.1016/S1389-0352(99)00004-5
Carr S, 2004, MOL CELL PROTEOMICS, V3, P531, DOI 10.1074/mcp.T400006-MCP200
Charboneau Lu, 2002, Briefings in Functional Genomics & Proteomics, V1, P305, DOI 10.1093/bfgp/1.3.305
Chatterjee DK, 2008, PLOS ONE, V3, DOI 10.1371/journal.pone.0003265
Chen Jie, 2009, Cancer Genomics & Proteomics, V6, P331
Cochrane G, 2009, NUCLEIC ACIDS RES, V37, pD19, DOI 10.1093/nar/gkn765
Colinge J, 2004, PROTEOMICS, V4, P1977, DOI 10.1002/pmic.200300708
Craig R, 2004, BIOINFORMATICS, V20, P1466, DOI 10.1093/bioinformatics/bth092
Csosz E, 2012, J PROTEOMICS, V75, P2196, DOI 10.1016/j.jprot.2012.01.019
de Mol NJ, 2012, METHODS MOL BIOL, V800, P33, DOI 10.1007/978-1-61779-349-3_4
DENNER LA, 1987, J STEROID BIOCHEM, V27, P235, DOI 10.1016/0022-4731(87)90315-3
DENNER LA, 1990, J BIOL CHEM, V265, P16548
Dettmer K, 2007, MASS SPECTROM REV, V26, P51, DOI 10.1002/mas.20108

Deutsch EW, 2008, EMBO REP, V9, P429, DOI 10.1038/embor.2008.56
Deutsch EW, 2008, PHYSIOL GENOMICS, V33, P18, DOI 10.1152/physiolgenomics.00298.2007
Deutsch EW, 2010, PROTEOMICS, V10, P1150, DOI 10.1002/pmic.200900375
Dubrovska A, 2005, PROTEOMICS, V5, P4678, DOI 10.1002/pmic.200500002
ENG JK, 1994, J AM SOC MASS SPECTR, V5, P976, DOI 10.1016/1044-0305(94)80016-2
Faria-Campos A, 2011, BMC GENOMICS, V12, DOI 10.1186/1471-2164-12-S4-S15
FENN JB, 1989, SCIENCE, V246, P64, DOI 10.1126/science.2675315
Fondell JD, 1996, P NATL ACAD SCI USA, V93, P8329, DOI 10.1073/pnas.93.16.8329
Fugmann T, 2011, KIDNEY INT, V80, P272, DOI 10.1038/ki.2011.116
Gorg A, 2004, PROTEOMICS, V4, P3665, DOI 10.1002/pmic.200401031
Grottrup B, 2012, PROTEOMICS, V12, P356, DOI 10.1002/pmic.201290017
Gunaratne R, 2010, P NATL ACAD SCI USA, V107, P15653, DOI 10.1073/pnas.1007424107
Haab BB, 2001, GENOME BIOL, V2
Hall DA, 2004, SCIENCE, V306, P482, DOI 10.1126/science.1096773
He M, 2008, NAT METHODS, V5, P175, DOI [10.1038/nmeth.1178, 10.1038/NMETH.1178]
He MY, 2010, METHODS MOL BIOL, V615, P345, DOI 10.1007/978-1-60761-535-4_24
He MY, 2001, NUCLEIC ACIDS RES, V29, part. no., DOI 10.1093/nar/29.15.e73
Hu ZZ, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0020410
Hunter S, 2012, NUCLEIC ACIDS RES, V40, pD306, DOI 10.1093/nar/gkr948
Igarashi Y, 2009, NUCLEIC ACIDS RES, V37, pD611, DOI 10.1093/nar/gkn683
Improta G, 2011, J PROTEOME RES, V10, P3089, DOI 10.1021/pr200065t
Institute of Medicine, 2012, EV TRANSL OM LESS LE
James P, 1997, Q REV BIOPHYS, V30, P279, DOI 10.1017/S0033583597003399
James P, 2011, J PROTEOME RES, V10, P3311, DOI 10.1021/pr200632u
Jones AME, 2012, PROTEOMICS, V12, P340, DOI 10.1002/pmic.201290014
Jones P, 2010, METHODS MOL BIOL, V604, P297, DOI 10.1007/978-1-60761-444-9_20
Joyce AR, 2006, NAT REV MOL CELL BIO, V7, P198, DOI 10.1038/nrm1857
Kang UB, 2010, J PROTEOME RES, V9, P3750, DOI 10.1021/pr9011014
KARAS M, 1985, ANAL CHEM, V57, P2935, DOI 10.1021/ac00291a042
Keller A, 2005, MOL SYST BIOL, V1, DOI 10.1038/msb4100024
Kerrien S, 2007, BMC BIOL, V5, DOI 10.1186/1741-7007-5-44
Kim HJ, 2012, CLIN BIOCHEM, V45, P60, DOI 10.1016/j.clinbiochem.2011.10.006
Kim SH, 2005, BIOCHEM BIOPH RES CO, V330, P423, DOI 10.1016/j.bbrc.2005.02.173
Kinsinger CR, 2012, PROTEOMICS, V12, P11, DOI 10.1002/pmic.201100562
Kohlbacher O, 2007, BIOINFORMATICS, V23, pE191, DOI 10.1093/bioinformatics/btl299
Kosako H, 2009, NAT STRUCT MOL BIOL, V16, P1026, DOI 10.1038/nsmb.1656
Kruger M, 2008, P NATL ACAD SCI USA, V105, P2451, DOI 10.1073/pnas.0711713105
Lahesmaa-Korpinen AM, 2010, PROTEOMICS, V10, P3515, DOI 10.1002/pmic.200900727
Lam H, 2007, PROTEOMICS, V7, P655, DOI 10.1002/pmic.200600625
Lane L, 2012, NUCLEIC ACIDS RES, V40, pD76, DOI 10.1093/nar/gkr1179
Laserna EJ, 2009, MOL ENDOCRINOL, V23, P1799, DOI 10.1210/me.2009-0165
Lefkowitz RJ, 2004, TRENDS PHARMACOL SCI, V25, P413, DOI 10.1016/j.tips.2004.06.006
Listgarten J, 2005, MOL CELL PROTEOMICS, V4, P419, DOI 10.1074/mcp.R500005-MCP200
Ma ZQ, 2011, BIOINFORMATICS, V27, P3214, DOI 10.1093/bioinformatics/btr544
Malorni L, 2006, PROTEOMICS, V6, P5973, DOI 10.1002/pmic.200600333
Malovannaya A, 2011, CELL, V145, P787, DOI 10.1016/j.cell.2011.05.006
Marouga R, 2005, ANAL BIOANAL CHEM, V382, P669, DOI 10.1007/s00216-005-3126-3
Martens GA, 2010, PLOS ONE, V5, DOI 10.1371/journal.pone.0014214

Martens L, 2011, MOL CELL PROTEOMICS, V10, DOI 10.1074/mcp.R110.000133
Mendoza LG, 1999, BIOTECHNIQUES, V27, P778, DOI 10.2144/99274rr01
Mijalski T, 2005, P NATL ACAD SCI USA, V102, P8621, DOI 10.1073/pnas.0407672102
Monetti M, 2011, NAT METHODS, V8, P655, DOI [10.1038/nmeth.1647, 10.1038/NMETH.1647]
Moody MD, 2001, BIOTECHNIQUES, V31, P186, DOI 10.2144/01311dd03
Nakatani S, 2011, EXP DIABETES RES, DOI 10.1155/2011/979354
Nand A, 2012, PROTEIN CELL, V3, P84, DOI 10.1007/s13238-012-2012-y
Nelson EK, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-71
Nesvizhskii AI, 2007, NAT METHODS, V4, P787, DOI 10.1038/NMETH1088
Nilsen J, 2007, J NEUROSCI, V27, P14069, DOI 10.1523/JNEUROSCI.4391-07.2007
Nishizuka S, 2003, P NATL ACAD SCI USA, V100, P14229, DOI 10.1073/pnas.2331323100
Oberg AL, 2009, J PROTEOME RES, V8, P2144, DOI 10.1021/pr8010099
Ochsner SA, 2012, PHYSIOL GENOMICS, DOI [10.1152/physiolgenomics.00033, DOI 10.1152/PHYSIOLGENOMICS.00033]
Ochsner SA, 2008, NAT METHODS, V5, P991, DOI 10.1038/nmeth1208-991
Omenn GS, 2011, METHODS MOL BIOL, V696, P247, DOI 10.1007/978-1-60761-987-1_15
Ong Shao-En, 2007, Methods Mol Biol, V359, P37
Orchard S, 2003, PROTEOMICS, V3, P1374, DOI 10.1002/pmic.200300496
Orchard S, 2008, BRIEF BIOINFORM, V9, P166, DOI 10.1093/bib/bbm061
Orchard Sandra, 2007, Proteomics, V7 Suppl 1, P28, DOI 10.1002/pmic.200700286
Orchard Sandra, 2007, Proteomics, V7, P337, DOI 10.1002/pmic.200600915
Orchard S, 2007, NAT BIOTECHNOL, V25, P894, DOI 10.1038/nbt1324
Orchard S, 2012, NAT METHODS, V9, P345, DOI [10.1038/NMETH.1931, 10.1038/nmeth.1931]
Orchard S, 2012, PROTEOMICS, V12, P351, DOI 10.1002/pmic.201290016
Oyama M, 2011, J BIOL CHEM, V286, P818, DOI 10.1074/jbc.M110.156877
Pardo M, 2012, ENDOCRINE, V41, P374, DOI 10.1007/s12020-012-9617-z
Pedrioli PGA, 2004, NAT BIOTECHNOL, V22, P1459, DOI 10.1038/nbt1031
Perkins DN, 1999, ELECTROPHORESIS, V20, P3551, DOI 10.1002/(SICI)1522-2683(19991201)20:18<3551::AID-ELPS3551>3.0.CO;2-2
POWER RF, 1991, SCIENCE, V252, P1546, DOI 10.1126/science.2047861
Prasad TSK, 2009, METHODS MOL BIOL, V577, P67, DOI 10.1007/978-1-60761-232-2_6
Pratt B, 2012, BIOINFORMATICS, V28, P136, DOI 10.1093/bioinformatics/btr615
Punta M, 2012, NUCLEIC ACIDS RES, V40, pD290, DOI 10.1093/nar/gkr1065
Rachez C, 1998, GENE DEV, V12, P1787, DOI 10.1101/gad.12.12.1787
Ramachandran N, 2004, SCIENCE, V305, P86, DOI 10.1126/science.1097639
Ramachandran N, 2008, NAT METHODS, V5, P535, DOI 10.1038/NMETH.1210
Rhodes DR, 2007, NEOPLASIA, V9, P166, DOI 10.1593/neo.07112
Robertson MP, 2001, NAT BIOTECHNOL, V19, P650, DOI 10.1038/90256
Rodriguez H, 2009, J PROTEOME RES, V8, P3689, DOI 10.1021/pr900023z
Ruepp A, 2010, NUCLEIC ACIDS RES, V38, pD497, DOI 10.1093/nar/gkp914
Satoh M, 2009, J REPROD DEVELOP, V55, P316, DOI 10.1262/jrd.20217
SCHENA M, 1995, SCIENCE, V270, P467, DOI 10.1126/science.270.5235.467
She XW, 2004, NATURE, V431, P927, DOI 10.1038/nature03062
Sitaraman K, 2011, METHODS MOL BIOL, V723, P185, DOI 10.1007/978-1-61779-043-0_12
Smith BE, 2011, METHODS MOL BIOL, V696, P123, DOI 10.1007/978-1-60761-987-1_8
Souza TA, 2008, MOL ENDOCRINOL, V22, P2689, DOI 10.1210/me.2008-0290
Speer R, 2005, CURR OPIN MOL THER, V7, P240
Sreekumar A, 2001, CANCER RES, V61, P7585
Stark C, 2011, NUCLEIC ACIDS RES, V39, pD698, DOI 10.1093/nar/gkq1116
Steinberg XP, 2012, BIOCHEMISTRY-US, V51, P952, DOI 10.1021/bi201593q
Stoevesandt O, 2011, NEW BIOTECHNOL, V28, P282, DOI 10.1016/j.nbt.2010.09.004

```
   TANAKA K, 1988, RAPID COMMUN MASS SP, V2, P151, DOI DOI
10.1002/RCM.1290020802
   Tarallo R, 2011, PROTEOMICS, V11, P172, DOI 10.1002/pmic.201000217
   Taylor CF, 2007, NAT BIOTECHNOL, V25, P887, DOI 10.1038/nbt1329
   Thingholm TE, 2011, MOL CELL PROTEOMICS, V10, DOI 10.1074/mcp.M110.006650
   Tibes R, 2006, MOL CANCER THER, V5, P2512, DOI 10.1158/1535-7163.MCT-06-0334
   Trudgian DC, 2010, BIOINFORMATICS, V26, P1131, DOI
10.1093/bioinformatics/btq081
   Turinsky AL, 2010, DATABASE-OXFORD, DOI 10.1093/database/baq026
   Unwin RD, 2006, BLOOD, V107, P4687, DOI 10.1182/blood-2005-12-4995
   Viswanathan S, 2006, NAT PROTOC, V1, P1351, DOI 10.1038/nprot.2006.234
   Vitek O, 2009, PLOS COMPUT BIOL, V5, DOI 10.1371/journal.pcbi.1000366
   von Haller PD, 2003, MOL CELL PROTEOMICS, V2, P426, DOI 10.1074/mcp/D300002-
MCP200
   von Haller PD, 2003, MOL CELL PROTEOMICS, V2, P428, DOI 10.1074/mcp.M00041-
MCP200
   Wang PH, 2012, BIOINFORMATICS, V28, P1404, DOI 10.1093/bioinformatics/bts150
   Wilkins MR, 2006, PROTEOMICS, V6, P4, DOI 10.1002/pmic.200500856
   Wu CJ, 2011, J PROTEOME RES, V10, P1088, DOI 10.1021/pr100864b
   Zhang N, 2002, PROTEOMICS, V2, P1406, DOI 10.1002/1615-
9861(200210)2:10<1406::AID-PROT1406>3.0.CO;2-9
NR 135
TC 7
Z9 7
U1 0
U2 12
PU OXFORD UNIV PRESS INC
PI CARY
PA JOURNALS DEPT, 2001 EVANS RD, CARY, NC 27513 USA
SN 0888-8809
EI 1944-9917
J9 MOL ENDOCRINOL
JI Mol. Endocrinol.
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PY 2012
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IS 10
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AF Rahmouni, H. Boussi
   Solomonides, T.
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Mont, M. Casassa
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TI A Model-driven Privacy Compliance Decision Support for Medical Data Sharing in Europe
SO METHODS OF INFORMATION IN MEDICINE
LA English
DT Article
DE Privacy; EU data protection directive; healthgrid; Semantic Web technologies
ID CONFIDENTIALITY

AB Objectives: Clinical practitioners and medical researchers often have to share health data with other colleagues across Europe. Privacy compliance in this context is very important but challenging. Automated privacy guidelines are a practical way of increasing users' awareness of privacy obligations and help eliminating unintentional breaches of privacy. In this paper we present an ontology-plus-rules based approach to privacy decision support for the sharing of patient data across European platforms.

Methods: We use ontologies to model the required domain and context information about data sharing and privacy requirements. In addition, we use a set of Semantic Web Rule Language rules to reason about legal privacy requirements that are applicable to a specific context of data disclosure. We make the complete set invocable through the use of a semantic web application acting as an interactive privacy guideline system can then invoke the full model in order to provide decision support.

Results: When asked, the system will generate privacy reports applicable to a specific case of data disclosure described by the user. Also reports showing guidelines per Member State may be obtained.

Conclusion: The advantage of this approach lies in the expressiveness and extensibility of the modelling and inference languages adopted and the ability they confer to reason with complex requirements interpreted from high level regulations. However, the system cannot at this stage fully simulate the role of an ethics committee or review board.

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CR Beyleveld D, 2004, IMPLEMENTATION DATA
Breton V, 2005, ST HEAL T, V112, P249
Casassa Mont M., 2007, PRIME ARCHITECTURE V
*FOND RECH SANT QU, 2006, GOV FRAM DAT BANKS B
Horrocks I., 2004, SEMANTIC WEB RULE LA
*INF COMM OFF, 2010, GUID DAT PROT
Iversen A, 2006, BRIT MED J, V332, P165, DOI 10.1136/bmj.332.7534.165
Kalra D, 2005, METHOD INFORM MED, V44, P193
Mantas J, 2010, METHOD INFORM MED, V49, P105, DOI 10.3414/ME5119
McCullagh K., 2006, P 21 BILETA C GLOB H
McGuinness D. L., 2004, OWL WEB ONTOLOGY LAN
*PRIMELIFE, 2008, PRIV ID MAN EUR LIF
*PROT, 2010, PROT ONT ED KNOWL AC

```
   Rahman H. Ur, 2009, P 22 IEEE INT S COMP, P1
   Rahmouni HB, 2010, PHILOS T R SOC A, V368, P4057, DOI 10.1098/rsta.2010.0169
   Sandia National Labs, 2008, JESS RUL ENG JAV PLA
   Warren R, 2007, CLIN RADIOL, V62, P1044, DOI 10.1016/j.crad.2006.09.032
   2010, DATA SHARING INTELLE
   2008, CABIG DATA SHARING I
   2010, CABIG DOCUMENTATION
   2010, PRIVACY DECISSION SU
NR 21
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PU SCHATTAUER GMBH-VERLAG MEDIZIN NATURWISSENSCHAFTEN
PI STUTTGART
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WC Computer Science, Information Systems; Health Care Sciences & Services;
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AU Vallejo-Torres, L
   Morris, S
   Carr-Hill, R
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AF Vallejo-Torres, Laura
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TI Can regional resource shares be based only on prevalence data? An
   empirical investigation of the proportionality assumption
SO SOCIAL SCIENCE & MEDICINE
LA English
DT Article
DE Resource allocation formula; Epidemiological approach; Utilisation
   approach; Proportionality; Health care
ID RISK ADJUSTMENT; HEALTH; CAPITATION
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AB The needs component of the current formulae for allocating resources for hospital services and prescribing in England is based on a utilisation approach. This assumes that expenditure on NHS activity in different geographical areas reflects relative needs and supply conditions, and that these can be disentangled by regression models to yield an estimate of relative need. These assumptions have been challenged on the grounds that the needs of some groups may be systematically 'unmet'. Critics have suggested an alternative based on variations in the prevalence of health conditions, called the 'epidemiological approach'.

The epidemiological approach uses direct measures of morbidity to allocate health care resources. It divides the total national budget into disease programmes based on primary diagnosis, computes the proportion of total cases for each programme in each geographical area, and then allocates budgets to geographical areas proportional to their share of total cases. The main obstacle to the epidemiological approach has been seen as its very demanding data requirements. But it also faces methodological challenges. These centre on the assumption of proportionality which, at the area level to which resources will be allocated, requires that the average level of need for 'cases' within each disease programme is the same in every area.

We illustrate the epidemiological approach, and test the proportionality assumption underpinning it, using data from the 2002-2004 rounds of the Health Survey for England. We find regional variation in disease severity for major diseases, which suggests that health care needs for some conditions vary by area. Further analysis suggests that the epidemiological approach might systematically underallocate resources to rural areas, areas with younger populations, and deprived areas. Since the proportionality assumption underpinning the epidemiological approach does not hold, its adoption would fail to take account of variations in severity. This casts some doubt on the utility of the approach for resource allocation at the present time. (C) 2009 Elsevier Ltd. All rights reserved.

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OI Vallejo-Torres, Laura/0000-0001-5833-6066; Vallejo Torres, Laura/0000-0001-5833-6066; Sutton, Matt/0000-0002-6635-2127
FU Chief Scientist Office [HERU1]
CR Asthana S, 2004, SOC SCI MED, V58, P539, DOI 10.1016/S0277-9536(03)00217-X
ASTHANA S, 2008, RADICAL STAT, V98, P6
ASTHANA S, 2007, REV WEIGHTED CAPITAT
ASTHANA S, 2008, DEV RESOURCE ALLOCAT
ASTHANA S, 2006, NHS DEFICITS, V2
Chernichovsky D, 2003, HEALTH POLICY, V65, P1, DOI 10.1016/S0168-8510(02)00112-4
*DEP HLTH, 2005, PROGR BUDG DAT NAT P
*DEP HLTH, 2006, UN EXP BOOK
*DEP HLTH, 2007, EXPL NHS DEF 2003 04
Department of Health, 2008, RES ALL WEIGHT CAP F
*EUROQOL GROUP, 1990, HLTH POLICY, V16, P199, DOI DOI 10.1016/0168-8510(90)90421-9

```
   GRAVELLE H, 2003, HEALTH ECON, V12, P984
   MCCONNACHIE A, 2004, DERIVATION ADJUSTMEN
   *NAT ASS WAL HLTH, 2001, TARG POOR HLTH PROF
   NOBLE M, 2004, ENGL IND DEPR 2004
   *OFF NAT STAT, 2007, SUP OUTP AR MID POP
   *OFF NAT STAT, 2007, CENS ENGL WAL
   PARKIN N, 2001, CARE MONOGRAPH, V3
   Rice N, 2001, MILBANK Q, V79, P81, DOI 10.1111/1468-0009.00197
   Rice N., 1999, APPROACHES CAPITATIO
   Smith PC, 2001, J ROY STAT SOC A STA, V164, P217, DOI 10.1111/1467-985X.00200
   Stone M, 2006, J R STAT SOC A STAT, V169, P143, DOI 10.1111/j.1467-
985X.2005.00392.x
   Sutton M, 1999, SOC SCI MED, V49, P867, DOI 10.1016/S0277-9536(99)00169-0
   Sutton M, 2002, ALLOCATION RESOURCES
NR 24
TC 7
Z9 7
U1 0
U2 7
PU PERGAMON-ELSEVIER SCIENCE LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0277-9536
J9 SOC SCI MED
JI Soc. Sci. Med.
PD DEC
PY 2009
VL 69
IS 11
BP 1634
EP 1642
DI 10.1016/j.socscimed.2009.09.020
PG 9
WC Public, Environmental & Occupational Health; Social Sciences, Biomedical
SC Public, Environmental & Occupational Health; Biomedical Social Sciences
GA 528EO
UT WOS:000272424600011
PM 19819058
DA 2019-08-06
ER

PT J
AU Sieber, JE
AF Sieber, Joan E.
TI Introduction: Data sharing and disclosure limitation techniques
SO JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS
LA English
DT Editorial Material
AB THIS SPECIAL SECTION OF JERHRE is in response to the needs of institutions to
develop advanced data sharing capabilities. On October 1, 2003, the National
Institutes of Health (NIH) initiated a requirement that investigator-initiated
proposals for grants with direct costs over $500,000 in any year incorporate
plans to accommodate sharing research data. The requirement stipulates that such
plans describe the procedures through which shared data would be rendered "free
of identifiers that would permit linkages to individual research participants
and variables that could lead to deductive disclosure of the identity of
individual subjects." (http://grants2.nih.gov/grants/policy/data_sharing). We
expect that many researchers who deal with human research data are unfamiliar
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with the procedures presented in the ensuing articles. These sophisticated procedures have been developed to help protect confidentiality of subjects' data in files that are shared, while simultaneously preserving the analytic value of data for secondary users. Among these are procedures developed by government statisticians that include innovative methods to prevent deductive disclosure of identities. More recently, academic researchers and data experts have adapted or extended these methods. Together, these methods aim to achieve both disclosure limitation and retention of key analytic usefulness of the shared data.

CR ANDERSON M, 2000, LERE CHIFFRE SYSTEME, P105
   Fienberg S. E., 1985, SHARING RES DATA
   O'Rourke JM, 2006, J EMPIR RES HUM RES, V1, P63, DOI 10.1525/jer.2006.1.3.63
   ROBERTS L, 1990, SCIENCE, V148, P953
   Rodgers W, 2006, J EMPIR RES HUM RES, V1, P85, DOI 10.1525/jer.2006.1.3.85
   Sieber J. E, 1991, SHARING SOCIAL SCI D
   Trumbo Bruce E., 2002, LEARNING STAT REAL D
   Zarate AO, 2006, J EMPIR RES HUM RES, V1, P51, DOI 10.1525/jer.2006.1.3.51

NR 8
TC 7
Z9 7
U1 0
U2 0
PU UNIV CALIFORNIA PRESS
PI BERKELEY
PA C/O JOURNALS DIVISION, 2000 CENTER ST, STE 303, BERKELEY, CA 94704-1223
   USA
SN 1556-2646
J9 J EMPIR RES HUM RES
JI J. Empir. Res. Hum. Res. Ethics
PD SEP
PY 2006
VL 1
IS 3
BP 47
EP 49
DI 10.1525/jer.2006.1.3.47
PG 3
WC Ethics; Medical Ethics
SC Social Sciences - Other Topics; Medical Ethics
GA V44MO
UT WOS:000203007000006
PM 19385822
DA 2019-08-06
ER

PT S
AU Marcheschi, P
   Mazzarisi, A
   Dalmiani, S
   Benassi, A
AF Marcheschi, P
   Mazzarisi, A
   Dalmiani, S
   Benassi, A
GP IEEE
TI HL7 clinical document architecture to share cardiological images and
   structured data in next generation infrastructure
SO Computers in Cardiology 2004, Vol 31
SE COMPUTERS IN CARDIOLOGY

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LA English
DT Proceedings Paper
CT 31st Annual Scientific Meeting on Computers in Cardiology
CY SEP 19-22, 2004
CL Chicago, IL
SP IEEE, Natl Inst Hlth, Evanston NW Healthcare, European Soc Cardiol
AB In medicine and in cardiology different standards are used for treatment of
clinical and iconographic information. Among the most relevant there are HL7 for
clinical data and DICOM for images and signals. The advent of Electronic Health
Record Systems (EHR) and the request for data integration coming from different
imaging modalities and diagnostic instrumentation, offer us a technological
panorama difficult to manage. There is an increasing demand to select the most
meaningful information in a simple and effective way, without the duty and the
necessity to create from scratch new ways of data communication and sharing.
Hence an agreement, in order to be able to feed a new multidisciplinary
information databases, is necessary. To reach this goal, we used the emergent
development of HL7 in the field of the structure of Clinical Document
Architecture (CDA).
C1 CNR, Inst Clin Physiol, I-56100 Pisa, Italy.
RP Marcheschi, P (reprint author), CNR, Inst Clin Physiol, I-56100 Pisa, Italy.
CR Dolin RH, 2001, J AM MED INFORM ASSN, V8, P552, DOI
10.1136/jamia.2001.0080552
   FRAZIER P, 2001, STUDIES HLTH TECHNOL, V84
   Gosling J., 2000, JAVA LANGUAGE SPECIF
   HAROLD ER, 2001, PROCESSING XML JAVA
   Mazzarisi A, 2003, COMPUT CARDIOL, V30, P403, DOI 10.1109/CIC.2003.1291177
   MCLAUGHLIN B, JAVA XML
   PARISOT C, 2004, IHE IHE IT INFRASTRU
   ROCKWELL W, 2001, XML XSLT JAVA JSP CA
   EBXML TECHNICAL ARCH
   HL7 REFERENCE INFORM
NR 10
TC 7
Z9 8
U1 0
U2 3
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 0276-6574
BN 0-7803-8927-1
J9 COMPUT CARDIOL
PY 2004
VL 31
BP 617
EP 620
DI 10.1109/CIC.2004.1443014
PG 4
WC Cardiac & Cardiovascular Systems; Computer Science, Interdisciplinary
   Applications; Engineering, Biomedical; Peripheral Vascular Disease
SC Cardiovascular System & Cardiology; Computer Science; Engineering
GA BCK53
UT WOS:000229753800155
OA Green Published
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PT J
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```
AU Rahimzadeh, V
   Schickhardt, C
   Knoppers, BM
   Senecal, K
   Vears, DF
   Fernandez, CV
   Pfister, S
   Plon, S
   Terry, S
   Williams, J
   Williams, MS
   Cornel, M
   Friedman, J
AF Rahimzadeh, Vasiliki
   Schickhardt, Christoph
   Knoppers, Bartha M.
   Senecal, Karine
   Vears, Danya F.
   Fernandez, Conrad V.
   Pfister, Stefan
   Plon, Sharon
   Terry, Sharon
   Williams, Janet
   Williams, Marc S.
   Cornel, Martina
   Friedman, Janm.
TI Key Implications of Data Sharing in Pediatric Genomics
SO JAMA PEDIATRICS
LA English
DT Review
ID HEALTH-CARE; BIG; RECOMMENDATIONS; PRIVACY; CONSENT; SCIENCE; SYSTEM
AB Accurate clinical interpretation of children's whole-genome and whole-exome
sequences relies on comparing the patient's linked genomic and phenotypic data
with variant reference databases of both healthy and affected patients. The
robustness of such comparisons, in turn, is made possible by sharing pediatric
genomic and associated clinical data. Despite this, sparse ethical-legal policy
attention has been paid to making such sharing routine in practice. The
interdisciplinary Paediatric Task Team of the Global Alliance for Genomics and
Health considered in detail the current ethical, legal, and social implications
of sharing genomic and associated clinical data involving children. An initial
set of points to consider was presented at a meeting of the Paediatric Task Team
at the 4th Plenary of the Global Alliance for Genomics and Health. The Key
Implications for Data Sharing (KIDS) framework for pediatric genomics was
developed based on feedback from this group and was supplemented by findings
from a critical appraisal of the data-sharing literature. The final points to
consider that comprise the KIDS framework are categorized into the following 4
primary themes: children's involvement, parental consent, balancing benefits and
risks, and data protection and release requirements.
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RI Pfister, Stefan M/F-6860-2013
OI Pfister, Stefan M/0000-0002-5447-5322; Friedman, Jan/0000-0002-7482-9570
FU Canadian Institutes of Health Research Vanier Canada Graduate Scholarship [CIHR 359258]; Canada Research Chair in Law and Medicine; Can-SHARE; National Institutes of Health [5 U01 HG007436]; German Federal Ministry of Education and Research [01GP10404A]; Research Fund Flanders (Belgium); Ministere de l'Economie, de la Science et de l'Innovation du Quebec (Canada) [PSR-SIIRI-850]
FX This study was supported by Canadian Institutes of Health Research Vanier Canada Graduate Scholarship CIHR 359258, Canada Research Chair in Law and Medicine, Can-SHARE, grant 5 U01 HG007436 from the National Institutes of Health, grant 01GP10404A from the German Federal Ministry of Education and Research, Research Fund Flanders (Belgium), and grant PSR-SIIRI-850 from the Ministere de l'Economie, de la Science et de l'Innovation du Quebec (Canada)
CR Alahmad GH, 2014, E MEDITERR HEALTH J, V20, P681
Beskow LM, 2012, HUM GENET, V131, P1423, DOI 10.1007/s00439-012-1177-z
Bloss CS, 2013, GENOME MED, V5, DOI 10.1186/gm511
Brothers KB, 2013, PERS MED, V10, P349, DOI [10.2217/PME.13.34, 10.2217/pme.13.34]
Burton PR, 2015, BIOINFORMATICS, V31, P3241, DOI 10.1093/bioinformatics/btv279
Burton PR, 2009, INT J EPIDEMIOL, V38, P263, DOI 10.1093/ije/dyn147
Chambers DA, 2016, JAMA-J AM MED ASSOC, V315, P1941, DOI 10.1001/jama.2016.3867
Cho YJ, 2011, J CLIN ONCOL, V29, P1424, DOI 10.1200/JCO.2010.28.5148
Clayton EW, 2014, AM J BIOETHICS, V14, P3, DOI 10.1080/15265161.2013.879945
Council for International Organizations of Medical Sciences (CIOMS), 2016, INT ETH GUID HLTH RE
Craig DW, 2011, NAT REV GENET, V12, P730, DOI 10.1038/nrg3067
Dyke SOM, 2016, NPJ GENOM MED, V1, DOI 10.1038/npjgenmed.2016.24
Dyke SOM, 2016, PLOS GENET, V12, DOI 10.1371/journal.pgen.1005772
Eduardo R, 2015, J CLIN RES BIOETH, V6, P228, DOI [10.4172/2155-9627.1000228, DOI 10.4172/2155-9627.1000228]
Forrest CB, 2014, HEALTH AFFAIR, V33, P1171, DOI 10.1377/hlthaff.2014.0127
Green RC, 2016, AM J HUM GENET, V98, P1051, DOI 10.1016/j.ajhg.2016.04.011
Green RC, 2013, GENET MED, V15, P565, DOI 10.1038/gim.2013.73
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Heeney C, 2011, PUBLIC HEALTH GENOM, V14, P17, DOI 10.1159/000294150
Hens K, 2013, EUR J HUM GENET, V21, P2, DOI 10.1038/ejhg.2012.99
Hens K, 2011, EUR J HUM GENET, V19, P735, DOI 10.1038/ejhg.2011.29
Hens K, 2011, J PEDIATR-US, V158, P842, DOI 10.1016/j.jpeds.2010.12.036
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454

```
   Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
   Knoppers Bartha Maria, 2016, IRB, V38, P1
   Kosseim P, 2014, GENOME BIOL, V15, DOI 10.1186/s13059-014-0430-2
   Kranendonk EJ, 2017, EUR J PEDIATR, V176, P75, DOI 10.1007/s00431-016-2810-y
   Kranendonk EJ, 2016, EUR J HUM GENET, V24, P30, DOI 10.1038/ejhg.2015.59
   McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
   Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
   Philippakis AA, 2015, HUM MUTAT, V36, P915, DOI 10.1002/humu.22858
   Raza S, 2015, DATA SHARING SUPPORT
   Roski J, 2014, HEALTH AFFAIR, V33, P1115, DOI 10.1377/hlthaff.2014.0147
   Ross LF, 2008, AM J MED GENET C, V148C, P1, DOI 10.1002/ajmg.c.30162
   Shabani M, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002339
   Shringarpure SS, 2015, AM J HUM GENET, V97, P631, DOI
10.1016/j.ajhg.2015.09.010
   Stingone JA, 2017, CURR OPIN PEDIATR, V29, P231, DOI
10.1097/MOP.0000000000000467
   Tozzi AE, 2013, ORPHANET J RARE DIS, V8, DOI 10.1186/1750-1172-8-76
   United Nations General Assembly, 1989, UN CONV RIGHTS CHILD
   Watson MS, 2015, GENET MED, V17, DOI [10.1038/gim.2015.94,
10.1038/gim.2014.151]
   Wright CF, 2016, NAT REV GENET, V17, P1, DOI 10.1038/nrg.2015.5
NR 42
TC 6
Z9 6
U1 2
U2 3
PU AMER MEDICAL ASSOC
PI CHICAGO
PA 330 N WABASH AVE, STE 39300, CHICAGO, IL 60611-5885 USA
SN 2168-6203
EI 2168-6211
J9 JAMA PEDIATR
JI JAMA Pediatr.
PD MAY
PY 2018
VL 172
IS 5
BP 476
EP 481
DI 10.1001/jamapediatrics.2017.5500
PG 6
WC Pediatrics
SC Pediatrics
GA GF0RO
UT WOS:000431638900017
PM 29554172
DA 2019-08-06
ER

PT J
AU Sirven, N
   Rapp, T
AF Sirven, Nicolas
   Rapp, Thomas
TI The Dynamics of Hospital Use among Older People Evidence for Europe
   Using SHARE Data
SO HEALTH SERVICES RESEARCH
LA English
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DT Article

DE Demand for health; long-term care; frailty; health prevention; dynamic panel

ID HOUSEHOLD PANEL SURVEY; FRAILTY; CARE; HEALTH; DISABILITY; IMPACT; COSTS; LIFE

AB Objective. Hospital services use, which is a major driver of total health expenditures, is expected to rise over the next decades in Europe, especially because of population aging. The purpose of this article is to better understand the dynamics of older people's demand for hospital care over time in a cross-country setting.

Data source. We used data from the Survey on Health, Ageing, and Retirement in Europe (SHARE), in 10 countries between 2004 and 2011.

Study Design. We estimated a dynamic panel model of hospital admission for respondents aged 50 years or more.

Principal Findings. Following prior research, we found evidence of state dependence in hospital use over time. We also found that rise in frailty-among other health covariates- is a strong predictor of increased hospital use. Progression by one point on the frailty scale [0; 5] is associated with an additional risk of about 2.1 percent on average.

Conclusions. Our results support promotion of early detection of frailty in primary care, and improvement of coordination between actors within the health system, as potential strategies to reduce avoidable or unnecessary hospital use among frail elderly.

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RP Rapp, T (reprint author), Harvard TH Chan Sch Publ Hlth, Dept Hlth Policy & Management, Kresge 431-677 Huntington Ave, Boston, MA 02115 USA.

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FU SPRINTT project of the Innovative Medicines Initiative Joint Undertaking [115,621]; European Union; European Commission [QLK6-CT-2001-00360, RII-CT-2006-062193, CIT5-CT-2005-028857, CIT4-CT-2006-028812, 211909, 227822, 261982]; U.S. National Institute on Aging [U01 AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, R21 AG025169, Y1-AG-4553-01, IAG BSR06-11, OGHA 04-064]; German Ministry of Education and Research

FX The research leading to these results has received support from the SPRINTT project of the Innovative Medicines Initiative Joint Undertaking under grant Agreement number 115,621, resources of which are composed of financial contribution from the European Union's Seventh Framework Program (FP7/2007-2013) and EFPIA companies' "in kind contribution." This article uses data from SHARE wave 4 release 1.1.1, as of March 28, 2013 (DOI: 10.6103/SHARE.w4.111) or SHARE wave 1 and 2 release 2.6.0, as of November 29, 2013 (DOI: 10.6103/SHARE.w1.260 and 10.6103/SHARE.w2.260) or SHARELIFE release 1, as of November 24, 2010 (DOI: 10.6103/SHARE.w3.100). The SHARE data collection has been primarily funded by the European Commission through the 5th Framework Program (project QLK6-CT-2001-00360 in the thematic program Quality of Life), through the 6th Framework Program (projects SHARE-I3, RII-CT-2006-062193, COMPARE, CIT5-CT-2005-028857, and SHARELIFE, CIT4-CT-2006-028812) and through the 7th Framework Program (SHARE-PREP, NO. 211909, SHARE-LEAP, No. 227822 and SHARE M4, No. 261982). Additional funding from the U.S. National Institute on Aging (U01 AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, R21 AG025169, Y1-AG-4553-01, IAG BSR06-11, and OGHA 04-064) and the German Ministry of Education and Research as well as from various national sources is gratefully

```
   acknowledged (see www.share-project.org for a full list of funding
   institutions).
CR Bjorvatn A, 2013, EUR J HEALTH ECON, V14, P809, DOI 10.1007/s10198-012-0426-3
   Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
   Brunenberg DE, 2005, MED CARE, V43, P1018, DOI
10.1097/01.mlr.0000178266.75744.35
   Carlsen F, 2007, EUR J HEALTH ECON, V8, P17, DOI 10.1007/s10198-006-0001-x
   CHAMBERLAIN G, 1992, J BUS ECON STAT, V10, P20, DOI 10.2307/1391799
   Contoyannis P, 2004, J APPL ECONOMET, V19, P473, DOI 10.1002/jae.755
   De Lepeleire J, 2009, BRIT J GEN PRACT, V59, P364, DOI 10.3399/bjgp09X420653
   Dusheiko M, 2011, J HEALTH ECON, V30, P919, DOI
10.1016/j.jhealeco.2011.08.001
   Fiorentini G, 2011, EUR J HEALTH ECON, V12, P297, DOI 10.1007/s10198-010-
0230-x
   Fitzgerald J, 1998, J HUM RESOUR, V33, P300, DOI 10.2307/146434
   Forder J, 2009, HEALTH ECON, V18, P1322, DOI 10.1002/hec.1438
   Freedman VA, 2008, SOC SCI MED, V66, P1588, DOI
10.1016/j.socscimed.2007.11.037
   Fried LP, 2001, J GERONTOL A-BIOL, V56, pM146, DOI 10.1093/gerona/56.3.M146
   Fried LP, 2004, J GERONTOL A-BIOL, V59, P255
   Greenacre M., 2006, MULTIPLE CORRES ANAL
   Heckman J.J., 1981, INCIDENTAL PARAMETER
   Hughes D, 2003, J HEALTH ECON, V22, P999, DOI 10.1016/S0167-6296(03)00048-1
   Ilinca S, 2015, HEALTH SERV RES, V50, P305, DOI 10.1111/1475-6773.12211
   Kohn JL, 2013, HEALTH ECON, V22, P687, DOI 10.1002/hec.2845
   Lang PO, 2009, GERONTOLOGY, V55, P539, DOI 10.1159/000211949
   Lee Y., 2005, EC FINANCE WORKSHOP
   McAdams-DeMarco MA, 2013, J AM GERIATR SOC, V61, P896, DOI 10.1111/jgs.12266
   NIJMAN T, 1992, J APPL ECONOM, V7, P243, DOI 10.1002/jae.3950070303
   Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
   Santos-Eggimann B, 2009, J GERONTOL A-BIOL, V64, P675, DOI
10.1093/gerona/glp012
   Subra J, 2012, J NUTR HEALTH AGING, V16, P714, DOI 10.1007/s12603-012-0391-7
   Wooldridge JM, 2005, J APPL ECONOM, V20, P39, DOI 10.1002/jae.770
NR 27
TC 6
Z9 6
U1 0
U2 6
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0017-9124
EI 1475-6773
J9 HEALTH SERV RES
JI Health Serv. Res.
PD JUN
PY 2017
VL 52
IS 3
BP 1168
EP 1184
DI 10.1111/1475-6773.12518
PG 17
WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA EZ1OD
UT WOS:000404479400016
```

```
PM 27319798
OA Green Published
DA 2019-08-06
ER

PT J
AU Gibson, J
   Russ, TC
   Adams, MJ
   Clarke, TK
   Howard, DM
   Hall, LS
   Fernandez-Pujals, AM
   Wigmore, EM
   Hayward, C
   Davies, G
   Murray, AD
   Smith, BH
   Porteous, DJ
   Deary, IJ
   McIntosh, AM
AF Gibson, J.
   Russ, T. C.
   Adams, M. J.
   Clarke, T-K
   Howard, D. M.
   Hall, L. S.
   Fernandez-Pujals, A. M.
   Wigmore, E. M.
   Hayward, C.
   Davies, G.
   Murray, A. D.
   Smith, B. H.
   Porteous, D. J.
   Deary, I. J.
   McIntosh, A. M.
TI Assessing the presence of shared genetic architecture between
   Alzheimer's disease and major depressive disorder using genome-wide
   association data
SO TRANSLATIONAL PSYCHIATRY
LA English
DT Article
ID APOLIPOPROTEIN-E GENOTYPE; COMMUNITY-BASED COHORT; LATE-LIFE DEPRESSION;
   AGE-OF-ONSET; RISK-FACTOR; COGNITIVE DECLINE; TEMPORAL RELATIONSHIP;
   IDENTIFIES VARIANTS; FAMILY-HISTORY; SYMPTOMS
AB Major depressive disorder (MDD) and Alzheimer's disease (AD) are both common
in older age and frequently co-occur. Numerous phenotypic studies based on
clinical diagnoses suggest that a history of depression increases risk of
subsequent AD, although the basis of this relationship is uncertain. Both
illnesses are polygenic, and shared genetic risk factors could explain some of
the observed association. We used genotype data to test whether MDD and AD have
an overlapping polygenic architecture in two large population-based cohorts,
Generation Scotland's Scottish Family Health Study (GS:SFHS; N = 19 889) and UK
Biobank (N = 25 118), and whether age of depression onset influences any
relationship. Using two complementary techniques, we found no evidence that the
disorders are influenced by common genetic variants. Using linkage
disequilibrium score regression with genome-wide association study (GWAS)
summary statistics from the International Genomics of Alzheimer's Project, we
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report no significant genetic correlation between AD and MDD (r(G) = -0.103, P = 0.59). Polygenic risk scores (PRS) generated using summary data from International Genomics of Alzheimer's Project (IGAP) and the Psychiatric Genomics Consortium were used to assess potential pleiotropy between the disorders. PRS for MDD were nominally associated with participant-recalled AD family history in GS: SFHS, although this association did not survive multiple comparison testing. AD PRS were not associated with depression status or late-onset depression, and a survival analysis showed no association between age of depression onset and genetic risk for AD. This study found no evidence to support a common polygenic structure for AD and MDD, suggesting that the comorbidity of these disorders is not explained by common genetic variants.

C1 [Gibson, J.; Russ, T. C.; Adams, M. J.; Clarke, T-K; Howard, D. M.; Hall, L. S.; Fernandez-Pujals, A. M.; Wigmore, E. M.; McIntosh, A. M.] Univ Edinburgh, Ctr Clin Brain Sci, Div Psychiat, Edinburgh, Midlothian, Scotland.

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CR Allen N, 2012, HEALTH POLICY TECHN, V1, P123, DOI 10.1016/j.hlpt.2012.07.003
Alzheimer's Society, 2016, DEMENTIA
[Anonymous], 2015, NATURE, V523, P588
Becker JT, 2009, AM J GERIAT PSYCHIAT, V17, P653, DOI 10.1097/JGP.0b013e3181aad1fe
Berger AK, 1999, NEUROLOGY, V53, P1998, DOI 10.1212/WNL.53.9.1998
Bukh Jens Drachmann, 2011, Clin Pract Epidemiol Ment Health, V7, P140, DOI 10.2174/1745017901107010140
Bulik-Sullivan B, 2015, NAT GENET, V47, P1236, DOI 10.1038/ng.3406
Bulik-Sullivan BK, 2015, NAT GENET, V47, P291, DOI 10.1038/ng.3211
Chen PJ, 1999, ARCH GEN PSYCHIAT, V56, P261, DOI 10.1001/archpsyc.56.3.261
Cortes A, 2013, NAT GENET, V45, P730, DOI 10.1038/ng.2667
Dal Forno G, 2005, ANN NEUROL, V57, P381, DOI 10.1002/ana.20405
Devanand DP, 1996, ARCH GEN PSYCHIAT, V53, P175
Diniz BS, 2013, BRIT J PSYCHIAT, V202, P329, DOI 10.1192/bjp.bp.112.118307
Dudbridge F, 2013, PLOS GENET, V9, DOI 10.1371/journal.pgen.1003348
Euesden J, 2015, BIOINFORMATICS, V31, P1466, DOI 10.1093/bioinformatics/btu848
Fan PL, 2006, ACTA PSYCHIAT SCAND, V113, P48, DOI 10.1111/j.1600-0447.2005.00686.x
First M. B., 2002, STRUCTURED CLIN INTE
Flint J, 2014, NEURON, V81, P484, DOI 10.1016/j.neuron.2014.01.027
Galatzer-Levy IR, 2013, PERSPECT PSYCHOL SCI, V8, P651, DOI 10.1177/1745691613504115
Gatz JL, 2005, J GERONTOL A-BIOL, V60, P744, DOI 10.1093/gerona/60.6.744
Geda YE, 2006, ARCH NEUROL-CHICAGO, V63, P435, DOI 10.1001/archneur.63.3.435
Geerlings MI, 2000, BRIT J PSYCHIAT, V176, P568, DOI 10.1192/bjp.176.6.568
Green RC, 2003, ARCH NEUROL-CHICAGO, V60, P753, DOI 10.1001/archneur.60.5.753
Hamilton G, 2012, NEUROSCI LETT, V510, P6, DOI 10.1016/j.neulet.2011.12.059
Harold D, 2009, NAT GENET, V41, P1088, DOI 10.1038/ng.440
Holtzer R, 2005, J AM GERIATR SOC, V53, P2083, DOI 10.1111/j.1532-5415.2005.00535.x
Hyde CL, 2016, NAT GENET, V48, P1031, DOI 10.1038/ng.3623
Jorm AF, 2001, AUST NZ J PSYCHIAT, V35, P776, DOI 10.1046/j.1440-1614.2001.00967.x
Julian LJ, 2009, MULT SCLER, V15, P311, DOI 10.1177/1352458508099478
Kessler RC, 2005, ARCH GEN PSYCHIAT, V62, P593, DOI 10.1001/archpsyc.62.6.593
Kitzlerova E, 2007, NEUROENDOCRINOL LETT, V28, P832
Korczyn AD, 2009, J NEUROL SCI, V283, P139, DOI 10.1016/j.jns.2009.02.346
Lambert JC, 2013, NAT GENET, V45, P1452, DOI 10.1038/ng.2802
Lambert JC, 2009, NAT GENET, V41, P1094, DOI 10.1038/ng.439
Launer LJ, 2002, AGEING RES REV, V1, P61, DOI 10.1016/S0047-6374(01)00364-5
Lee HCB, 2003, BIOL PSYCHIAT, V54, P353, DOI 10.1016/S0006-3223(03)00543-2
Levinson DF, 2014, BIOL PSYCHIAT, V76, P510, DOI 10.1016/j.biopsych.2014.07.029
Li G, 2011, ARCH GEN PSYCHIAT, V68, P970, DOI 10.1001/archgenpsychiatry.2011.86
Liu JZ, 2017, NAT GENET, V49, P325, DOI 10.1038/ng.3766
Lubke GH, 2014, MOL PSYCHIATR, V19, P923, DOI 10.1038/mp.2013.109

Lubke GH, 2012, BIOL PSYCHIAT, V72, P707, DOI 10.1016/j.biopsych.2012.03.011
MacQueen G, 2011, MOL PSYCHIATR, V16, P252, DOI 10.1038/mp.2010.80
Maier R., 2014, CURR EPIDEMIOL REP, V1, P220, DOI DOI 10.1007/S40471-014-0023-3
Manchia M, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0076295
Mauricio M, 2000, AM J GERIAT PSYCHIAT, V8, P196, DOI 10.1176/appi.ajgp.8.3.196
MENDLEWICZ J, 1981, BRIT J PSYCHIAT, V139, P463, DOI 10.1192/bjp.139.5.463
Milaneschi Y, 2016, MOL PSYCHIATR, V21, P516, DOI 10.1038/mp.2015.86
Ownby RL, 2006, ARCH GEN PSYCHIAT, V63, P530, DOI 10.1001/archpsyc.63.5.530
Palla L, 2015, AM J HUM GENET, V97, P250, DOI 10.1016/j.ajhg.2015.06.005
Pedersen CB, 2014, JAMA PSYCHIAT, V71, P573, DOI 10.1001/jamapsychiatry.2014.16
Power RA, 2017, BIOL PSYCHIAT, V81, P325, DOI 10.1016/j.biopsych.2016.05.010
Purandare N, 2001, INT J GERIATR PSYCH, V16, P960, DOI 10.1002/gps.449
Purcell SM, 2009, NATURE, V460, P748, DOI 10.1038/nature08185
R Core Team, 2015, R LANG ENV STAT COMP
Ridge PG, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0079771
Saczynski JS, 2010, NEUROLOGY, V75, P35, DOI 10.1212/WNL.0b013e3181e62138
Schweitzer I, 2002, INT J GERIATR PSYCH, V17, P997, DOI 10.1002/gps.525
Smith BH, 2006, BMC MED GENET, V7, DOI 10.1186/1471-2350-7-74
Smith BH, 2013, INT J EPIDEMIOL, V42, P689, DOI 10.1093/ije/dys084
Smith DJ, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0075362
Sneed JR, 2011, AM J GERIAT PSYCHIAT, V19, P99, DOI 10.1097/JGP.0b013e318202fc8a
SPECK CE, 1995, EPIDEMIOLOGY, V6, P366, DOI 10.1097/00001648-199507000-00006
Stewart R, 2001, PSYCHOL MED, V31, P431
Sudlow C, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001779
Sullivan PF, 2013, MOL PSYCHIATR, V18, P497, DOI 10.1038/mp.2012.21
The British Psychological Society, 2013, PREV DEPR UK
Tozzi F, 2008, PSYCHOL MED, V38, P641, DOI 10.1017/S0033291707002681
Van Cauwenberghe C, 2016, GENET MED, V18, P421, DOI 10.1038/gim.2015.117
van der Sluis S, 2013, MOL PSYCHIATR, V18, P2, DOI 10.1038/mp.2012.65
Vermeer SE, 2003, NEW ENGL J MED, V348, P1215, DOI 10.1056/NEJMoa022066
Wilson RS, 2002, NEUROLOGY, V59, P364, DOI 10.1212/WNL.59.3.364
WINOKUR G, 1979, ARCH GEN PSYCHIAT, V36, P47
World Health Organization, 2016, DEPRESSION
Wray NR, 2012, MOL PSYCHIATR, V17, P36, DOI 10.1038/mp.2010.109
Zubenko GS, 1996, BIOL PSYCHIAT, V40, P1008, DOI 10.1016/S0006-3223(96)00046-7
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SE Annual Review of Genomics and Human Genetics
LA English
DT Review; Book Chapter
DE patents; data sharing; sociology of science; model organisms; knowledge
   commons; science policy
ID HUMAN-GENOME-PROJECT; EXPRESSED SEQUENCE TAGS; PROTEOMICS DATA RELEASE;
   INTERNATIONAL SUMMIT; SNP CONSORTIUM; PRIVACY; POLICY; BRCA; HISTORY;
   ACCESS
AB The Human Genome Project modeled its open science ethos on nematode biology,
most famously through daily release of DNA sequence data based on the 1996
Bermuda Principles. That open science philosophy persists, but daily, unfettered
release of data has had to adapt to constraints occasioned by the use of data
from individual people, broader use of data not only by scientists but also by
clinicians and individuals, the global reach of genomic applications and diverse
national privacy and research ethics laws, and the rising prominence of a
diverse commercial genomics sector. The Global Alliance for Genomics and Health
was established to enable the data sharing that is essential for making meaning
of genomic variation. Data-sharing policies and practices will continue to
evolve as researchers, health professionals, and individuals strive to construct
a global medical and scientific information commons.
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CR Adams MD, 2003, P NATL ACAD SCI USA, V100, P3025, DOI 10.1073/pnas.0637478100
   ADAMS MD, 1991, SCIENCE, V252, P1651, DOI 10.1126/science.2047873
   Adams MD, 1996, SCIENCE, V274, P534, DOI 10.1126/science.274.5287.534
   ADLER RG, 1992, SCIENCE, V257, P908, DOI 10.1126/science.1502557
   Anderlik MR, 2001, ANNU REV GENOM HUM G, V2, P401, DOI
10.1146/annurev.genom.2.1.401
```

ANDERSON A, 1992, SCIENCE, V256, P462
Angier N, 1994, NEW YORK TIMES 0920, pC3
Angrist M, 2009, PERS MED, V6, P691, DOI 10.2217/PME.09.48
Angrist Misha, 2010, HERE IS HUMAN BEING
Ankeny RA, J HIST BIOL IN PRESS
Ankeny Rachel A, 2015, POSTGENOMICS PERSPEC, P126
[Anonymous], 2014, NATURE, V507, P273
[Anonymous], 2011, PREC MED BUILD KNOWL
[Anonymous], 1998, SCIENCE, V282, P2012, DOI DOI 10.1126/SCIENCE.282.5396.2012
Arias JJ, 2015, J LAW BIOSCI, V2, P56, DOI 10.1093/jlb/lsu032
Baldwin AL, 2013, GENOME MED, V5, DOI 10.1186/gm412
Balter M, 1998, SCIENCE, V280, P30, DOI 10.1126/science.280.5360.30
Baylor Coll. Med, 2016, INF COMM
Bean LJH, 2013, HUM MUTAT, V34, P1183, DOI 10.1002/humu.22364
Bentley DR, 1996, SCIENCE, V274, P533, DOI 10.1126/science.274.5287.533
Bentley DR, 1998, TRENDS GENET, V14, P381, DOI 10.1016/S0168-9525(98)01591-1
Beroud C, 2016, HUM MUTAT, V37, P1318, DOI 10.1002/humu.23113
BRANDT KA, 1993, B MED LIBR ASSOC, V81, P285
Branscomb E, 2011, COMMUNICATION 1017
Branum R, 2015, J LAW MED ETHICS, V43, P576, DOI 10.1111/jlme.12301
Burris J, 1998, NAT GENET, V20, P333, DOI 10.1038/3803
Calia Kurt Geoffrey, 1992, BIOTECHNOL LAW REP, V11, P540
CANTOR CR, 1990, SCIENCE, V248, P49, DOI 10.1126/science.2181666
Cheon JY, 2014, GENOME MED, V6, DOI 10.1186/s13073-014-0121-3
Church GM, 2005, MOL SYST BIOL, V1, DOI 10.1038/msb4100040
Clarke L, 2012, NAT METHODS, V9, P1, DOI [10.1038/NMETH.1974, 10.1038/nmeth.1974]
Collins F, 1998, COMMUNICATION 0309
Collins F, 2012, COMMUNICATION 0412
Collins F, 1997, COMMUNICATION 0321
Collins FS, 2004, NATURE, V431, P931, DOI 10.1038/nature03001
Collins FS, 2003, NATURE, V422, P835, DOI 10.1038/nature01626
Consort. Law Values Health Environ. Life Sci, 2016, LAWSEQ BUILD SOUND L
Contreras J. L., 2011, MINN J L SCI TECH, V120, P61
Contreras JL, 2016, GEORGETOWN LAW J, V105, P1
Contreras JL, 2015, TRENDS GENET, V31, P55, DOI 10.1016/j.tig.2014.12.006
Cook-Deegan R, 2010, ANNU REV GENOM HUM G, V11, P383, DOI 10.1146/annurev-genom-082509-141811
Cook-Deegan Robert, 1994, GENE WARS SCI POLITI
Counc. Eur. Comm. Minist, 2006, REC REC 2006 4 COMM
Cozzarelli NR, 2004, P NATL ACAD SCI USA, V101, P3721, DOI 10.1073/pnas.0400437101
Curnutte MA, 2014, NAT BIOTECHNOL, V32, P980, DOI 10.1038/nbt.3030
Davies K, 1996, BREAKTHROUGH RACE FI
De Chadarevian Soraya, 2002, DESIGNS LIFE MOL BIO
DICKSON D, 1994, NATURE, V371, P365
Dove ES, 2015, J LAW MED ETHICS, V43, P675, DOI 10.1111/jlme.12311
Eggington JM, 2014, CLIN GENET, V86, P229, DOI 10.1111/cge.12315
Eisenberg RS, 2006, IND CORP CHANGE, V15, P1013, DOI 10.1093/icc/dtl025
Eisenberg Rebecca S, 1990, Emory Law J, V39, P721
Eisenberg RS, 1996, TRENDS BIOTECHNOL, V14, P302, DOI 10.1016/0167-7799(96)10040-8
Feingold EA, 2004, SCIENCE, V306, P636, DOI 10.1126/science.1105136
GarciaSancho M, 2012, SCI TECHNOL MED MOD, P1, DOI 10.1057/9780230370937
Gibbs RA, 2003, NATURE, V426, P789, DOI 10.1038/nature02168
Glob. Alliance Genom. Health, 2017, GLOB ALL
Glob. Alliance Genom. Health, 2013, CREAT GLOB ALL EN RE

Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN H
Goffeau A, 1996, SCIENCE, V274, P546, DOI 10.1126/science.274.5287.546
Gold ER, 2010, GENET MED, V12, pS39, DOI 10.1097/GIM.0b013e3181d72661
Greely HT, 2007, ANNU REV GENOM HUM G, V8, P343, DOI 10.1146/annurev.genom.7.080505.115721
Green ED, 2015, NATURE, V526, P29, DOI 10.1038/526029a
Guyer M, 1998, GENOME RES, V8, P413
HALL JM, 1990, SCIENCE, V250, P1684, DOI 10.1126/science.2270482
HARDIN G, 1968, SCIENCE, V162, P1243
Hardin G, 1998, SCIENCE, V280, P682, DOI 10.1126/science.280.5364.682
Harris R, 2001, CURR BIOL, V11, pR202, DOI 10.1016/S0960-9822(01)00104-X
Harrison SM, 2016, CURR PROTOC HUM GENE, V89, P1
Hawkins N, 2012, IIC-INT REV INTELL P, V43, P641
Hayden EC, 2014, NATURE, V507, P294, DOI 10.1038/507294a
HEALY B, 1992, NEW ENGL J MED, V327, P664, DOI 10.1056/NEJM199208273270930
Hess C, 2007, UNDERSTANDING KNOWLE
HILGARTNER S, 1994, KNOWLEDGE, V15, P355, DOI 10.1177/107554709401500401
Hilgartner Stephen, 1998, PRIVATE SCI BIOTECHN, P202
Holden AL, 2002, BIOTECHNIQUES, P22
Holtzman NA., 1989, P CAUTION PREDICTING
Holtzman NA, 1997, PROMOTING SAFE EFFEC
HUDSON TJ, 1995, SCIENCE, V270, P1945, DOI 10.1126/science.270.5244.1945
Istrail S, 2004, P NATL ACAD SCI USA, V101, P1916, DOI 10.1073/pnas.0307971100
Jasanoff S, 2011, BASIC BIOETH, P1
Jasanoff Sheila, 2005, DESIGNS NATURE SCI D
Joint Genome Inst, 2016, HIST
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Lander ES, 2001, NATURE, V409, P860, DOI 10.1038/35057062
Mailman MD, 2007, NAT GENET, V39, P1181
Manolio TA, 2007, NAT GENET, V39, P1045, DOI 10.1038/ng2127
Marshall E, 2001, SCIENCE, V291, P1192, DOI 10.1126/science.291.5507.1192
MARSHALL E, 1995, SCIENCE, V267, P783, DOI 10.1126/science.7846520
Martinell J., 1992, BIOTECHNOL LAW REP, V11, P578
Matthijs G, 2006, FAM CANCER, V5, P95, DOI 10.1007/s10689-005-2580-6
McElheny Victor K, 2010, DRAWING MAP LIFE INS
McGuire AL, 2010, ANNU REV GENOM HUM G, V11, P361, DOI 10.1146/annurev-genom-082509-141711
McKusick V. A., 1987, GENOMICS, V1, P1, DOI DOI 10.1016/0888-7543(87)90098-X
Merges Robert P., 1995, AIPLA Q J, V23, P1
MIKI Y, 1994, SCIENCE, V266, P66, DOI 10.1126/science.7545954
MURRAY JC, 1994, SCIENCE, V265, P2049, DOI 10.1126/science.8091227
Myers EW, 2002, P NATL ACAD SCI USA, V99, P4145, DOI 10.1073/pnas.092136699
National Research Council, 1988, MAPP SEQ HUM GEN
Natl.Hum.Genome Res.Inst.(NHGRI), 1996, NHGRI POL REG INT PR
Natl. Hum. Genome Res. Inst. (NHGRI), 2009, ENCODE CONS DAT REL
Natl. Hum. Genome Res. Inst. (NHGRI), 2000, NHGRI POL REL DAT DE
Natl. Hum. GenomeRes. Inst. (NHGRI), 1996, REP INT STRAT M HUM
Natl. Inst. Health (NIH), 2007, POL SHAR DAT OBR NIH
NIH, 2014, NIH GEN DAT SHAR POL
O'Neill G., 2009, LABONLINE 0403
OECD, 1980, OECD GUID PROT PRIV
Off. Technol. Assess, 1988, OTABA373
Office of Technology Assessment, 1984, OTABPBA32
Office of Technology Assessment, 1994, HUM GEN PROJ PAT DNA
Olson MV, 2002, J MOL BIOL, V319, P931, DOI 10.1016/S0022-2836(02)00333-9
OLSON MV, 1995, SCIENCE, V270, P394, DOI 10.1126/science.270.5235.394

Open Hum, 2016, OP HUM CONTR RES CIT
Organ. Econ. Coop. Dev. (OECD), 2013, OECD WORK PRIV
Organization for Economic Co-operation and Development (OECD), 2009, GUID HUM BIOB GEN RE
Ostrom AL, 2015, J SERV RES-US, V18, P127, DOI 10.1177/1094670515576315
OSTROM E, 1986, PUBLIC CHOICE, V48, P3
Ostrom E., 1993, I INCENTIVES SUSTAIN
Ostrom E, 1990, GOVERNING COMMONS EV
Ostrom E, 2010, CORNELL LAW REV, V95, P807
Park Sandra S., 2014, N C JL TECH, V15, P519
Parthasarathy Shobita, 2007, BUILDING GENETIC MED
Philippakis AA, 2015, HUM MUTAT, V36, P915, DOI 10.1002/humu.22858
Polski MM, 1999, W9827 WORKSH POL THE
Qiang BQ, 2004, J MOL MED, V82, P214, DOI 10.1007/s00109-003-0515-y
Ray T., 2015, GENOMEWEB 0505
Ray T., 2016, GENOMEWEB 1118
Ray T., 2014, GENOMEWEB 0806
Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
ROBERTS L, 1991, SCIENCE, V254, P184, DOI 10.1126/science.1925568
Rodriguez H, 2008, J PROTEOME RES, V7, P4609, DOI 10.1021/pr800779q
Rodriguez H, 2009, J PROTEOME RES, V8, P3689, DOI 10.1021/pr900023z
Rothstein MA, 2015, J LAW MED ETHICS, V43, P673, DOI 10.1111/jlme.12310
Saulnier KM, 2016, J LAW MED ETHICS, V44, P7, DOI 10.1177/1073110516644185
Schuler GD, 1996, SCIENCE, V274, P540, DOI 10.1126/science.274.5287.540
Secr. Advis. Comm. Genet. Health Soc. (SACGHS), 2008, US SYST OV GEN TEST
Sherkow JS, 2015, ANNU REV GENET, V49, P161, DOI 10.1146/annurev-genet-112414-054731
Shreeve J., 2004, GENOME WAR CRAIG VEN
Simoncelli Tania, 2015, Perspectives on Science, V23, P106, DOI 10.1162/POSC_a_00161
SMITH TF, 1990, GENOMICS, V6, P701, DOI 10.1016/0888-7543(90)90509-S
Spurdle AB, 2012, HUM MUTAT, V33, P2, DOI 10.1002/humu.21628
Stevens H, 2015, TECHNOL CULT, V56, P839, DOI 10.1353/tech.2015.0119
Strandburg Katherine J, 2017, GOVERNING MED KNOWLE
Strasser BJ, 2011, ISIS, V102, P60, DOI 10.1086/658657
Sulston J, 2011, COMMUNICATION 1115
THOMPSON L, 1993, SCIENCE, V259, P22
Thorisson GA, 2003, NUCLEIC ACIDS RES, V31, P124, DOI 10.1093/nar/gkg052
Thorogood A, 2015, J LAW MED ETHICS, V43, P690, DOI 10.1111/jlme.12312
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
UN Educ. Sci. Cult. Organ, 2005, UN DECL BIOETH HUM R
UN Educ. Sci. Cult. Organ, 2003, INT DECL HUM GEN DAT
UN General Assembly, 1948, UN DECL HUM RIGHTS
United Nations Educational Scientific and Cultural Organization, 1997, UN DECL HUM GEN HUM
Unterhuber R, 1997, NATURE, V387, P111, DOI 10.1038/387111a0
US Dep. Energy (DOE) Natl. Inst. Health (NIH), 1990, DOEER0452P, V90-1590
US Food and Drug Administration, 2016, US PUBL HUM GEN VAR
US Food and Drug Administration (FDA), 2017, DISC PAP LAB DEV TES
US Food Drug Admin. (FDA), 2014, DRAFT GUID IND FDA S
Vail PJ, 2015, J COMMUNITY GENET, V6, P351
van Zimmeren E, 2014, GENET SOC, P151
Varian Hal R., 2005, EC INFORM TECHNOLOGY
Venter JC, 1998, SCIENCE, V280, P1540, DOI 10.1126/science.280.5369.1540
Venter JC, 2001, SCIENCE, V291, P1304, DOI 10.1126/science.1058040
Waterston R, 1998, SCIENCE, V282, P53, DOI 10.1126/science.282.5386.53

```
   Waterston RH, 2002, P NATL ACAD SCI USA, V99, P3712, DOI
10.1073/pnas.042692499
   WATSON JD, 1953, COLD SPRING HARB SYM, V18, P123, DOI
10.1101/SQB.1953.018.01.020
   WATSON JD, 1990, SCIENCE, V248, P44, DOI 10.1126/science.2181665
   WATSON JD, 1953, NATURE, V171, P737, DOI 10.1038/171737a0
   Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
   Wellcome Trust, 2017, STAT GEN DAT REL
   Wellcome Trust, 2003, SHAR DAT LARG SCAL B
   Wellcome Trust Natl. Inst. Health (NIH) US Dep. Energy (DOE), 1998, 3 INT
STRAT M HUM GE
   Williams HL, 2013, J POLIT ECON, V121, P1, DOI 10.1086/669706
   Williamson AR, 1999, DRUG DISCOV TODAY, V4, P115, DOI 10.1016/S1359-
6446(99)01303-3
   Wilson RK, 1999, TRENDS GENET, V15, P51, DOI 10.1016/S0168-9525(98)01666-7
   WOOSTER R, 1994, SCIENCE, V265, P2088, DOI 10.1126/science.8091231
   WOOSTER R, 1995, NATURE, V378, P789, DOI 10.1038/378789a0
NR 177
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AF Cerliani, Leonardo
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TI Disentangling subgroups of participants recruiting shared as well as
   different brain regions for the execution of the verb generation task: A
   data-driven fMRI study
SO CORTEX
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LA English
DT Article
DE ICA; fMRI; Verb generation; Inter-subject variability
ID INDEPENDENT COMPONENT ANALYSIS; PRIMARY-PROGRESSIVE-APHASIA;
   RESTING-STATE NETWORKS; INTERSUBJECT VARIABILITY; ACTIVATION PATTERNS;
   PREFRONTAL CORTEX; COGNITIVE ANATOMY; READING ALOUD; CONNECTIVITY;
   DEGENERACY
AB The spatial pattern of task-related brain activity in fMRI studies might be expected to change according to several variables such as handedness and age. However this spatial heterogeneity might also be due to other unmodeled sources of inter-subject variability. Since group level results reflect patterns of task-evoked brain activity common to most of the subjects in the sample, they could conceal the presence of subgroups recruiting other brain regions beyond the common pattern. To deal with these issues, data-driven methods can be used to detect the presence of sources of inter-subject variability that might be hard to identify and therefore model a priori. Here we assess the potential of Independent Component Analysis (ICA) to detect the presence of unexpected subgroups of participants. To this end, we acquired task-evoked fMRI data on 45 healthy adults using the verb generation (VGEN) task, in which participants are visually presented with the noun of an object of everyday use, and asked to covertly generate a verb describing the corresponding action. As expected, the task elicited activity in a temporo-parieto-frontal network typically found in previous VGEN experiments. We then quantified the contribution of every subject to nine task-related spatio-temporal processes identified by ICA. A cluster analysis of this quantity yielded three subgroups of participants. Differences between the three identified subgroups were distributed in left and right prefrontal, posterior parietal and extrastriate occipital regions. These results could not be explained by differences in sex, age or handedness across the participants. Furthermore, some regions where a significant difference was found between subgroups were not present in the group-level pattern of task-related activity. We discuss the potential application of this approach for characterizing brain activity in different subgroups of patients with neuropsychiatric or neurological conditions. (C) 2016 Elsevier Ltd. All rights reserved.
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CR ANNETT M, 1970, BRIT J PSYCHOL, V61, P303, DOI 10.1111/j.2044-8295.1970.tb01248.x
Beckmann C. F., 2012, NEUROIMAGE
Beckmann CF, 2003, NEUROIMAGE, V20, P1052, DOI 10.1016/S1053-8119(03)00435-X
Beckmann CF, 2005, NEUROIMAGE, V25, P294, DOI 10.1016/j.neuroimage.2004.10.043
Beckmann CF, 2004, IEEE T MED IMAGING, V23, P137, DOI 10.1109/TMI.2003.822821
Beckmann CF, 2005, PHILOS T ROY SOC B, V360, P1001, DOI 10.1098/rstb.2005.1634
BECKMANN CF, 2003, 9 INT C FUNCT MAPP H, V19, pS985
Berlingeri M, 2008, COGN NEUROPSYCHOL, V25, P528, DOI 10.1080/02643290701674943
Bizzi A, 2008, RADIOLOGY, V248, P579, DOI 10.1148/radiol.2482071214
Catani M, 2013, BRAIN, V136, P2619, DOI 10.1093/brain/awt163
Catani M, 2012, CORTEX, V48, P273, DOI 10.1016/j.cortex.2011.12.001
Cerliani L, 2015, JAMA PSYCHIAT, V72, P767, DOI 10.1001/jamapsychiatry.2015.0101
Crescentini C, 2010, J COGNITIVE NEUROSCI, V22, P1140, DOI 10.1162/jocn.2009.21255
D'Esposito M, 2003, NAT REV NEUROSCI, V4, P863, DOI 10.1038/nrn1246
Damoiseaux JS, 2006, P NATL ACAD SCI USA, V103, P13848, DOI 10.1073/pnas.0601417103
Dehaene S, 2011, TRENDS COGN SCI, V15, P254, DOI 10.1016/j.tics.2011.04.003
Di Martino A, 2014, MOL PSYCHIATR, V19, P659, DOI 10.1038/mp.2013.78
Fair DA, 2012, P NATL ACAD SCI USA, V109, P6769, DOI 10.1073/pnas.1115365109
Filippini N, 2009, P NATL ACAD SCI USA, V106, P7209, DOI 10.1073/pnas.0811879106
Fox MD, 2005, P NATL ACAD SCI USA, V102, P9673, DOI 10.1073/pnas.0504136102
Friston KJ, 2003, TRENDS COGN SCI, V7, P151, DOI 10.1016/S1364-6613(03)00054-8
Gates KM, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0091322
Gorno-Tempini ML, 2004, ANN NEUROL, V55, P335, DOI 10.1002/ana.10825
Grezes J, 2001, HUM BRAIN MAPP, V12, P1, DOI 10.1002/1097-0193(200101)12:1<1::AID-HBM10>3.0.CO;2-V
Handwerker DA, 2004, NEUROIMAGE, V21, P1639, DOI 10.1016/j.neuroimage.2003.11.029
Holland SK, 2001, NEUROIMAGE, V14, P837, DOI 10.1006/nimg.2001.0875
HOLMES AP, 1998, NEUROIMAGE, V7, pS754, DOI DOI 10.1073/PNAS.1332441100
Horowitz-Kraus T, 2014, FRONT HUM NEUROSCI, V8, DOI 10.3389/fnhum.2014.00447
Hyvarinen A, 1999, IEEE T NEURAL NETWOR, V10, P626, DOI 10.1109/72.761722
Jafri MJ, 2008, NEUROIMAGE, V39, P1666, DOI 10.1016/j.neuroimage.2007.11.001
Jobard G, 2011, J NEUROLINGUIST, V24, P113, DOI 10.1016/j.jneuroling.2010.09.002
Karunanayaka P, 2011, FRONT SYST NEUROSCI, V5, DOI 10.3389/fnsys.2011.00029
Karunanayaka P, 2010, NEUROIMAGE, V51, P472, DOI 10.1016/j.neuroimage.2009.12.108
Kherif F, 2003, NEUROIMAGE, V20, P2197, DOI 10.1016/j.neuroimage.2003.08.018
Kherif F, 2009, J COGNITIVE NEUROSCI, V21, P654, DOI 10.1162/jocn.2009.21084
Leiguarda RC, 2000, BRAIN, V123, P860, DOI 10.1093/brain/123.5.860
Martin RC, 2006, PSYCHON B REV, V13, P396, DOI 10.3758/BF03193859
Mazoyer B, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0101165
McKeown MJ, 1998, P NATL ACAD SCI USA, V95, P803, DOI 10.1073/pnas.95.3.803
Miller MB, 2007, INT J PSYCHOPHYSIOL, V63, P205, DOI 10.1016/j.ijpsycho.2006.03.019
Miller MB, 2012, NEUROIMAGE, V59, P83, DOI 10.1016/j.neuroimage.2011.05.060
Minka T, 2000, 514 MIT MED LAB VIS
Newman MEJ, 2006, P NATL ACAD SCI USA, V103, P8577, DOI 10.1073/pnas.0601602103

Noppeney U, 2006, NEUROIMAGE, V30, P885, DOI 10.1016/j.neuroimage.2005.10.010
Noppeney U, 2004, J ANAT, V205, P433, DOI 10.1111/j.0021-8782.2004.00343.x
Persson J, 2004, NEUROIMAGE, V23, P1382, DOI 10.1016/j.neuroimage.2004.08.004
Picard N, 2001, CURR OPIN NEUROBIOL, V11, P663, DOI 10.1016/S0959-4388(01)00266-5
Poldrack RA, 2006, TRENDS COGN SCI, V10, P59, DOI 10.1016/j.tics.2005.12.004
Price CJ, 2002, TRENDS COGN SCI, V6, P416, DOI 10.1016/S1364-6613(02)01976-9
Pruim RHR, 2015, NEUROIMAGE, V112, P267, DOI 10.1016/j.neuroimage.2015.02.064
Rombouts SARB, 2005, NEUROIMAGE, V26, P1078, DOI 10.1016/j.neuroimage.2005.03.022
Rombouts SARB, 2009, HUM BRAIN MAPP, V30, P256, DOI 10.1002/hbm.20505
Salimi-Khorshidi G, 2014, NEUROIMAGE, V90, P449, DOI 10.1016/j.neuroimage.2013.11.046
Schippers MB, 2011, NEUROIMAGE, V57, P22, DOI 10.1016/j.neuroimage.2011.02.008
Seghier ML, 2008, NEUROIMAGE, V42, P1226, DOI 10.1016/j.neuroimage.2008.05.029
Smith SM, 2004, NEUROIMAGE, V23, pS208, DOI 10.1016/j.neuroimage.2004.07.051
Smith SM, 2015, NAT NEUROSCI, V18, P1565, DOI 10.1038/nn.4125
Smith SM, 2009, P NATL ACAD SCI USA, V106, P13040, DOI 10.1073/pnas.0905267106
Tavor I, 2016, SCIENCE, V352, P216, DOI 10.1126/science.aad8127
Thiebaut de Schotten M, 2011, NAT NEUROSCI, V14, P1245, DOI 10.1038/nn.2905
Thompson-Schill SL, 1999, NEURON, V23, P513, DOI 10.1016/S0896-6273(00)80804-1
Thompson-Schill SL, 1997, P NATL ACAD SCI USA, V94, P14792, DOI 10.1073/pnas.94.26.14792
Woolrich MW, 2009, NEUROIMAGE, V45, pS173, DOI 10.1016/j.neuroimage.2008.10.055
Woolrich MW, 2004, NEUROIMAGE, V21, P1732, DOI 10.1016/j.neuroimage.2003.12.023
Worsley KJ, 1996, HUM BRAIN MAPP, V4, P58, DOI 10.1002/(SICI)1097-0193(1996)4:1<58::AID-HBM4>3.0.CO;2-O

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TI Data Resource Profile: Cross-national and cross-study sociodemographic
and health-related harmonized domains from SAGE plus ELSA, HRS and SHARE
(SAGE+, Wave 1)
SO INTERNATIONAL JOURNAL OF EPIDEMIOLOGY
LA English
DT Article
ID COHORT PROFILE; PROJECT
AB Four longitudinal studies were included in this rigorous harmonization
process: the Study on global AGEing and adult health (SAGE); English
Longitudinal Study on Ageing (ELSA); US Health and Retirement Study (HRS); and
Survey of Health, Ageing and Retirement in Europe (SHARE). An ex-post harmonized
process was applied to nine health-related thematic domains (socio-demographic
and economic, health states, overall self-report of health and mental state,
health examinations, physical and mental performance tests, risk factors,
chronic conditions, social network and subjective well-being) for data from the
2004 wave of each study. Large samples of adults aged 50 years and older were
available from each study: SAGE, n = 18 886; ELSA, n = 9181; HRS, n = 19 303;
and SHARE, n = 29 917. The microdata, along with further details about the
harmonization process and all metadata, are available through the World Health
Organization (WHO) data archive at
[http://apps.who.int/healthinfo/systems/surveydata/index.php/catalog]. Further
information and enquiries can be made to [sagesurvey@who.int] or the
corresponding author. The data resource will continue to be updated with data
across additional waves of these surveys and new waves.
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```
CR Albala C, 2005, REV PANAM SALUD PUBL, V17, P307, DOI 10.1590/S1020-
49892005000500003
   Anstey KJ, 2010, INT J EPIDEMIOL, V39, P44, DOI 10.1093/ije/dyn276
   Banks J, 2006, JAMA-J AM MED ASSOC, V295, P2037, DOI 10.1001/jama.295.17.2037
   Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
   Crimmins EM, 2011, EUR J PUBLIC HEALTH, V21, P81, DOI 10.1093/eurpub/ckq022
   Hamilton CM, 2011, AM J EPIDEMIOL, V174, P253, DOI 10.1093/aje/kwr193
   Hense HW, 2011, INT J EPIDEMIOL, V40, P5, DOI 10.1093/ije/dyr002
   International Household Survey Network, 2012, MET STAND IHSN TECHN
   Kowal P, 2012, INT J EPIDEMIOL, V41, P1639, DOI 10.1093/ije/dys210
   Leonardi M, 2014, CLIN PSYCHOL PSYCHOT, V21, P193, DOI 10.1002/cpp.1856
   Marmot M, 2007, P2058 I FISC STUD NA
   Minicuci N, 2003, AGING CLIN EXP RES, V15, P187
   National Institute of Aging, 2007, GROW OLD AM HLTH RET
   National Institute on Aging, 2010, REG INT DIFF HLTH LO
   National Research Council, 2001, PREP AG WORLD CAS CR
   Sonnega A, 2014, INT J EPIDEMIOL, V43, P576, DOI 10.1093/ije/dyu067
   Steptoe A, 2013, INT J EPIDEMIOL, V42, P1640, DOI 10.1093/ije/dys168
   Suzman R, 2010, GLOBAL HEALTH ACTION, V3, P5, DOI 10.3402/gha.v3i0.5480
   WHO, 2014, GLOBAL STATUS REPORT ON VIOLENCE PREVENTION 2014, P1
   World Health Organization (WHO), 2011, GLOB REC PHYS ACT HL
NR 20
TC 6
Z9 6
U1 0
U2 2
PU OXFORD UNIV PRESS
PI OXFORD
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TI Managing information well: Toward an ontology-driven informatics
   platform for data sharing and secondary use in epilepsy self-management
   research centers
SO HEALTH INFORMATICS JOURNAL
LA English
DT Article
DE epilepsy; informatics; seizures; self-management
ID QUALITY-OF-LIFE; DEEP BRAIN-STIMULATION; DEPRESSION; INFRASTRUCTURE;
   PROGRAM
AB Epilepsy is a chronic neurological condition that requires active self-management to reduce personal and population burden. The Managing Epilepsy Well Network, funded by the US Centers for Disease Control and Prevention, conducts research on epilepsy self-management. There is an urgent need to develop an integrated informatics platform to maximize the secondary use of existing Managing Epilepsy Well Network data. We have implemented multiple steps to develop an informatics platform, including: (a) a survey of existing outcome data, (b) identification of common data elements, and (c) an integrated database using an epilepsy domain ontology to reconcile data heterogeneity. The informatics platform enables assessment of epilepsy self-management samples by site and in aggregate to support data interpretations for clinical care and ongoing epilepsy self-management research. The Managing Epilepsy Well informatics platform is expected to help advance epilepsy self-management, improve health outcomes, and has potential application in other thematic research networks.
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CR Aliasgharpour M, 2013, SEIZURE-EUR J EPILEP, V22, P48, DOI 10.1016/j.seizure.2012.10.005
Begley CE, 2000, EPILEPSIA, V41, P342, DOI 10.1111/j.1528-1157.2000.tb00166.x
Bodenreider O, 2011, AMIA ANN S, P2129
Bodenreider O, 2006, BRIEF BIOINFORM, V7, P256, DOI 10.1093/bib/bbl027
Boon P, 2007, EPILEPSIA, V48, P1551, DOI 10.1111/j.1528-1167.2007.01005.x
Centers for Disease Control and Prevention, BEH RISK FACT SURV S
Chaytor N, 2011, EPILEPSY BEHAV, V20, P545, DOI 10.1016/j.yebeh.2011.01.017
Ciechanowski P, 2010, EPILEPSY BEHAV, V19, P225, DOI 10.1016/j.yebeh.2010.06.003
Coleman MT, 2005, AM FAM PHYSICIAN, V72, P1503
Committee on the Public Health Dimensions of the Epilepsies, 2012, EPILEPSY SPECTRUM PR
Cramer JA, 1996, EPILEPSIA, V37, P577, DOI 10.1111/j.1528-1157.1996.tb00612.x
Cramer JA, 1998, EPILEPSIA, V39, P81, DOI 10.1111/j.1528-1157.1998.tb01278.x
Cui L, 2012, AM MED INF ASS AMIA
Dilorio C, 2009, PREV CHRONIC DIS, V6
Dilorio C, 2009, EPILEPSY BEHAV, V14, P232, DOI 10.1016/j.yebeh.2008.10.016
Dilorio CK, 2010, EPILEPSY BEHAV, V19, P218, DOI 10.1016/j.yebeh.2010.07.027
Doan AnHai, 2012, PRINCIPLEDATA INTE
Fielding RT, 2002, ACM T INTERNET TECHN, V2, P115, DOI DOI 10.1145/514183.514185
FISHER RS, 1993, NEUROLOGY, V43, pS12
Gadde S, 2012, NEUROINFORMATICS, V10, P19, DOI 10.1007/s12021-011-9119-9
Gershon RC, 2012, QUAL LIFE RES, V21, P475, DOI 10.1007/s11136-011-9958-8
Halevy A, 2006, P 32 INT C VER LARG
Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
Helmer KG, 2011, J AM MED INFORM ASSN, V18, P416, DOI 10.1136/amiajnl-2010-000032
Holdren J. P., 2010, REALIZING FULL POTEN
Holtzheimer PE, 2012, ARCH GEN PSYCHIAT, V69, P150, DOI 10.1001/archgenpsychiatry.2011.1456
Keator DB, 2009, METHODS MOL BIOL, V569, P1, DOI 10.1007/978-1-59745-524-4_1
Kellinghaus C, 2006, NERVENARZT, V77, P961, DOI 10.1007/s00115-006-2123-x
Lebo T., 2013, PROV O PROV ONTOLOGY
Loddenkemper T, 2005, EPILEPTIC DISORD, V7, P308
Loring DW, 2011, EPILEPSIA, V52, P1186, DOI 10.1111/j.1528-1167.2011.03018.x
National Institute of Neurological Disorders and Stroke (NINDS), MEAS QUAL LIF NEUR D
Nixon A, 2013, HEALTH QUAL LIFE OUT, V11, DOI 10.1186/1477-7525-11-38
Sahoo SS, 2014, J AM MED INFORM ASSN, V21, P263, DOI 10.1136/amiajnl-2013-002156
Sahoo SS, 2014, J AM MED INFORM ASSN, V21, P82, DOI 10.1136/amiajnl-2013-001696
Sahoo SS, 2013, EPILEPSIA, V54, P1335, DOI 10.1111/epi.12211
Sahoo SS, 2012, AM MED INF ASS AMIA
Shegog R, 2013, EPILEPSY BEHAV, V29, P133, DOI 10.1016/j.yebeh.2013.07.002
SHETH AP, 1990, COMPUT SURV, V22, P183

```
   Thompson A, 2010, J EVAL CLIN PRACT, V16, P520, DOI 10.1111/j.1365-
2753.2009.01153.x
   Thompson NJ, 2010, EPILEPSY BEHAV, V19, P247, DOI 10.1016/j.yebeh.2010.07.031
   Thurman DJ, 2011, EPILEPSIA, V52, P2, DOI 10.1111/j.1528-1167.2011.03121.x
   Zhang GQ, 2014, AM MED INF ASS AMIA
   Zhang Guo-Qiang, 2010, Summit Transl Bioinform, V2010, P76
NR 44
TC 6
Z9 6
U1 0
U2 19
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1460-4582
EI 1741-2811
J9 HEALTH INFORM J
JI Health Inform. J.
PD SEP
PY 2016
VL 22
IS 3
BP 548
EP 561
DI 10.1177/1460458215572924
PG 14
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA DU9NC
UT WOS:000382543400010
PM 25769938
DA 2019-08-06
ER

PT J
AU Schofield, PN
   Ward, JM
   Sundberg, JP
AF Schofield, Paul N.
   Ward, Jerrold M.
   Sundberg, John P.
TI Show and tell: disclosure and data sharing in experimental pathology
SO DISEASE MODELS & MECHANISMS
LA English
DT Article
DE Mouse; Histopathology; Data sharing; Peer review; Reproducibility
ID EXPERIMENTAL-DESIGN; GUT MICROBIOME; ANIMAL-MODELS; C57BL/6N MICE; MOUSE
   MODELS; MUTANT MICE; REPRODUCIBILITY; CANCER; HISTOPATHOLOGY; PHENOTYPES
AB Reproducibility of data from experimental investigations using animal models
is increasingly under scrutiny because of the potentially negative impact of
poor reproducibility on the translation of basic research. Histopathology is a
key tool in biomedical research, in particular for the phenotyping of animal
models to provide insights into the pathobiology of diseases. Failure to
disclose and share crucial histopathological experimental details compromises
the validity of the review process and reliability of the conclusions. We
discuss factors that affect the interpretation and validation of histopathology
data in publications and the importance of making these data accessible to
promote replicability in research.
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FU National Institutes of Health; Ellison Medical Foundation
FX Work in the authors' laboratories is funded by the National Institutes of Health and the Ellison Medical Foundation. No specific funding was received for this article.
CR Adissu HA, 2014, DIS MODEL MECH, V7, P515, DOI 10.1242/dmm.015263
   Baker D, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001756
   Barthold SW, 2004, GENETICA, V122, P75, DOI 10.1007/s10709-004-1439-3
   Begley CG, 2015, CIRC RES, V116, P116, DOI 10.1161/CIRCRESAHA.114.303819
   Begley CG, 2012, NATURE, V483, P531, DOI 10.1038/483531a
   Bentham J, 2010, HUM MOL GENET, V19, P3394, DOI 10.1093/hmg/ddq251
   Berndt A, 2014, VET PATHOL, V51, P846, DOI 10.1177/0300985813501335
   Beura LK, 2016, NATURE, V532, P512, DOI 10.1038/nature17655
   Buchler G, 2012, INFLAMM BOWEL DIS, V18, P943, DOI 10.1002/ibd.21895
   Bult CJ, 2015, NUCLEIC ACIDS RES, V43, pD818, DOI 10.1093/nar/gku987
   Campbell JH, 2012, ISME J, V6, P2033, DOI 10.1038/ismej.2012.54
   Coan PM, 2011, J PHYSIOL-LONDON, V589, P3659, DOI 10.1113/jphysiol.2011.208629
   Collins FS, 2014, NATURE, V505, P612, DOI 10.1038/505612a
   Ericsson AC, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0116704
   Florez-Vargas O, 2016, ELIFE, V5, DOI 10.7554/eLife.13615
   Freedman LP, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002165
   Garrett WS, 2007, CELL, V131, P33, DOI 10.1016/j.cell.2007.08.017
   Jorgensen BP, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0103398
   Justice MJ, 2016, DIS MODEL MECH, V9, P101, DOI 10.1242/dmm.024547
   Karp NA, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002151
   Kayagaki N, 2011, NATURE, V479, P117, DOI 10.1038/nature10558
   Kilkenny C, 2010, PLOS BIOL, V8, DOI 10.1371/journal.pbio.1000412
   Kilkenny C, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007824
   Kovacs A, 2011, MICROB ECOL, V61, P423, DOI 10.1007/s00248-010-9787-2
   Laukens D, 2016, FEMS MICROBIOL REV, V40, P117, DOI 10.1093/femsre/fuv036
   Li CCY, 2011, PLOS GENET, V7, DOI 10.1371/journal.pgen.1001380
   Li QL, 2014, LAB INVEST, V94, P623, DOI 10.1038/labinvest.2014.52
   Low BE, 2014, INVEST OPHTH VIS SCI, V55, P387, DOI 10.1167/iovs.13-13278
   Maggio-Price L, 2006, CANCER RES, V66, P828, DOI 10.1158/0008-5472.CAN-05-2448
   Mak IWY, 2014, AM J TRANSL RES, V6, P114
   Markle JGM, 2013, SCIENCE, V339, P1084, DOI 10.1126/science.1233521
   Mattapallil MJ, 2012, INVEST OPHTH VIS SCI, V53, P2921, DOI 10.1167/iovs.12-9662
   *NAT NEUR ED, 2009, NAT NEUROSCI, V12, P1075
   Newberry EP, 2015, AM J PHYSIOL-GASTR L, V309, pG648, DOI 10.1152/ajpgi.00170.2015
   Newman JV, 2001, J INFECT DIS, V184, P227, DOI 10.1086/321998
   Powell N, 2012, IMMUNITY, V37, P674, DOI 10.1016/j.immuni.2012.09.008
   POZZILLI P, 1993, IMMUNOL TODAY, V14, P193, DOI 10.1016/0167-5699(93)90160-M
   Reardon S, 2016, NATURE, V530, P264, DOI 10.1038/nature.2016.19335
   Reliene R, 2006, DNA REPAIR, V5, P651, DOI 10.1016/j.dnarep.2006.02.001
   Richter SH, 2009, NAT METHODS, V6, P257, DOI [10.1038/nmeth.1312, 10.1038/NMETH.1312]

```
   Schofield PN, 2010, VET PATHOL, V47, P1016, DOI 10.1177/0300985810374845
   Schofield PN, 2012, DIS MODEL MECH, V5, P19, DOI 10.1242/dmm.008334
   Schofield PN, 2009, NATURE, V461, P171, DOI 10.1038/461171a
   Scudamore CL, 2016, J PATHOL, V238, P359, DOI 10.1002/path.4642
   Simon MM, 2013, GENOME BIOL, V14, DOI 10.1186/gb-2013-14-7-r82
   Sundberg JP, 2016, VET PATHOL, V53, P456, DOI 10.1177/0300985815612556
   Sundberg JP, 2009, J INVEST DERMATOL, V129, P1599, DOI 10.1038/jid.2009.81
   Sundberg JP, 2011, PATHOBIOL AGING AGE, V1, P1, DOI DOI 10.3402/PBA.V1I0.7179
   Nguyen TLA, 2015, DIS MODEL MECH, V8, P1, DOI 10.1242/dmm.017400
   Treuting PM, 2012, VET PATHOL, V49, P44, DOI 10.1177/0300985811431446
   Vanden Berghe T, 2015, IMMUNITY, V43, P200, DOI 10.1016/j.immuni.2015.06.011
   Ward JM, 1997, TOXICOL PATHOL, V25, P590, DOI 10.1177/019262339702500608
   Warden CH, 2008, CELL METAB, V7, P277, DOI 10.1016/j.cmet.2008.03.014
NR 53
TC 6
Z9 6
U1 0
U2 6
PU COMPANY OF BIOLOGISTS LTD
PI CAMBRIDGE
PA BIDDER BUILDING CAMBRIDGE COMMERCIAL PARK COWLEY RD, CAMBRIDGE CB4 4DL,
   CAMBS, ENGLAND
SN 1754-8403
EI 1754-8411
J9 DIS MODEL MECH
JI Dis. Model. Mech.
PD JUN 1
PY 2016
VL 9
IS 6
BP 601
EP 605
DI 10.1242/dmm.026054
PG 5
WC Cell Biology; Pathology
SC Cell Biology; Pathology
GA DN5EG
UT WOS:000377088600002
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PT J
AU Joly, Y
   de Vries-Seguin, E
   Chalmers, D
   Ouellette, BFF
   Yamada, J
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   Knoppers, BM
AF Joly, Yann
   de Vries-Seguin, Emilie
   Chalmers, Don
   Ouellette, B. F. Francis
   Yamada, Joseph
   Bobrow, Martin
   Knoppers, Bartha M.
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CA ICGC Data Access Compliance Off
   ICGC Int Data Access Comm
TI Analysis of five years of controlled access and data sharing compliance
   at the International Cancer Genome Consortium
SO NATURE GENETICS
LA English
DT Letter
C1 [Joly, Yann; Knoppers, Bartha M.] McGill Univ, Fac Med, Ctr Genom & Policy,
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CR Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
   Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
   Rothstein MA, 2016, HASTINGS CENT REP, V46, P5, DOI 10.1002/hast.539
   Shabani M, 2015, EMBO MOL MED, V7, P507, DOI 10.15252/emmm.201405002
NR 4
TC 6
Z9 6
U1 0
U2 7
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1061-4036
EI 1546-1718
J9 NAT GENET
JI Nature Genet.
PD MAR
PY 2016
VL 48
IS 3
BP 224
EP 225
DI 10.1038/ng.3499
PG 2
WC Genetics & Heredity
SC Genetics & Heredity
GA DE8QW
UT WOS:000370902600002
PM 26906679
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PT J
AU Becnel, LB
   Pereira, S
   Drummond, JA
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Doddapaneni, HV
Hu, JH
Muzny, D
McGuire, AL
Wheeler, DA
Gibbs, RA
AF Becnel, Lauren B.
Pereira, Stacey
Drummond, Jennifer A.
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Muzny, Donna
McGuire, Amy L.
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Gibbs, Richard A.
TI An open access pilot freely sharing cancer genomic data from participants in Texas
SO SCIENTIFIC DATA
LA English
DT Article; Data Paper
ID INFORMED CONSENT; BIOBANKING

AB Genomic data sharing in cancer has been restricted to aggregate or controlled-access initiatives to protect the privacy of research participants. By limiting access to these data, it has been argued that the autonomy of individuals who decide to participate in data sharing efforts has been superseded and the utility of the data as research and educational tools reduced. In a pilot Open Access (OA) project from the CPRIT-funded Texas Cancer Research Biobank, many Texas cancer patients were willing to openly share genomic data from tumor and normal matched pair specimens. For the first time, genetic data from 7 human cancer cases with matched normal are freely available without requirement for data use agreements nor any major restriction except that end users cannot attempt to re-identify the participants (http://txcrb.org/open.html).

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FU Cancer Prevention Research in Texas (CPRIT) [RP101353]; NHGRI [U54 HG003273]; NCI/NIH as part of its Cancer Center Support Grant program [P30 CA125123]
FX We thank the patients and their families who participated in the Texas Cancer Research Biobank, Heidi Dowst and other members of the Texas Cancer Research Biobank, Divya Kalru and Walker Hale for assistance in submitting data to the SRA, Gerald Wright for assistance with the TCRB website and Narayanan Veeraraghavan, Andrew Carroll, Mike Lin and Singer Ma for revalidating with the Mercury pipeline the TCRB OA FASTQ files on

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   the DNAnexus cloud and hosting the FASTQ and BAM files in their
   cloudspace. This work was funded by the Cancer Prevention Research in
   Texas (CPRIT) through a multi-investigator research award RP101353, with
   some additional support from the NHGRI as part of its Genome Center
   program, U54 HG003273, and the NCI/NIH as part of its Cancer Center
   Support Grant program, P30 CA125123.
CR Bainbridge MN, 2011, GENOME BIOL, V12, DOI 10.1186/gb-2011-12-7-r68
   Ball MP, 2012, P NATL ACAD SCI USA, V109, P11920, DOI 10.1073/pnas.1201904109
   Becnel L., 2015, TCRB OPEN ACCESS REP
   Becnel L., 2015, NCBI SEQUENCE READ A
   BERGLER JH, 1980, CLIN PHARMACOL THER, V27, P435, DOI 10.1038/clpt.1980.60
   Biankin AV, 2012, NATURE, V491, P399, DOI 10.1038/nature11547
   Cancer Genome Atlas Research Network, 2013, Nature, V499, P43, DOI
10.1038/nature12222
   Challis D, 2012, BMC BIOINFORMATICS, V13, DOI 10.1186/1471-2105-13-8
   Dove ES, 2015, EUR J HUM GENET, V23, P1271, DOI 10.1038/ejhg.2014.196
   Dowst H, 2015, BIOINFORMATICS, V31, P1655, DOI 10.1093/bioinformatics/btv012
   Forbes SA, 2015, NUCLEIC ACIDS RES, V43, pD805, DOI 10.1093/nar/gku1075
   Green ED, 2011, NATURE, V470, P204, DOI 10.1038/nature09764
   Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Honeyman JN, 2014, SCIENCE, V343, P1010, DOI 10.1126/science.1249484
   Joffe S, 2001, LANCET, V358, P1772, DOI 10.1016/S0140-6736(01)06805-2
   Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
   McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
   Reid JG, 2014, BMC BIOINFORMATICS, V15, DOI 10.1186/1471-2105-15-30
   Robinson JO, 2013, J EMPIR RES HUM RES, V8, P42, DOI 10.1525/jer.2013.8.4.42
   Rodriguez LL, 2013, SCIENCE, V339, P275, DOI 10.1126/science.1234593
   Schaeffer MH, 1996, AM J MED, V100, P261, DOI 10.1016/S0002-9343(97)89483-1
   SCHULTZ AL, 1975, WESTERN J MED, V123, P76
   Shen YF, 2010, GENOME RES, V20, P273, DOI 10.1101/gr.096388.109
   Sherry ST, 2001, NUCLEIC ACIDS RES, V29, P308, DOI 10.1093/nar/29.1.308
   Simeon-Dubach D, 2014, CLIN BIOCHEM, V47, P300, DOI
10.1016/j.clinbiochem.2013.12.018
   Song S, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0045835
   Wang K, 2010, NUCLEIC ACIDS RES, V38, DOI 10.1093/nar/gkq603
   Ye K, 2009, BIOINFORMATICS, V25, P2865, DOI 10.1093/bioinformatics/btp394
NR 29
TC 6
Z9 6
U1 0
U2 2
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 2052-4463
J9 SCI DATA
JI Sci. Data
PD FEB 16
PY 2016
VL 3
AR UNSP 160010
DI 10.1038/sdata.2016.10
PG 10
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA EF3GH
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PT J
AU Chambers, DA
   Rupp, A
AF Chambers, David A.
   Rupp, Agnes
TI Sharing State Mental Health Data for Research: Building Toward Ongoing
   Learning in Mental Health Care Systems
SO ADMINISTRATION AND POLICY IN MENTAL HEALTH AND MENTAL HEALTH SERVICES
   RESEARCH
LA English
DT Article
DE Mental health; Health services research; State data; Data pooling
AB With the rise of "big data," the opportunities to use administrative and
clinical data to evaluate impact of state level program initiatives are greatly
expanded. The National Institute of Mental Health has in recent years supported
research studies pooling data across states to address state-relevant questions.
This commentary summarizes these activities and describes future platforms that
may enhance ongoing work in this area.
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RI PAN, ZEQIANG/X-6341-2018
CR Hoagwood KE, 2016, ADM POLICY MENT HLTH, V43, P67, DOI 10.1007/s10488-014-
0620-y
   National Institute of Mental Health, 2008, RFA MH 09 050 US POO
   The National Advisory Mental Health Council's Services Research and Clinical
Epidemiology Workgroup, 2006, ROAD AH RES PARTN TR
NR 3
TC 6
Z9 6
U1 0
U2 7
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0894-587X
EI 1573-3289
J9 ADM POLICY MENT HLTH
JI Adm. Policy. Ment. Health
PD SEP
PY 2015
VL 42
IS 5
BP 586
EP 587
DI 10.1007/s10488-015-0624-2
PG 2
WC Health Policy & Services; Public, Environmental & Occupational Health
SC Health Care Sciences & Services; Public, Environmental & Occupational
   Health
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GA CP7SW
UT WOS:000360089400007
PM 25583270
DA 2019-08-06
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PT S
AU Hochedlinger, N
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   Hayn, D
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   Tsiknakis, M
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AF Hochedlinger, Nina
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   Koumakis, Lefteris
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BE Hayn, D
   Schreier, G
   Ammenwerth, E
   Horbst, A
TI Standardized Data Sharing in a Paediatric Oncology Research Network - A
   Proof-of-Concept Study
SO EHEALTH2015 - HEALTH INFORMATICS MEETS EHEALTH: INNOVATIVE HEALTH
   PERSPECTIVES: PERSONALIZED HEALTH
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 9th Scientific eHealth Conference
CY JUN 18-19, 2015
CL Vienna, AUSTRIA
DE Paediatric Oncology; XSLT; Interoperability; Clinical Trial;
   Standardisation; Secondary Use; Biobanking
ID PLATFORM
AB Data that has been collected in the course of clinical trials are potentially
valuable for additional scientific research questions in so called secondary use
scenarios. This is of particular importance in rare disease areas like
paediatric oncology. If data from several research projects need to be connected,
so called Core Datasets can be used to define which information needs to be
extracted from every involved source system. In this work, the utility of the
Clinical Data Interchange Standards Consortium (CDISC) Operational Data Model
(ODM) as a format for Core Datasets was evaluated and a web tool was developed
which received Source ODM XML files and - via Extensible Stylesheet Language
Transformation (XSLT) - generated standardized Core Dataset ODM XML files. Using
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this tool, data from different source systems were extracted and pooled for
joined analysis in a proof-of-concept study, facilitating both, basic syntactic
and semantic interoperability.
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FU European Union's Seventh Framework Programme [HEALTH-F2-2011-261474]
FX The research leading to these results has received funding from the
   European Union's Seventh Framework Programme for research, technological
   development and demonstration under grant agreement no
   HEALTH-F2-2011-261474 (ENCCA).
CR Gartner R, 2011, J DIGITAL INFORM
   Gaze MN, 2010, RADIOTHER ONCOL, V97, P593, DOI 10.1016/j.radonc.2010.08.017
   Hayat M. A., 2012, NEUROBLASTOMA DIAGNO
   Kay M., 2008, XSLT 2 0 XPATH 2 0 P
   Muilu J, 2007, EUR J HUM GENET, V15, P718, DOI 10.1038/sj.ejhg.5201850
   Nitzlnader M., 2014, THESIS
   Nitzlnader M., 2015, ARCHITECTURE ADV BIO
   Nitzlnader M, 2014, STUD HEALTH TECHNOL, V198, P211, DOI 10.3233/978-1-61499-
397-1-211
   Norlin L, 2012, BIOPRESERV BIOBANK, V10, P343, DOI 10.1089/bio.2012.0003
   Pialorsi P., 2013, MICROSOFT SHAREPOINT
   Schreier G, 2009, FRONT BIOSCI-LANDMRK, V14, P2738, DOI 10.2741/3410
   Stenzhorn H, 2010, STUD HEALTH TECHNOL, V160, P1090, DOI 10.3233/978-1-60750-
588-4-1090
   Vassal G, 2015, EUR J CANCER, V51, P218, DOI 10.1016/j.ejca.2014.10.029
   Wright S., 2013, PROSHAREPOINT 2013 A
NR 14
TC 6
Z9 6
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
EI 1879-8365
BN 978-1-61499-524-1; 978-1-61499-523-4
J9 STUD HEALTH TECHNOL
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BL6LT
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PM 26063254
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DA 2019-08-06
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PT J
AU Sorani, MD
   Yue, JK
   Sharma, S
   Manley, GT
   Ferguson, AR
   Cooper, SR
   Dams-O'Connor, K
   Gordon, WA
   Lingsma, HF
   Maas, AIR
   Menon, DK
   Morabito, DJ
   Mukherjee, P
   Okonkwo, DO
   Puccio, AM
   Valadka, AB
   Yuh, EL
AF Sorani, Marco D.
   Yue, John K.
   Sharma, Sourabh
   Manley, Geoffrey T.
   Ferguson, Adam R.
   Cooper, Shelly R.
   Dams-O'Connor, Kristen
   Gordon, Wayne A.
   Lingsma, Hester F.
   Maas, Andrew I. R.
   Menon, David K.
   Morabito, Diane J.
   Mukherjee, Pratik
   Okonkwo, David O.
   Puccio, Ava M.
   Valadka, Alex B.
   Yuh, Esther L.
CA TRACK TBI Investigators
TI Genetic Data Sharing and Privacy
SO NEUROINFORMATICS
LA English
DT Editorial Material
DE Data; Privacy; Genetic; Biospecimen; Biobank; Sharing
ID TRAUMATIC BRAIN-INJURY; ELECTRONIC HEALTH RECORD; DE-IDENTIFICATION;
   MEDICAL-RECORDS; RESEARCH PURPOSES; FUTURE; INFORMATION; ACCESS; RISK;
   REIDENTIFICATION
C1 [Sorani, Marco D.; Yue, John K.; Sharma, Sourabh; Manley, Geoffrey T.;
Ferguson, Adam R.; Cooper, Shelly R.; Dams-O'Connor, Kristen; Gordon, Wayne A.;
Lingsma, Hester F.; Maas, Andrew I. R.; Menon, David K.; Morabito, Diane J.;
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FU NINDS NIH HHS [NS069409-02S1, NS069409, U01 NS086090, RC2 NS069409, NS067092, NS069537]; National Institute for Health Research [NF-SI-0512-10090]

CR Aberdeen J, 2010, INT J MED INFORM, V79, P849, DOI 10.1016/j.ijmedinf.2010.09.007
Acquisti A, 2009, P NATL ACAD SCI USA, V106, P10975, DOI 10.1073/pnas.0904891106
Amin W, 2008, BMC CANCER, V8, DOI 10.1186/1471-2407-8-236
Angrist M, 2013, NATURE, V494, P7, DOI 10.1038/494007a
Asslaber M, 2007, PATHOBIOLOGY, V74, P251, DOI 10.1159/000104453
Benitez K, 2010, J AM MED INFORM ASSN, V17, P169, DOI 10.1136/jamia.2009.000026
Braun R, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000668
Cassa CA, 2006, J AM MED INFORM ASSN, V13, P160, DOI 10.1197/jamia.M1920
Craig DW, 2011, NAT REV GENET, V12, P730, DOI 10.1038/nrg3067
Dams-O'Connor K, 2013, J NEUROTRAUM, V30, P2014, DOI 10.1089/neu.2013.3049
Diaz-Arrastia R, 2014, J NEUROTRAUM, V31, P19, DOI 10.1089/neu.2013.3040
Eguale Tewodros, 2005, AMIA Annu Symp Proc, P947
Franc MA, 2011, CLIN PHARMACOL THER, V89, P537, DOI 10.1038/clpt.2010.306
Friedlin FJ, 2008, J AM MED INFORM ASSN, V15, P601, DOI 10.1197/jamia.M2702
Furuta K, 2011, JPN J CLIN ONCOL, V41, P295, DOI 10.1093/jjco/hyq172
Glahn DC, 2013, P NATL ACAD SCI USA, V110, P19006, DOI 10.1073/pnas.1313735110
Gorgolewski KJ, 2013, FRONT NEUROSCI-SWITZ, V7, DOI 10.3389/fnins.2013.00009
Gostin LO, 2001, JAMA-J AM MED ASSOC, V285, P3015, DOI 10.1001/jama.285.23.3015
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hall W, 2004, ADDICT BEHAV, V29, P1481, DOI 10.1016/j.addbeh.2004.06.001
Huang LC, 2010, J MED SYST, V34, P313, DOI 10.1007/s10916-008-9243-8
Johnson SB, 2010, J AM MED INFORM ASSN, V17, P689, DOI 10.1136/jamia.2009.002063
Kao WT, 2010, P NATL ACAD SCI USA, V107, P15619, DOI 10.1073/pnas.1005410107
Kho ME, 2009, BMJ-BRIT MED J, V338, DOI 10.1136/bmj.b866
King T, 2012, INT J MED INFORM, V81, P279, DOI 10.1016/j.ijmedinf.2012.01.005
Landi William, 2003, AMIA Annu Symp Proc, P905
Lane J, 2010, HEALTH SERV RES, V45, P1456, DOI 10.1111/j.1475-6773.2010.01141.x
Lingsma HF, 2014, J NEUROTRAUMA
Liu J., 2009, AMIA ANN S P, P370
Loukides G, 2010, P NATL ACAD SCI USA, V107, P7898, DOI 10.1073/pnas.0911686107
Malin BA, 2005, J AM MED INFORM ASSN, V12, P28, DOI 10.1197/jamia.M1603
Malin B, 2007, ARTIF INTELL MED, V40, P223, DOI 10.1016/j.artmed.2007.04.002
Malin B, 2011, J AM MED INFORM ASSN, V18, P3, DOI 10.1136/jamia.2010.004622
Malin Bradley, 2006, AMIA Annu Symp Proc, P524
Mennes M, 2013, NEUROIMAGE, V82, P683, DOI 10.1016/j.neuroimage.2012.10.064
Meyer J, 2012, COMPUT METH PROG BIO, V107, P425, DOI 10.1016/j.cmpb.2010.12.016
Meystre SM, 2010, BMC MED RES METHODOL, V10, DOI 10.1186/1471-2288-10-70
Noumeir R, 2007, J DIGIT IMAGING, V20, P284, DOI 10.1007/s10278-006-1051-4
Poline JB, 2012, FRONT NEUROINFORM, V6, DOI 10.3389/fninf.2012.00009
Roden DM, 2008, CLIN PHARMACOL THER, V84, P362, DOI 10.1038/clpt.2008.89
Rodgers W, 2006, J EMPIR RES HUM RES, V1, P85, DOI 10.1525/jer.2006.1.3.85
Gonzalez DR, 2010, EUR RADIOL, V20, P1896, DOI 10.1007/s00330-010-1745-3
Scheuner MT, 2008, JAMA-J AM MED ASSOC, V299, P1320, DOI 10.1001/jama.299.11.1320

```
   Tamersoy Acar, 2010, AMIA Annu Symp Proc, V2010, P782
   Thomas SM, 2002, AMIA 2002 SYMPOSIUM, PROCEEDINGS, P777
   Van Horn JD, 2008, NEUROINFORMATICS, V6, P117, DOI 10.1007/s12021-008-9019-9
   Willison DJ, 2008, J MED ETHICS, V34, P308, DOI 10.1136/jme.2006.020032
   Yue JK, 2013, J NEUROTRAUM, V30, P1831, DOI 10.1089/neu.2013.2970
   Yuh EL, 2013, ANN NEUROL, V73, P224, DOI 10.1002/ana.23783
NR 49
TC 6
Z9 6
U1 2
U2 14
PU HUMANA PRESS INC
PI TOTOWA
PA 999 RIVERVIEW DRIVE SUITE 208, TOTOWA, NJ 07512 USA
SN 1539-2791
EI 1559-0089
J9 NEUROINFORMATICS
JI Neuroinformatics
PD JAN
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VL 13
IS 1
BP 1
EP 6
DI 10.1007/s12021-014-9248-z
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WC Computer Science, Interdisciplinary Applications; Neurosciences
SC Computer Science; Neurosciences & Neurology
GA AZ7UD
UT WOS:000348422200001
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OA Green Accepted
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PT J
AU Hawley, G
   Jackson, C
   Hepworth, J
   Wilkinson, SA
AF Hawley, Glenda
   Jackson, Claire
   Hepworth, Julie
   Wilkinson, Shelley A.
TI Sharing of clinical data in a maternity setting: How do paper hand-held
   records and electronic health records compare for completeness?
SO BMC HEALTH SERVICES RESEARCH
LA English
DT Article
DE Maternity; Shared-care; General practitioner (GP); Paper hand-held
   record (PHR); Electronic health record (EHR); Best Practice Variable
ID QUALITY
AB Background: Historically, the paper hand-held record (PHR) has been used for
sharing information between hospital clinicians, general practitioners and
pregnant women in a maternity shared-care environment. Recently in alignment
with a National e-health agenda, an electronic health record (EHR) was
introduced at an Australian tertiary maternity service to replace the PHR for
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collection and transfer of data. The aim of this study was to examine and compare the completeness of clinical data collected in a PHR and an EHR.

Methods: We undertook a comparative cohort design study to determine differences in completeness between data collected from maternity records in two phases. Phase 1 data were collected from the PHR and Phase 2 data from the EHR. Records were compared for completeness of best practice variables collected The primary outcome was the presence of best practice variables and the secondary outcomes were the differences in individual variables between the records.

Results: Ninety-four percent of paper medical charts were available in Phase 1 and 100% of records from an obstetric database in Phase 2. No PHR or EHR had a complete dataset of best practice variables. The variables with significant improvement in completeness of data documented in the EHR, compared with the PHR, were urine culture, glucose tolerance test, nuchal screening, morphology scans, folic acid advice, tobacco smoking, illicit drug assessment and domestic violence assessment (p = 0.001). Additionally the documentation of immunisations (pertussis, hepatitis B, varicella, fluvax) were markedly improved in the EHR (p = 0.001). The variables of blood pressure, proteinuria, blood group, antibody, rubella and syphilis status, showed no significant differences in completeness of recording.

Conclusion: This is the first paper to report on the comparison of clinical data collected on a PHR and EHR in a maternity shared-care setting. The use of an EHR demonstrated significant improvements to the collection of best practice variables. Additionally, the data in an EHR were more available to relevant clinical staff with the appropriate log-in and more easily retrieved than from the PHR. This study contributes to an under-researched area of determining data quality collected in patient records.

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FU Australian Postgraduate Scholarship (APA); Australian Primary Health Care Research Institute (APHCRI); National Health and Medical Research Council

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CR Australasian Diabetes in Pregnancy Society (ADIPS), ADIPS CONS GUID TEST
Batterham R, 2002, SOC SCI MED, V54, P1225, DOI 10.1016/S0277-9536(01)00092-2
CLEARY R, 1994, BRIT J OBSTET GYNAEC, V101, P1042, DOI 10.1111/j.1471-0528.1994.tb13579.x
Commonwealth of Australia, 2009, BUILD 21 CENT PRIM H
DAVID RJ, 1980, AM J PUBLIC HEALTH, V70, P964, DOI 10.2105/AJPH.70.9.964

```
   HAMILTON S G, 1956, Practitioner, V176, P79
   Hawley G, 2014, BMC PREGNANCY CHILDB, V14, DOI 10.1186/1471-2393-14-52
   Homer C, 2013, CLIN PRACTICE GUIDEL
   Homer C, 2011, CLIN PRACTI IN PRESS
   Lau R R, 1982, J Community Health, V7, P250, DOI 10.1007/BF01318958
   Mater Health Services and South East Alliance of General Practice, MAT MOTH
HOSP GP MAT
   Mikkelsen G, 2001, INT J MED INFORM, V63, P123, DOI 10.1016/S1386-
5056(01)00152-6
   Murray J, 2012, J PUBLIC HLTH OXF
   National Health and Medical Research Council (NHMRC), 2010, NAT GUID COLL MAT
CA
   National Institute for Health and Care Excellence (NICE), QUAL STAND ANT CAR
   National Institute for Health and Care Excellence (NICE), ANT CAR
   National Toxicology Program, 2011, Natl Toxicol Program Tech Rep Ser, P1
   New South Wales Department of Health, 2000, NSW FRAM MAT SERV
   O'Sullivan TA, 2011, NUTR DIET, V68, P179, DOI 10.1111/j.1747-
0080.2011.01525.x
   Roshanov PS, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-63
   Sullivan F, 2006, ABC HLTH INFORM
   Thoroddsen A, 2012, SCAND J CARING SCI
   WILLIAMS DRR, 1989, DIABETIC MED, V6, P320, DOI 10.1111/j.1464-
5491.1989.tb01172.x
NR 23
TC 6
Z9 6
U1 0
U2 15
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1472-6963
J9 BMC HEALTH SERV RES
JI BMC Health Serv. Res.
PD DEC 21
PY 2014
VL 14
AR 650
DI 10.1186/s12913-014-0650-x
PG 9
WC Health Care Sciences & Services
SC Health Care Sciences & Services
GA AZ7XA
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OA DOAJ Gold, Green Published
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PT J
AU May, SG
   Cheng, PH
   Tietbohl, CK
   Trujillo, L
   Reilly, K
   Frosch, DL
   Lin, GA
AF May, Suepattra G.
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Cheng, Peter H.
Tietbohl, Caroline K.
Trujillo, Laurel
Reilly, Kelly
Frosch, Dominick L.
Lin, Grace A.

TI Shared Medical Appointments to Screen for Geriatric Syndromes: Preliminary Data from a Quality Improvement Initiative

SO JOURNAL OF THE AMERICAN GERIATRICS SOCIETY

LA English

DT Article

DE shared medical appointments; dementia; depression; fall risk; patient education; geriatrics

ID EPIDEMIOLOGY; DEPRESSION; DEMENTIA; MOBILITY; VISITS; ACCESS; RISK; GO

AB Older adults are at greater risk of developing conditions that affect health outcomes, quality of life, and costs of care. Screening for geriatric conditions such as memory loss, fall risk, and depression may contribute to the prevention of adverse physical and mental comorbidities, unnecessary hospitalizations, and premature nursing home admissions. Because screening is not consistently performed in primary care settings, a shared medical appointment (SMA) program was developed to fill this gap in care. The goals of the program were to improve early identification of at-risk individuals and ensure appropriate follow-up for memory loss, fall risk, and depression; facilitate discussion about prevention, diagnosis, and treatment of these conditions; implement strategies to reduce risks for these conditions; and increase access to screening and expand preventive health services for older adults. Between August 2011 and May 2013, 136 individuals aged 60 and older participated in the program. Three case studies highlighting the psychosocial and physiological findings of participation in the program are presented. Preliminary data suggest that SMAs are an effective model of regularly screening at-risk older adults that augments primary care practice by facilitating early detection and referral for syndromes that may otherwise be missed or delayed.

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FU Informed Medical Decisions Foundation (IMDF); IMDF

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```
CR Aliyu MH, 2003, J NATL MED ASSOC, V95, P1158
   Ayoub WT, 2009, OSTEOPOROSIS INT, V20, P37, DOI 10.1007/s00198-008-0635-x
   Bartley KB, 2010, J CARDIOVASC NURS, V25, P13, DOI
10.1097/JCN.0b013e3181b8e82e
   Bronson DL, 2004, CLEV CLIN J MED, V71, P369, DOI 10.3949/ccjm.71.5.369
   Ebell MH, 2009, AM FAM PHYSICIAN, V79, P497
   Hendrie HC, 1998, AM J GERIAT PSYCHIAT, V6, pS3, DOI 10.1097/00019442-
199821001-00002
   Hibbard JH, 2004, HEALTH SERV RES, V39, P1005, DOI 10.1111/j.1475-
6773.2004.00269.x
   Jaber Raja, 2006, Fam Pract Manag, V13, P37
   Jaber R, 2006, J AM BOARD FAM MED, V19, P276, DOI 10.3122/jabfm.19.3.276
   KATZ S, 1983, J AM GERIATR SOC, V31, P721, DOI 10.1111/j.1532-
5415.1983.tb03391.x
   Kroenke K, 2001, J GEN INTERN MED, V16, P606, DOI 10.1046/j.1525-
1497.2001.016009606.x
   Lavoie JG, 2013, BMC HEALTH SERV RES, V13, DOI 10.1186/1472-6963-13-155
   LAWTON MP, 1969, GERONTOLOGIST, V9, P9, DOI 10.1093/geront/9.1.9
   Lenze EJ, 2007, J AM GERIATR SOC, V55, P81, DOI 10.1111/j.1532-
5415.2006.01017.x
   Perruccio AV, 2013, J GERONTOL A-BIOL, V68, P293, DOI 10.1093/gerona/gls151
   PODSIADLO D, 1991, J AM GERIATR SOC, V39, P142, DOI 10.1111/j.1532-
5415.1991.tb01616.x
   Reuben DB, 2003, J AM GERIATR SOC, V51, P1787, DOI 10.1046/j.1532-
5415.2003.51565.x
   Rubenstein LZ, 2006, AGE AGEING, V35, P37, DOI 10.1093/ageing/afl084
   Wall JC, 2000, J REHABIL RES DEV, V37, P109
   Wenger NS, 2003, ANN INTERN MED, V139, P740, DOI 10.7326/0003-4819-139-9-
200311040-00008
NR 20
TC 6
Z9 6
U1 0
U2 21
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0002-8614
EI 1532-5415
J9 J AM GERIATR SOC
JI J. Am. Geriatr. Soc.
PD DEC
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VL 62
IS 12
BP 2415
EP 2419
DI 10.1111/jgs.13142
PG 5
WC Geriatrics & Gerontology; Gerontology
SC Geriatrics & Gerontology
GA AW8FX
UT WOS:000346497600025
PM 25440111
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PT J
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AU Gasner, MR
   Fuld, J
   Drobnik, A
   Varma, JK
AF Gasner, M. Rose
   Fuld, Jennifer
   Drobnik, Ann
   Varma, Jay K.
TI Legal and Policy Barriers to Sharing Data Between Public Health Programs
   in New York City: A Case Study
SO AMERICAN JOURNAL OF PUBLIC HEALTH
LA English
DT Article
ID HIV; SURVEILLANCE; INTEGRATION; HEPATITIS; STD; TB
AB Integration of public health surveillance data within health departments is important for public health activities and cost-efficient coordination of care. Access to and use of surveillance data are governed by public health law and by agency confidentiality and security policies.

In New York City, we examined public health laws and agency policies for data sharing across HIV, sexually transmitted disease, tuberculosis, and viral hepatitis surveillance programs. We found that recent changes to state laws provide greater opportunities for data sharing but that agency policies must be updated because they limit increased data integration.

Our case study can help other health departments conduct similar reviews of laws and policies to increase data sharing and integration of surveillance data.
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FX The Centers for Disease Control and Prevention (CDC-PS10_10175)
   supported this work through cooperative agreement no. 1U38PS003142-02
   (Program Collaboration and Service Integration).
CR *CDCP, 2003, MMWR-MORBID M   S, V52, P19
   *CDCP, 2003, MMWR-MORBID MORTAL W, V52, P1
   Centers for Disease Control and Prevention, 2010, PUBL HLTH SYST 10 ES
   Centers for Disease Control and Prevention, 2009, PROG COLL SERV INT E
   Centers for Disease Control and Prevention, 2011, DAT SEC CONF GUID HI
   Delcher Philip Christopher, 2008, J Public Health Manag Pract, V14, pE1, DOI 10.1097/01.PHH.0000311902.95948.f5
   Department of Health and Mental Hygiene, HEAR MAYORS FISCAL Y
   Dowell D, 2009, PUBLIC HEALTH REP, V124, P31, DOI 10.1177/00333549091240S206
   Fairchild AL, 2007, PUBLIC HEALTH REP, V122, P7, DOI 10.1177/00333549071220S103
   Frieden TR, 2000, LANCET, V355, P1088, DOI 10.1016/S0140-6736(00)02048-1
   Harris TG, 2010, CLIN INFECT DIS, V50, P1524, DOI 10.1086/652654
   Institute of Medicine, PUBL HLTH
   Institute of Medicine Committee on Public Health Strategies to Improve Health, 2012, PUBL HLTH INV HEALTH
   New York City Department of Health and Mental Hygiene, 2013, EP NYC INT HLTH DAT
   New York City Department of Health and Mental Hygiene Bureau of Sexually Transmitted Disease Control, 4 Q 2010 Q REP
   New York City Department of Health and Mental Hygiene Bureau of Tuberculosis Control, 3 YEAR SUMM 2009 201

```
   New York City Department of Health and Mental Hygiene HIV Epidemiology and
Field Services Program, HIV AIDS ANN SURV ST
   Roush S, 1999, JAMA-J AM MED ASSOC, V282, P164, DOI 10.1001/jama.282.2.164
   Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI
10.1142/S0218488502001648
   Taylor MM, 2013, JAIDS-J ACQ IMM DEF, V64, P115, DOI
10.1097/QAI.0b013e318299cf00
   Trieu L, 2010, AM J PUBLIC HEALTH, V100, P1031, DOI 10.2105/AJPH.2009.177725
   United States Census Bureau, STAT COUNT QUICKFACT
   Weinstock H, 2009, PUBLIC HEALTH REP, V124, P5, DOI
10.1177/00333549091240S202
NR 23
TC 6
Z9 6
U1 0
U2 1
PU AMER PUBLIC HEALTH ASSOC INC
PI WASHINGTON
PA 800 I STREET, NW, WASHINGTON, DC 20001-3710 USA
SN 0090-0036
EI 1541-0048
J9 AM J PUBLIC HEALTH
JI Am. J. Public Health
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IS 6
BP 993
EP 997
DI 10.2105/AJPH.2013.301775
PG 5
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA AP0YC
UT WOS:000341791500028
PM 24825197
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ER

PT J
AU Callier, S
   Husain, R
   Simpson, R
AF Callier, Shawneequa
   Husain, Rajah
   Simpson, Rachel
TI Genomic data-sharing: what will be our legacy?
SO FRONTIERS IN GENETICS
LA English
DT Article
DE privacy; ELSI; genetic research; personalized medicine; ethics; medical
ID HEALTH DISPARITIES; GENETIC RESEARCH; RESEARCH ETHICS; MEDICINE;
   CHALLENGE; SOCIETY; CONSENT
AB Prior to 1974, the Tuskegee Syphilis experiments, expansive use of the HeLa
cells, and other blatant instances of research abuse pervaded the medical
research field. Ongoing challenges to informed consent, privacy and data-sharing
will influence the stories that research participants today share with future
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generations. This has significant implications for the advancement of genomic science, and the public's perception of genomic research.

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CR Goldenberg AJ, 2013, PERS MED, V10, P623, DOI [10.2217/pme.13.75, 10.2217/PME.13.75]
Green ED, 2011, NATURE, V470, P204, DOI 10.1038/nature09764
Henderson G, 2008, GENET MED, V10, P193, DOI 10.1097/GIM.0b013e318164e4f5
Henderson GE, 2012, J LAW MED ETHICS, V40, P1008, DOI 10.1111/j.1748-720X.2012.00728.x
Javitt G., 2010, MINNESOTA J LAW SCI, V11, P713
Lee SS, 2009, PUBLIC HEALTH GENOM, V12, P170, DOI 10.1159/000189630
McGuire AL, 2008, NAT REV GENET, V9, P152, DOI 10.1038/nrg2302
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
McGuire AL, 2010, ANNU REV GENOM HUM G, V11, P361, DOI 10.1146/annurev-genom-082509-141711
McGuire AL, 2010, TRENDS GENET, V26, P199, DOI 10.1016/j.tig.2009.12.007
National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, BELM REP ETH PRINC G
Ramos E, 2014, PHARMACOGENOMICS J, V14, P217, DOI 10.1038/tpj.2013.24
Ramos E, 2012, PERS MED, V9, P839, DOI 10.2217/PME.12.100
Ramos E, 2009, BMC MED GENOMICS, V2, DOI 10.1186/1755-8794-2-29
Rotimi CN, 2010, NEW ENGL J MED, V363, P1551, DOI 10.1056/NEJMra0911564
Singer-Vine J., 2010, CONSENT CONUNDRUM
Skloot R., 2013, IMMORTAL LIFE HENRIE
Skloot R., 2010, IMMORTAL LIFE HENRIE
The Office for Human Research Protection, 1991, FED POL PROT HUM SUB
Watts J., 2012, POOR BLACK WOMAN WHO

NR 20
TC 6
Z9 6
U1 1
U2 6
PU FRONTIERS MEDIA SA
PI LAUSANNE
PA PO BOX 110, EPFL INNOVATION PARK, BUILDING I, LAUSANNE, 1015,
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SN 1664-8021
J9 FRONT GENET
JI Front. Genet.
PD MAR 5
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AR UNSP 34
DI 10.3389/fgene.2014.00034
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WC Genetics & Heredity
SC Genetics & Heredity
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PT J
AU Eckels, J
   Nathe, C
   Nelson, EK
   Shoemaker, SG
   Van Nostrand, E
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   Harris, LJ
   Bollenbeck, M
   Fong, Y
   Tomaras, GD
   Piehler, B
AF Eckels, Josh
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TI Quality control, analysis and secure sharing of Luminex (R) immunoassay
   data using the open source LabKey Server platform
SO BMC BIOINFORMATICS
LA English
DT Article
ID T-CELL ASSAYS; IMMUNODEFICIENCY-VIRUS; CANCER-IMMUNOTHERAPY;
   ANALYSIS-SYSTEM; MULTIPLEX; ANTIBODIES; TRIALS; SENSITIVITY; CHALLENGES;
   INFECTION
AB Background: Immunoassays that employ multiplexed bead arrays produce high
information content per sample. Such assays are now frequently used to evaluate
humoral responses in clinical trials. Integrated software is needed for the
analysis, quality control, and secure sharing of the high volume of data
produced by such multiplexed assays. Software that facilitates data exchange and
provides flexibility to perform customized analyses (including multiple curve
fits and visualizations of assay performance over time) could increase
scientists' capacity to use these immunoassays to evaluate human clinical trials.

   Results: The HIV Vaccine Trials Network and the Statistical Center for
HIV/AIDS Research and Prevention collaborated with LabKey Software to enhance
the open source LabKey Server platform to facilitate workflows for multiplexed
bead assays. This system now supports the management, analysis, quality control,
and secure sharing of data from multiplexed immunoassays that leverage Luminex
xMAP (R) technology. These assays may be custom or kit-based. Newly added
features enable labs to: (i) import run data from spreadsheets output by Bio-Plex Manager (TM) software; (ii) customize data processing, curve fits, and
algorithms through scripts written in common languages, such as R; (iii) select
script-defined calculation options through a graphical user interface; (iv)
collect custom metadata for each titration, analyte, run and batch of runs; (v)
calculate dose-response curves for titrations; (vi) interpolate unknown
concentrations from curves for titrated standards; (vii) flag run data for
exclusion from analysis; (viii) track quality control metrics across runs using

Levey-Jennings plots; and (ix) automatically flag outliers based on expected values. Existing system features allow researchers to analyze, integrate, visualize, export and securely share their data, as well as to construct custom user interfaces and workflows.

Conclusions: Unlike other tools tailored for Luminex immunoassays, LabKey Server allows labs to customize their Luminex analyses using scripting while still presenting users with a single, graphical interface for processing and analyzing data. The LabKey Server system also stands out among Luminex tools for enabling smooth, secure transfer of data, quality control information, and analyses between collaborators. LabKey Server and its Luminex features are freely available as open source software at http://www.labkey.com under the Apache 2.0 license.

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FU Bill and Melinda Gates Foundation [OPP1032317, 3830913]; National Institute of Health (NIH/NIAID/DAIDS) [5U01 AI46725-05, UM1-AI-068618, U01-AI-068635]; Duke University Center for AIDS Research (CFAR) Grant [P30 AI 64518]
FX This work was supported by grants from the Bill and Melinda Gates Foundation to the Collaboration for AIDS Vaccine Discovery (OPP1032317 and 3830913), grants from the National Institute of Health (NIH/NIAID/DAIDS) to the HIV Vaccine Trials Network (HVTN) (5U01 AI46725-05, UM1-AI-068618 and U01-AI-068635), and the Duke University Center for AIDS Research (CFAR) Grant (P30 AI 64518).

CR Bastarache JA, 2011, J IMMUNOL METHODS, V367, P33, DOI 10.1016/j.jim.2011.01.005
Beck B., 2012, ASSAY GUIDANCE MANUA
Bellew M, 2009, J MED PRIMATOL, V38, P67
Breen EC, 2011, CLIN VACCINE IMMUNOL, V18, P1229, DOI 10.1128/CVI.05032-11
Britten CM, 2012, IMMUNITY, V37, P1, DOI 10.1016/j.immuni.2012.07.010
Britten CM, 2007, IMMUNOTHERAPY, V57, P285
Britten CM, 2010, CANCER IMMUNOL IMMUN, V60, P15
Burg SH, 2011, SCI TRANSL MED, V3, p108ps44
Burwitz BJ, 2011, J VIROL, V85, P13088, DOI 10.1128/JVI.05650-11
Chowdhury F, 2009, J IMMUNOL METHODS, V340, P55, DOI 10.1016/j.jim.2008.10.002
Christopolous A., 2004, FITTING MODELS BIOL
Churchyard GJ, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021225
Coordinating Committee of the Global HIV/AIDS Vaccine Enterprise, 2005, PLOS MED, V2, P25
Curtis KA, 2012, AIDS RES HUM RETROV, V28, P188, DOI [10.1089/aid.2011.0037, 10.1089/AID.2011.0037]
de Jager W, 2006, METHODS, V38, P294, DOI 10.1016/j.ymeth.2005.11.008
de Jager W, 2009, BMC IMMUNOL, V10, DOI 10.1186/1471-2172-10-52
De Rosa CS, 2011, J IMMUNOL, V187, P3391

Eckels J, 2002, INSTALLATION USE LAB
Ellington AA, 2010, CLIN CHEM, V56, P186, DOI 10.1373/clinchem.2009.127514
Ellington AA, 2009, CLIN CHEM, V55, P1092, DOI 10.1373/clinchem.2008.120717
Elshal MF, 2006, METHODS, V38, P317, DOI 10.1016/j.ymeth.2005.11.010
Fong Y., 2012, BIOMETRICS
Galon J, 2012, J TRANSL MED, V10, DOI 10.1186/1479-5876-10-205
Gottschalk PG, 2005, ANAL BIOCHEM, V343, P54, DOI 10.1016/j.ab.2005.04.035
GraphPad Prism, SCI GRAPH CURV FITT
Haynes BF, 2012, NEW ENGL J MED, V366, P1275, DOI 10.1056/NEJMoa1113425
Hoos A, 2011, NAT BIOTECHNOL, V29, P867, DOI 10.1038/nbt.2000
Hoos A, 2010, J NATL CANCER I, V102, P1388, DOI 10.1093/jnci/djq310
Huang Y, 2012, COMP REPRODUCIBILITY
Iversen PW, 2012, ASSAY GUIDANCE MANUA
Janetzki S, 2009, IMMUNITY, V31, P527, DOI 10.1016/j.immuni.2009.09.007
Kalos M, 2010, J TRANSL MED, V8, DOI 10.1186/1479-5876-8-26
Kang JH, 2012, METHODS, V56, P484, DOI 10.1016/j.ymeth.2012.03.023
Kricka LJ, 2007, MOL BIOTECHNOL, V38, P19
Leng SX, 2008, J GERONTOL A-BIOL, V63, P879, DOI 10.1093/gerona/63.8.879
LEVEY S, 1950, AM J CLIN PATHOL, V20, P1059
Martins TB, 2002, CLIN DIAGN LAB IMMUN, V9, P41, DOI 10.1128/CDLI.9.1.41-45.2002
Master SR, 2006, DRUG DISCOV TODAY, V11, P1007, DOI 10.1016/j.drudis.2006.09.010
Moody MA, 2012, J VIROL, V86, P7496, DOI 10.1128/JVI.00426-12
Moreland AJ, 2011, BMC GENOMICS, V12, DOI 10.1186/1471-2164-12-295
Nelson EK, 2013, BMC MED INFORM DECIS, V13, DOI 10.1186/1472-6947-13-5
Nelson EK, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-71
Opalka D, 2003, CLIN DIAGN LAB IMMUN, V10, P108, DOI 10.1128/CDLI.10.108-115-2003
Peiperl L, 2010, PLOS ONE, V5, DOI 10.1371/journal.pone.0013579
Pickering JW, 2002, AM J CLIN PATHOL, V117, P589
Piehler B, 2011, BMC IMMUNOL, V12, DOI 10.1186/1471-2172-12-33
Pine SO, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018526
Rao P, 2012, HUM IMMUNOL, V73, P1
Rauch A, 2006, J PROTEOME RES, V5, P112, DOI 10.1021/pr0503533
Rerks-Ngarm S, 2009, NEW ENGL J MED, V361, P2209, DOI 10.1056/NEJMoa0908492
Ritz C, 2005, J STAT SOFTW, V12, P1
Sarzotti-Kelsoe M, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000067
Shulman N, 2008, CYTOM PART A, V73A, P847, DOI 10.1002/cyto.a.20600
Taylor CF, 2008, NAT BIOTECHNOL, V26, P889, DOI 10.1038/nbt.1411
Tomaras GD, 2008, J VIROL, V82, P12449, DOI 10.1128/JVI.01708-08
xMAP Technology Multiplexing for Bioassays - Luminex Corporation, XMAP TECHN MULT BIOA
Yates NL, 2011, AIDS, V25, P2089, DOI 10.1097/QAD.0b013e32834b348e
R PROJECT STAT COMPU
NR 58
TC 6
Z9 6
U1 0
U2 24
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1471-2105
J9 BMC BIOINFORMATICS
JI BMC Bioinformatics
PD APR 30
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AR 145
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WC Biochemical Research Methods; Biotechnology & Applied Microbiology;
   Mathematical & Computational Biology
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology;
   Mathematical & Computational Biology
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PT J
AU Miller, JD
AF Miller, James D.
TI Sharing clinical research data in the United States under the health
   insurance portability and accountability act and the privacy rule
SO TRIALS
LA English
DT Editorial Material
AB Sharing of final research data from clinical research is an essential part of
the scientific method. The U.S. National Institutes of Health require some grant
applications to include plans for sharing final research data, which it defines
as the factual materials necessary to document, support, and validate research
findings. In the U.S., however, the Privacy Rule adopted under the Health
Insurance Portability and Accountability Act impedes the sharing of final
research data. In most situations, final research data may be shared only where
all information that could possibly be used to identify the subject has been
deleted, or where the subject has given authorization for specific research, or
an Institutional Review Board has granted a waiver.
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CR Bommersbach Jana, 2008, PHOENIX MAGAZINE
   *CT ATT GEN OFF, 2010, ATT GEN SUES HLTH NE
   Gostin LO, 2009, JAMA-J AM MED ASSOC, V301, P1373, DOI 10.1001/jama.2009.424
   Harmon A., 2010, NY TIMES
   Hrynaszkiewicz I, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-9
   Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
   Lander ES, 2001, NATURE, V409, P860, DOI 10.1038/35057062
   Mello MM, 2010, NEW ENGL J MED, V363, P204, DOI 10.1056/NEJMp1005203
   *NAT RES COUNC, 2003, SHAR PUBL REL DAT MA, V17, P21
   Ness RB, 2007, JAMA-J AM MED ASSOC, V298, P2164, DOI 10.1001/jama.298.18.2164
   *NIH, DAT SHAR POL IMPL GU
   Ochsner SA, 2008, NAT METHODS, V5, P991, DOI 10.1038/nmeth1208-991
   Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
   Piwowar HA, 2010, J INFORMETR, V4, P148, DOI 10.1016/j.joi.2009.11.010
   Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
   *US I MED, 2009, HIPAA PRIV RUL ENH P
   Venter JC, 2001, SCIENCE, V291, P1304, DOI 10.1126/science.1058040
   2010, FED REG         0714, P40868
   2010, FED REG         0714, P40893
NR 19
```

```
TC 6
Z9 6
U1 0
U2 6
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1745-6215
J9 TRIALS
JI Trials
PD NOV 19
PY 2010
VL 11
AR 112
DI 10.1186/1745-6215-11-112
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WC Medicine, Research & Experimental
SC Research & Experimental Medicine
GA 691PJ
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PT J
AU Zarcone, P
   Nordenberg, D
   Meigs, M
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   Jernigan, D
   Hinrichs, SH
AF Zarcone, Patina
   Nordenberg, Dale
   Meigs, Michelle
   Merrick, Ulrike
   Jernigan, Daniel
   Hinrichs, Steven H.
TI Community-Driven Standards-Based Electronic Laboratory Data-Sharing
   Networks
SO PUBLIC HEALTH REPORTS
LA English
DT Article
ID SYSTEM
AB Public health laboratories (PHLs) are critical components of the nation's
health-care system, serving as stewards of valuable specimens, delivering
important diagnostic results to support clinical and public health programs,
supporting public health policy, and conducting research. This article discusses
the need for and challenges of creating standards-based data-sharing networks
across the PHL community, which led to the development of the PHL
Interoperability Project (PHLIP). Launched by the Association of Public Health
Laboratories and the Centers for Disease Control and Prevention in September
2006, PHLIP has leveraged a unique community-based collaborative process,
catalyzing national capabilities to more effectively share electronic
laboratory-generated diagnostic information and bolster the nation's health
security. PHLIP is emerging as a model of accelerated innovation for the fields
of laboratory science, technology, and public health.
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FU Centers for Disease Control and Prevention (CDC) [CCU303019]
FX This article was supported by cooperative agreement #CCU303019 from the
   Centers for Disease Control and Prevention (CDC). The findings and
   conclusions in this article are those of the authors and do not
   necessarily represent the official position of CDC or the Agency for
   Toxic Substances and Disease Registry.
CR *ASS PUBL HLTH LAB, 2007, 2007 STAT TECHN AD S
   Association of Public Health Laboratories Public Health Informatics Institute,
2003, REQ PUBL HLTH LAB IN
   BEAN NH, 1992, AM J PUBLIC HEALTH, V82, P1273, DOI 10.2105/AJPH.82.9.1273
   Chute Christopher G, 2002, J Public Health Manag Pract, V8, P11
   EBELER JC, 2007, OPPORTUNITIES COORDI
   Effler P, 1999, JAMA-J AM MED ASSOC, V282, P1845, DOI
10.1001/jama.282.19.1845
   Moore KM, 2008, J PUBLIC HEALTH MAN, V14, P437, DOI
10.1097/01.PHH.0000333877.78443.f0
   Overhage J M, 2001, J Public Health Manag Pract, V7, P60
   Overhage JM, 2008, AM J PUBLIC HEALTH, V98, P344, DOI
10.2105/AJPH.2006.092700
   Wendel AM, 2009, CLIN INFECT DIS, V48, P1079, DOI 10.1086/597399
NR 10
TC 6
Z9 6
U1 0
U2 6
PU ASSOC SCHOOLS PUBLIC HEALTH
PI WASHINGTON
PA 1101 15TH ST NW, STE 910, WASHINGTON, DC 20005 USA
SN 0033-3549
J9 PUBLIC HEALTH REP
JI Public Health Rep.
PD MAY-JUN
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SU 2
BP 47
EP 56
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PG 10
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 581WB
UT WOS:000276554900006
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PT J
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AU Anderson, JG
Ramanujam, R
Hensel, DJ
Sirio, CA
AF Anderson, James G.
Ramanujam, Rangaraj
Hensel, Devon J.
Sirio, Carl A.
TI Reporting trends in a regional medication error data-sharing system
SO HEALTH CARE MANAGEMENT SCIENCE
LA English
DT Article
DE Data-sharing systems; Medication errors; Patient safety; Latent growth curve analysis
ID ADVERSE DRUG EVENTS; QUALITY IMPROVEMENT; PATIENT SAFETY; HEALTH-CARE

AB Inter-organizational systems for sharing data about medication errors have emerged as an important strategy for improving patient safety and are expected to encourage not only voluntary error reporting but also learning from errors. Yet, few studies have examined the hypothesized benefits of inter-organizational data sharing. The current study examined the developmental trends in information reported by hospitals participating in a regional reporting system for medication errors. A coalition of hospitals in southwestern Pennsylvania, under the auspices of the Pittsburgh Regional Healthcare Initiative (PRHI), implemented a voluntary system for quarterly sharing of information about medication errors. Over a 12-month period, 25 hospitals shared information about 17,000 medication errors. Using latent growth curve analysis, we examined longitudinal trends in the quarterly number of errors and associated corrective actions reported by each hospital. Controlling for size, teaching status, and JCAHO accreditation score, for the hospitals as a group, error reporting increased at a statistically significant rate over the four quarters. Moreover, despite significant baseline differences among hospitals, error reporting increased at similar rates across hospitals over subsequent quarters. In contrast, the reporting of corrective actions remained unchanged. However, the baseline levels of corrective actions reporting were significantly different across hospitals. Although data sharing systems promote error reporting, it is unclear whether they encourage corrective actions. If data sharing is intended to promote not just error reporting but also root-cause-analysis and process improvement, then the design of the reporting system should emphasize data about these processes as well as errors.

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FU AHRQ HHS [U18 HS015851]

CR Altman DE, 2004, NEW ENGL J MED, V351, P2041, DOI 10.1056/NEJMp048243
Aspden P, 2007, PREVENTING MED ERROR
Bollen KA, 2004, SOCIOL METHOD RES, V32, P336, DOI 10.1177/0049124103260222
Bollen KA, 2006, WILEY SER PROBAB ST, P1
BOLLEN KA, 1989, STRUCTURAL EQUATIONS
Byrne B. M., 2001, STRUCTURAL EQUATION

```
   CLASSEN DC, 1991, JAMA-J AM MED ASSOC, V266, P2847, DOI
10.1001/jama.266.20.2847
   Comden SW, 2002, STATEWIDE PATIENT SA
   Cook RI, 2000, BRIT MED J, V320, P791, DOI 10.1136/bmj.320.7237.791
   CULLEN DJ, 1995, JOINT COMM J QUAL IM, V21, P541, DOI 10.1016/S1070-
3241(16)30180-8
   Curran P. J., 2001, NEW METHODS ANAL CHA, P105, DOI DOI 10.1037/10409-004
   Curran PJ, 2002, MULT APPL BK SER, P59
   CURRAN PJ, 2002, MODELING INTRAINDIVI
   Halamka J, 2005, J AM MED INFORM ASSN, V12, P596, DOI 10.1197/jamia.M1866
   Hicks R, 2004, MEDMARX 5 ANNIVERSAR
   Institute of Medicine (US) Committee on Quality of Health Care in America,
2001, CROSS QUAL CHASM NEW
   Kohn L. T., 2000, ERR IS HUMAN BUILDIN
   Leape LL, 2002, NEW ENGL J MED, V347, P1633, DOI 10.1056/NEJMNEJMhpr011493
   Leape LL, 2005, JAMA-J AM MED ASSOC, V293, P2384, DOI
10.1001/jama.293.19.2384
   ROSENTHAL J, MAXIMIZING USE STATE
   ROSENTHAL J, 2004, STATE PATIENT SAFETY
   Rosenthal J, 2001, CURRENT STATE PROGRA
   Shojania KG, 2005, HEALTH AFFAIR, V24, P138, DOI 10.1377/hlthaff.24.1.138
   Sirio CA, 2003, HEALTH AFFAIR, V22, P157, DOI 10.1377/hlthaff.22.5.157
   SIRIO CA, 2005, ADV PATIENT SAFETY R, V3
   WACHTER RM, 2004, HLTH AFFAIRS W, V4, P534, DOI DOI 10.1377/HLTHAFF.W4.534
   WEINBERG J, 2005, ADV PATIENT SAF RES, V1, P405
NR 27
TC 6
Z9 6
U1 1
U2 10
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 1386-9620
J9 HEALTH CARE MANAG SC
JI Health Care Manag. Sci.
PD MAR
PY 2010
VL 13
IS 1
BP 74
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DI 10.1007/s10729-009-9111-1
PG 10
WC Health Policy & Services
SC Health Care Sciences & Services
GA 646ZP
UT WOS:000281585200007
PM 20402284
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PT J
AU Ganguly, S
   Kataria, P
   Juric, R
   Ertas, A
   Tanik, MM
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AF Ganguly, Sukanta
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Juric, Radmila
Ertas, Atila
Tanik, Murat M.
TI Sharing Information and Data Across Heterogeneous e-Health Systems
SO TELEMEDICINE JOURNAL AND E-HEALTH
LA English
DT Article
DE information sharing; data sharing; e-health systems; CADRA; Go-CID
AB Information and data sharing across heterogeneous e-health systems, focusing on the management of patient care, have become the backbone of modern delivery of sustainable telemedicine services. Information and data available to healthcare practitioners in such environments range from patient's medical records, stored in repositories at places where patients have been treated, to a variety of information related to medical research, pharmaceutical products, or information stored within social networks of healthcare interest groups. This study sought to demonstrate two different approaches enabling the sharing of information/data across heterogeneous e-health systems: (1) Context-Aware Data Retrieval Architecture (CADRA), which secures the extraction and presentation of e-health information to users in requested format, and (2) Generic Ontology for Context Aware, Interoperable, and Data Sharing (Go-CID) software applications, which secure semantic interoperation across heterogeneous e-health data sources. Proof-of-concept was demonstrated in both cases, CADRA and Go-CID, to achieve understanding and building of knowledge about e-health environments. This study invites practical solutions for interoperable e-health systems.
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RI Juric, Radmila/Q-9003-2018
OI Juric, Radmila/0000-0002-0441-0694; Ertas, Atila/0000-0002-5360-9659
CR BANGELS M, FLOW HLTH NETWORK SH
BUTZ A, 2006, PERV HLTH C WORKSH, P1
FAIREY M, 2006, BRIT J HEALTHC COMP, V23, P9
Fuchs F, 2005, Third IEEE International Conference on Pervasive Computing and Communications, Workshops, P8, DOI 10.1109/PERCOMW.2005.9
GANGULY S, 2008, P 11 INT C INT DES P
GREEN TJ, 2007, 978159593685107006 A
HORI M, 2005, INT C SYST SCI 2005
KATARIA P, 2007, P 11 IASTED C SOFT E
KATARIA P, 2008, P 11 INT C INT DES P
KATARIA P, 2008, P 4 IASTED C ADV COM
Kataria P., 2008, P 41 HAW INT C SYST
Kim J., 2001, PAN SYDN AR WORKSH V, P11
KOAY N, 2009, P 42 HAW IN IN PRESS
KUNG L, 2006, P 1 INT C INN COMP I, V3
Muramatsu J., 2006, P 9 INT C CONTR AUT, P1
Ranganathan A, 2003, PERS UBIQUIT COMPUT, V7, P353, DOI 10.1007/s00779-003-0251-x
SUNG S, 2006, P 22 IEEE INT C DAT, P6
Tian YH, 2006, IEEE T KNOWL DATA EN, V18, P1482, DOI 10.1109/TKDE.2006.178
VARDARAJAN R, 2008, IEEE INT C DAT ENG C, P883
*W3C, 2006, EXT MARK LANG XML 1

```
   *WEB SERV ARCH, 2004, 11 W3C WEB SERV ARCH
   2008, E HLTH EU C 6 7 MAY
   E HLTH 2003 HIGH LEV
NR 23
TC 6
Z9 6
U1 0
U2 11
PU MARY ANN LIEBERT, INC
PI NEW ROCHELLE
PA 140 HUGUENOT STREET, 3RD FL, NEW ROCHELLE, NY 10801 USA
SN 1530-5627
EI 1556-3669
J9 TELEMED J E-HEALTH
JI Telemed. J. e-Health
PD JUN
PY 2009
VL 15
IS 5
BP 454
EP 464
DI 10.1089/tmj.2008.0149
PG 11
WC Health Care Sciences & Services
SC Health Care Sciences & Services
GA 462FI
UT WOS:000267334300009
PM 19548826
DA 2019-08-06
ER

PT S
AU Simpson, A
   Power, D
   Russell, D
   Slaymaker, M
   Mostefaoui, GK
   Ma, XQ
   Wilson, G
AF Simpson, Andrew
   Power, David
   Russell, Douglas
   Slaymaker, Mark
   Mostefaoui, Ghita Kouadri
   Ma, Xiaoqi
   Wilson, Graeme
BE Solomonides, T
   Silverstein, JC
   Saltz, J
   Legre, Y
   Kratz, M
   Foster, I
   Breton, V
   Beck, JR
TI A healthcare-driven framework for facilitating the secure sharing of
   data across organisational boundaries
SO GLOBAL HEALTHGRID: E-SCIENCE MEETS BIOMEDICAL INFORMATICS
SE Studies in Health Technology and Informatics
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LA English
DT Proceedings Paper
CT 6th Healthgrid Conference
CY 2008
CL Chicago, IL
DE interoperability; federation; security
ID IMPLEMENTATION; DESIGN
AB We report upon the development of sif (for service-oriented interoperability
framework), a platform that has been developed to support the secure aggregation
of medical data from disparate sources. By taking a data-agnostic approach to
data access and transfer, sif provides a generic interface to data sources,
which allows the current version to expose data from any relational database and
any file system in a secure fashion. Application developers may then access and
utilise such data via a simple API. sif is being developed within the GIMI
(Generic Infrastructure for Medical Informatics) project; as such, we discuss
its various applications within that context.
C1 [Simpson, Andrew; Power, David; Russell, Douglas; Slaymaker, Mark; Mostefaoui,
Ghita Kouadri; Ma, Xiaoqi; Wilson, Graeme] OUCL, Oxford OX1 3QD, England.
RP Simpson, A (reprint author), OUCL, Wolfson Bldg,Parks Rd, Oxford OX1 3QD,
England.
EM Andrew.Simpson@comlab.ox.ac.uk
CR Antonioletti M, 2005, CONCURR COMP-PRACT E, V17, P357, DOI 10.1002/cpe.939
   ANTONIOLETTI M, 2007, P UK E SCI ALL HANDS
   Brady M., 2003, GRID COMPUTING MAKIN, P923
   BRETON V, 2004, P 4 IEEE INT S CLUST
   Calinescu R, 2007, P 5 IEEE INT C SOFTW
   Foster I, 1997, INT J SUPERCOMPUT AP, V11, P115, DOI
10.1177/109434209701100205
   Gale A, 2003, SEMINARS BREAST DIS, V6, P148
   Geddes J, 2005, COMP MED SY, P570, DOI 10.1109/CBMS.2005.76
   GEDDES J, 2006, P IEEE S COMP BAS ME
   Langella S., 2004, P GLOB GRID FOR 11 G, P20
   Ouksel AM, 1999, SIGMOD REC, V28, P5, DOI DOI 10.1145/309844.309849
   PITTFRANCIS J, 2006, COMP MATH MATH PHYS, V7, P177
   Power DJ, 2005, SOFTWARE PRACT EXPER, V35, P857, DOI 10.1002/spe.692
   RAJASEKAR A, 2003, COMPUTER SOC INDIA J, V33, P42
   Reddington F, 2007, HUM MUTAT, V28, P1151, DOI 10.1002/humu.20584
   Saltz J, 2006, BIOINFORMATICS, V22, P1910, DOI 10.1093/bioinformatics/btl272
   Simpson A, 2005, COMP MED SY, P564, DOI 10.1109/CBMS.2005.59
   Simpson A, 2007, INT J HEALTHC INF SY, V2, P75, DOI 10.4018/jhisi.2007040106
   SINNOTT RO, 2005, P UK E SCI ALL HANDS
   SLAYMAKER MA, 2006, P IEEE S COMP BAS ME
   SLAYMAKER MA, 2008, P SAC 2008
   TROMANS C, 2006, P INT WORKSH DIG MAM, P26
   TROMANS C, 2006, P IWDM 2006, P251
   YAP MH, 2008, UTILISATION SE UNPUB
NR 24
TC 6
Z9 6
U1 1
U2 2
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-58603-874-8
J9 STUD HEALTH TECHNOL
PY 2008
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VL 138
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EP 12
PG 10
WC Health Care Sciences & Services; Mathematical & Computational Biology;
   Medical Informatics
SC Health Care Sciences & Services; Mathematical & Computational Biology;
   Medical Informatics
GA BMO70
UT WOS:000273151300001
PM 18560103
DA 2019-08-06
ER

PT J
AU Wan, X
   Pavlidis, P
AF Wan, Xiang
   Pavlidis, Paul
TI Sharing and reusing gene expression profiling data in neuroscience
SO NEUROINFORMATICS
LA English
DT Review
DE microarray; gene expression analysis; meta-analysis
ID MICROARRAY DATA; PREFRONTAL CORTEX; POSTMORTEM BRAINS; BIPOLAR DISORDER;
   MOUSE; ATLAS; METAANALYSIS; DISCOVERY; CANCER; BIOINFORMATICS
AB As public availability of gene expression profiling data increases, it is
natural to ask how these data can be used by neuro scientists. Here we review
the public availability of high-throughput expression data in neuroscience and
how it has been reused, and tools that have been developed to facilitate reuse.
There is increasing interest in making expression data reuse a routine part of
the neuroscience tool-kit, but there are a number of challenges. Data must
become more readily available in public databases; efforts to encourage
investigators to make data available are important, as is education on the
benefits of public data release. Once released, data must be better-annotated.
Techniques and tools for data reuse are also in need of improvement. Integration
of expression profiling data with neuroscience-specific resources such as
anatomical atlases will further increase the value of expression data.
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OI Pavlidis, Paul/0000-0002-0426-5028
FU NIGMS NIH HHS [R01 GM076990, R01 GM076990-04, GM076990]
CR Aarnio V, 2005, J MOL NEUROSCI, V27, P261, DOI 10.1385/JMN:27:3:261
   Assou S, 2007, STEM CELLS, V25, P961, DOI 10.1634/stemcells.2006-0352
   Barnes M, 2005, NUCLEIC ACIDS RES, V33, P5914, DOI 10.1093/nar/gki890
   Barrett T, 2007, NUCLEIC ACIDS RES, V35, pD760, DOI 10.1093/nar/gkl887
   Berman H, 2007, NUCLEIC ACIDS RES, V35, pD301, DOI 10.1093/nar/gkl971
   Bota M, 2005, NEUROINFORMATICS, V3, P15, DOI 10.1385/NI:3:1:015
   Bowden DM, 2003, NEUROINFORMATICS, V1, P43, DOI 10.1385/NI:1:1:043
   Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
   Breitling R, 2004, FEBS LETT, V573, P83, DOI 10.1016/j.febslet.2004.07.055
   Brown PO, 2003, PLOS BIOL, V1, P1, DOI 10.1371/journal.pbio.0000036
   Chesler EJ, 2005, NAT GENET, V37, P233, DOI 10.1038/ng1518
```

CHIN MH, 2007, IN PRESS PHYSL GENOM
Choi JK, 2003, BIOINFORMATICS, V19, pi84, DOI 10.1093/bioinformatics/btg1010
Cooper H., 1994, HDB RES SYNTHESIS
Crosto CJ, 2007, BRIEF BIOINFORM, V8, P150
Eckersley P, 2003, NEUROINFORMATICS, V1, P149, DOI 10.1007/s12021-003-0002-1
Edgar R, 2002, NUCLEIC ACIDS RES, V30, P207, DOI 10.1093/nar/30.1.207
Eisen MB, 1998, P NATL ACAD SCI USA, V95, P14863, DOI 10.1073/pnas.95.25.14863
Eisenstein M, 2006, NATURE, V442, P1067, DOI [10.1038/4421067a, 10.1038/4421067b]
Enard W, 2002, SCIENCE, V296, P340, DOI 10.1126/science.1068996
Erraji-Benchekroun L, 2005, BIOL PSYCHIAT, V57, P549, DOI 10.1016/j.biopsych.2004.10.034
Galbraith DW, 2006, NATURE, V444, P31, DOI 10.1038/444031b
Ge XJ, 2005, GENOMICS, V86, P127, DOI 10.1016/j.ygeno.2005.04.008
Gentleman RC, 2004, GENOME BIOL, V5, DOI 10.1186/gb-2004-5-10-r80
Glorioso C, 2006, MOL PSYCHIATR, V11, P633, DOI 10.1038/sj.mp.4001835
Golub TR, 1999, SCIENCE, V286, P531, DOI 10.1126/science.286.5439.531
Gong SC, 2003, NATURE, V425, P917, DOI 10.1038/nature02033
Gu Jianying, 2004, Human Genomics, V1, P247
Gu JY, 2003, TRENDS GENET, V19, P63, DOI 10.1016/S0168-9525(02)00040-9
Hakak Y, 2001, P NATL ACAD SCI USA, V98, P4746, DOI 10.1073/pnas.081071198
Hsieh WP, 2003, GENETICS, V165, P747
HUNTER JE, 1990, METHODS META ANAL
Iwamoto K, 2004, J HUM GENET, V49, P227, DOI 10.1007/s10038-004-0136-5
Iwamoto K, 2004, MOL PSYCHIATR, V9, P406, DOI 10.1038/sj.mp.4001437
Jurata LW, 2004, J NEUROSCI METH, V138, P173, DOI 10.1016/j.jneumeth.2004.04.002
Kapushesky M, 2004, NUCLEIC ACIDS RES, V32, pW465, DOI 10.1093/nar/gkh470
Koslow SH, 2000, NAT NEUROSCI, V3, P863, DOI 10.1038/78760
Koslow SH, 2005, CLIN EEG NEUROSCI, V36, P55, DOI 10.1177/155005940503600204
Larsson O, 2006, OMICS, V10, P381, DOI 10.1089/omi.2006.10.381
Lee HK, 2004, GENOME RES, V14, P1085, DOI 10.1101/gr.1910904
Lein ES, 2007, NATURE, V445, P168, DOI 10.1038/nature05453
Lein ES, 2004, J NEUROSCI, V24, P3879, DOI 10.1523/JNEUROSCI.4710-03.2004
Li HQ, 2005, HUM MOL GENET, V14, P1119, DOI 10.1093/hmg/ddi124
Magdaleno S, 2006, PLOS BIOL, V4, P497, DOI 10.1371/journal.pbio.0040086
McCarroll SA, 2004, NAT GENET, V36, P197, DOI 10.1038/ng1291
Mirnics K, 2004, NAT NEUROSCI, V7, P434, DOI 10.1038/nn1230
Moreau Y, 2003, TRENDS GENET, V19, P570, DOI 10.1016/j.tig.2003.08.006
Muller MM, 2006, P NATL ACAD SCI USA, V103, P14250, DOI 10.1073/pnas.0606668103
Pan F, 2007, NUCLEIC ACIDS RES, V35, pD756, DOI 10.1093/nar/gkl798
Parkinson H, 2007, NUCLEIC ACIDS RES, V35, pD747, DOI 10.1093/nar/gkl995
PAVLIDIS P, 2001, GENOME BIOL, V2, pH42
Perkins DO, 2007, GENOME BIOL, V8, DOI 10.1186/gb-2007-8-2-r27
Polesskaya OO, 2003, J NEUROSCI RES, V74, P111, DOI 10.1002/jnr.10752
Ponomarev I, 2006, J NEUROSCI, V26, P5673, DOI 10.1523/JNEUROSCI.0860-06.2006
Rhodes DR, 2002, CANCER RES, V62, P4427
Rhodes DR, 2004, ANN NY ACAD SCI, V1020, P32, DOI 10.1196/annals.1310.005
Rhodes DR, 2004, NEOPLASIA, V6, P1, DOI 10.1016/S1476-5586(04)80047-2
Sandberg R, 2000, P NATL ACAD SCI USA, V97, P11038, DOI 10.1073/pnas.97.20.11038
Schadt EE, 2005, NAT GENET, V37, P710, DOI 10.1038/ng1589
Shields R, 2006, TRENDS GENET, V22, P65, DOI 10.1016/j.tig.2005.12.006
SIBILLE E, 2007, IN PRESS MOL PSYCHIA
Siddiqui AS, 2005, P NATL ACAD SCI USA, V102, P18485, DOI 10.1073/pnas.0509455102

Sokolov BP, 2003, J NEUROSCI RES, V72, P756, DOI 10.1002/jnr.10631
Spellman PT, 2002, GENOME BIOL, V3
Stansberg C, 2007, BMC GENOMICS, V8, DOI 10.1186/1471-2164-8-94
Stuart JM, 2003, SCIENCE, V302, P249, DOI 10.1126/science.1087447
Su AI, 2004, P NATL ACAD SCI USA, V101, P6062, DOI 10.1073/pnas.0400782101
Sugino K, 2006, NAT NEUROSCI, V9, P99, DOI 10.1038/nn1618
Sunkin SM, 2006, TRENDS GENET, V22, P211, DOI 10.1016/j.tig.2006.02.006
Tkachev D, 2003, LANCET, V362, P798, DOI 10.1016/S0140-6736(03)14289-4
Vazquez-Chona FR, 2005, MOL VIS, V11, P958
Watson Rory, 2007, BMJ, V334, P389, DOI 10.1136/bmj.39129.642130.DB
Williams RW, 2006, MAMM GENOME, V17, P496, DOI 10.1007/s00335-006-0006-x
Zapala MA, 2005, P NATL ACAD SCI USA, V102, P10357, DOI
10.1073/pnas.0503357102
Zhang Wen, 2004, J Biol, V3, P21, DOI 10.1186/jbiol16

NR 75
TC 6
Z9 6
U1 1
U2 4
PU HUMANA PRESS INC
PI TOTOWA
PA 999 RIVERVIEW DRIVE SUITE 208, TOTOWA, NJ 07512 USA
SN 1539-2791
EI 1559-0089
J9 NEUROINFORMATICS
JI Neuroinformatics
PY 2007
VL 5
IS 3
BP 161
EP 175
DI 10.1007/s12021-007-0012-5
PG 15
WC Computer Science, Interdisciplinary Applications; Neurosciences
SC Computer Science; Neurosciences & Neurology
GA 223XG
UT WOS:000250408500005
PM 17917127
OA Green Accepted
DA 2019-08-06
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PT S
AU Jovicich, J
Beg, MF
Pieper, S
Priebe, C
Miller, MM
Buckner, R
Rosen, B
AF Jovicich, J
Beg, MF
Pieper, S
Priebe, C
Miller, MM
Buckner, R
Rosen, B
GP IEEE Comp Soc

TI Biomedical informatics research network: Integrating multi-site
   neuroimaging data acquisition, data sharing and brain morphometric
   processing
SO 18th IEEE Symposium on Computer-Based Medical Systems, Proceedings
SE COMPUTER-BASED MEDICAL SYSTEMS : PROCEEDINGS OF THE ANNUAL IEEE
   SYMPOSIUM
LA English
DT Proceedings Paper
CT 18th IEEE Symposium on Computer-Based Medical Systems
CY JUN 23-24, 2005
CL Dublin, IRELAND
SP IEEE Comp Soc Tech Comm Computat Med, Trinity Coll Dublin, Dept Comp Sci, Sci
Fdn Ireland
ID SEGMENTATION
AB The Biomedical Informatics Research Network (BIRN) is a National Institutes
of Health (USA) initiative that fosters distributed collaborations in biomedical
science by utilizing information technology innovations. Morphometry BIRN is one
of its testbeds and has the goal to develop the ability to conduct clinical
imaging studies across multiple sites, to analyze structural imaging data with
the most powerful software regardless of development site, and to test new
hypotheses on large collections of subjects with well-characterized image and
clinical data. Through large-scale analyses of patient population data acquired
and pooled across sites, we are investigating neuroanatomic correlates of
Alzheimer's Disease Depression and Mild Cognitive Impairment subjects. This
paper describes progress in multi-site image calibration and in software
integration for multi-site image processing.
C1 Massachusetts Gen Hosp, Charlestown, MA USA.
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RI Priebe, Carey E./A-3305-2010
OI Jovicich, Jorge/0000-0001-9504-7503
CR Beg MF, 2005, INT J COMPUT VISION, V61, P139, DOI
10.1023/B:VISI.0000043755.93987.aa
   Duda R. O., 2000, PATTERN CLASSIFICATI
   Fischl B, 2004, NEUROIMAGE, V23, pS69, DOI 10.1016/j.neuroimage.2004.07.016
   Fischl B, 2002, NEURON, V33, P341, DOI 10.1016/S0896-6273(02)00569-X
   Martone ME, 2004, NAT NEUROSCI, V7, P467, DOI 10.1038/nn1229
   Venables W.N., 2002, MODERN APPL STAT S P
NR 6
TC 6
Z9 6
U1 0
U2 2
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1264 USA
SN 1063-7125
BN 0-7695-2355-2
J9 COMP MED SY
PY 2005
BP 288
EP 293
DI 10.1109/CBMS.2005.38
PG 6
WC Computer Science, Interdisciplinary Applications; Medical Informatics;
   Medicine, Research & Experimental; Radiology, Nuclear Medicine & Medical
   Imaging
SC Computer Science; Medical Informatics; Research & Experimental Medicine;
   Radiology, Nuclear Medicine & Medical Imaging

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GA BCS05
UT WOS:000230987800047
DA 2019-08-06
ER

PT B
AU Ballard, DJ
   Nicewander, D
   Skinner, C
AF Ballard, DJ
   Nicewander, D
   Skinner, C
BE Kohane, IS
TI Health care provider quality improvement organization medicare
   data-sharing: A diabetes quality improvement initiative.
SO AMIA 2002 SYMPOSIUM, PROCEEDINGS: BIOMEDICAL INFORMATICS: ONE DISCIPLINE
LA English
DT Proceedings Paper
CT Annual Symposium of the American-Medical-Informatics-Association
CY NOV   09, 2002
CL San Antonio, TX
SP Amer Med Informat Assoc
ID PROJECT; PROFILE
AB Background. This paper describes a collaborative Medicare claims data linkage
and sharing effort between the Baylor Health Care System (BHCS) and Texas
Medical Foundation (TMF, the Texas Quality Improvement Organization) designed to
assess the effect of three quality improvement interventions on care delivered
to elderly patients with diabetes. The randomized controlled trial is being
conducted among a network of primary care physician practices owned by BHCS and
focuses on measures of care process and outcome.
   Methods: Cohort definition and baseline measurement took place between
January I and December 31, 2000. BHCS administrative data and TMF-supplied
Medicare enrollment data were used to define the January 1, 2001 prevalence
cohort of Medicare diabetic beneficiaries meeting study inclusion criteria. A
total of 22 practices (with 92 physicians and 2,158 patients) were randomized to
one of three interventions, each of which involved performance measurement
feedback on three claims based measures of care process. Physician profiles,
generated by TMF using Medicare utilization files, were reported to study
physicians via academic detailing sessions with a BHCS physician educator.
   Results: The January 1 - December 31, 2000 baseline Medicare claims for the
January 1, 2001 prevalence cohort were provided to HTPN by TMF in October 2001,
representing a ten-month lag in the ability of Quality Improvement Organizations
to provide Part B data relative to a specific episode of care time frame.
Overall baseline rates for the claims-based process measures were: annual HbA(1c)
testing (86.1%), annual eye examination (60.8%), and annual lipid profile
(72.5%). As anticipated, medical-record based rates of annual eye examination
were significantly underrepresented Agreement between claims-based and medical
record-based measures was very close for annual HbA(1c) and annual lipid profile.
   Conclusions: The use of Medicare claims data, through collaboration with a
QIO, can help health care providers overcome a significant barrier associated
with quality improvement initiatives. Limitations associated with the use of
Medicare claims can impact implementation of intervention strategies, but do not
prevent them from being a practical tool for improving care.
RI Ballard, David/H-1062-2018
CR Aubert RE, 1998, ANN INTERN MED, V129, P605, DOI 10.7326/0003-4819-129-8-
199810150-00004
   Deichmann RE, 1999, DIABETES CARE, V22, P1612, DOI 10.2337/diacare.22.10.1612
   Donner A., 2000, DESIGN ANAL CLUSTER
```

```
   Fleming BB, 2001, DIABETES CARE, V24, P1815, DOI 10.2337/diacare.24.10.1815
   Hebert P L, 1999, Am J Med Qual, V14, P270, DOI 10.1177/106286069901400607
   Jencks SF, 2000, JAMA-J AM MED ASSOC, V284, P1670, DOI
10.1001/jama.284.13.1670
   Sutherland J E, 2001, J Am Board Fam Pract, V14, P243
   WEINER JP, 1995, JAMA-J AM MED ASSOC, V273, P1503, DOI
10.1001/jama.273.19.1503
NR 8
TC 6
Z9 6
U1 0
U2 2
PU HANLEY & BELFUS INC MED PUBLISHERS
PI PHILADELPHIA
PA 210 S 13TH ST, PHILADELPHIA, PA 19107 USA
BN 1-56053-600-4
PY 2002
BP 22
EP 25
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WC Computer Science, Information Systems; Medical Informatics
SC Computer Science; Medical Informatics
GA BY60A
UT WOS:000189418100005
PM 12463779
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ER

PT J
AU Studdert, DM
AF Studdert, DM
TI Direct contracts, data sharing and employee risk selection: New stakes
   for patient privacy in tomorrow's health insurance markets
SO AMERICAN JOURNAL OF LAW & MEDICINE
LA English
DT Review
ID WORKERS COMPENSATION; MANAGED CARE; PHYSICIANS; CAPITATION; EXPERIENCE;
   ADJUSTMENT; PROVIDERS; AUTONOMY; PAYMENTS; BENEFITS
C1 Rand Corp, Inst Civil Justice, Santa Monica, CA 90406 USA.
   Rand Corp, Hlth, Santa Monica, CA 90406 USA.
RP Studdert, DM (reprint author), Rand Corp, Inst Civil Justice, Santa Monica,
CA 90406 USA.
CR AKULA JL, 1997, HLTH AFF         JAN, P9
   BAKER LC, 1993, HLTH AFF S, P271
   BALLEN DT, 1994, CORNELL LAW REV, V79, P1291
   BAREFOOT BL, 1998, NC L REV, V77, P348
   BAREFOOT BL, 1998, NC L REV, V77, P283
   BARNETT AA, 1997, BUS HLTH        0101, P34
   BARR S, 1997, WASHINGTON POST 0927, pA1
   BAUMGARTEN A, 1996, BUS HLTH         JUL, P23
   BAYER R, 1992, AM J PUBLIC HEALTH, V82, P1158, DOI 10.2105/AJPH.82.8.1158
   Beauchamp Tom L., 1994, PRINCIPLES BIOMEDICA, V189, P226
   BECKER GS, 1968, J POLIT ECON, V76, P169, DOI 10.1086/259394
   BECKER GS, 1968, J POLIT ECON, V76, P172
   BERENSON R, 1997, HLTH AFF         MAR, P173
   BERK ML, 1992, HEALTH AFFAIR, V11, P145, DOI 10.1377/hlthaff.11.4.145
   Blendon RJ, 1998, HEALTH AFFAIR, V17, P80, DOI 10.1377/hlthaff.17.4.80
   BLENDON RJ, 1998, HLTH AFF         JUL, P86
```

BOBINSKI MA, 1994, U PITT LAW REV, V55, P291
Bodenheimer T, 1998, NEW ENGL J MED, V338, P1084, DOI 10.1056/NEJM199804093381525
Bodenheimer T, 1998, NEW ENGL J MED, V338, P1003, DOI 10.1056/NEJM199804023381422
BRANDT AM, 1985, NO MAGIC BULLET SOCI, P24
BRENNAN TA, 1995, NEW RULES REGULATION, P150
Brennan Troyen A, 1991, JUST DOCTORING MED E
Brown V Y, 1998, Ann Health Law, V7, P25
BROWN VY, 1998, ANN HLTH L, V7, P50
Buck JA, 1997, HEALTH AFFAIR, V16, P120, DOI 10.1377/hlthaff.16.4.120
BURROWS SN, 1997, HEALTHC FINANC MANAG, V8, P50
CASHEL TW, 1997, BU J SCI TECH, V3, P36
CENICEROS R, 1998, BUS INS   0406, P1
CHRISTIANSON JB, 1998, HLTH AFF   JUL, P162
CHRISTIANSON JB, 1998, HLTH AFFAIRS   JUL, P158
Colby JA, 1998, AM J LAW MED, V24, P443
COLBY JA, 1998, AM JL MED, V24, P464
COLEMAN DL, 1997, BUS HLTH   0301, P38
*COMM MAINT PRIV S, 1997, FOR REC PROT EL HLTH, P25
*CONGR BUDG OFF, 1998, EC BUDG OUTL FISC YE
Cox DF, 1997, MED CARE RES REV, V54, P259, DOI 10.1177/107755879705400301
DEENER B, 1994, DALLAS MORNING 0701, pD1
DIBLASE D, 1989, BUS INS   0626, P121
DICK RS, 1991, COMPUTER BASED PATIE, P4
DONALDSON MS, 1994, HLTH DATA INFORMATIO, P140
Dunn DL, 1998, INQUIRY-J HEALTH CAR, V35, P132
*E HLTH CAR CONS, 1991, DIR CONTR CONGTR ISS, P15
Emanuel EJ, 1991, ENDS HUMAN LIFE MED
EMMONS D, 1997, SOCIOECONOMIC CHARAC, P7
EMMONS DW, 1996, SOCIOECONOMIC CHARAC, P15
*EQ EMPL OPP COMM, 1993, INT ENF GUID APPL AD, P7
FEINBERG J, 1983, NOTRE DAME LAW REV, V58, P445
FIELD MJ, 1993, EMPLOYMENT HLTH BENE, P236
FIELD MJ, 1993, EMPLOYMENT HLTH BENE
FISHER MJ, 1998, NATL UNDERWRITE 0821, P39
GABEL J, 1989, HLTH AFF   SUM, P126
GABEL J, 1989, HLTH AFFAIRS   SUM, P116
Galvin R S, 1998, Integr Healthc Rep, P5
Gellman R M, 1984, North Carol Law Rev, V62, P255
GELLMAN RM, 1984, NC L REV, V62, P280
Ginsburg PB, 1998, HEALTH AFFAIR, V17, P141, DOI 10.1377/hlthaff.17.5.141
GOLDBERG RM, 1998, WALL STREET J   0717, pA14
GOLDMAN J, 1998, HLTH AFF   NOV, P47
Gostin L O, 1995, Health Matrix Clevel, V5, P1
Gostin L O, 1993, Health Matrix Clevel, V3, P89
GOSTIN LO, 1995, CORNELL LAW REV, V80, P451
GOSTIN LO, 1998, ALB L REV, V61, P679
GOSTIN LO, 1995, HLTH MATRIX, V5, P23
GOSTIN LO, 1998, ALB L REV, V61, P683
GOSTIN LO, 1993, HLTH MATRIX, V3, P104
GRUBER J, 1994, AM ECON REV, V84, P622
HALL MA, 1997, MAKING MED SPENDING, P171
Hashimoto DM, 1996, AM J LAW MED, V22, P233
HASHIMOTO DM, 1996, AM JL MED, V22, P258
Hibbard JH, 1998, HEALTH AFFAIR, V17, P181, DOI 10.1377/hlthaff.17.6.181
Hibbard JH, 1997, MILBANK Q, V75, P395, DOI 10.1111/1468-0009.00061
HILLMAN AL, 1992, MED CARE, V30, P136, DOI 10.1097/00005650-199202000-00005

HILLMAN DC, 1996, HLTH HOSP L, V29, P288
Himmelstein J, 1996, PUBLIC HEALTH REP, V111, P12
HIMMELSTEIN J, 1996, PUB HLTH REP, V111, P21
Hirshfeld E, 1997, Ann Health Law, V6, P1
HIRSHFELD E, 1997, ANN HLTH L, V6, P11
HOWATT G, 1998, STAR TRIB   0724, pD3
HOWATT G, 1998, STAR TRIB   1026, pD6
Jensen GA, 1997, HEALTH AFFAIR, V16, P125, DOI 10.1377/hlthaff.16.1.125
JOHNSSON J, DIRECT CONTRACTING H, P40
JOHNSSON J, 1992, HOSPITALS   0220, P56
JOHNSSON J, 1990, HOSPITALS   0305, P40
KENKEL PJ, 1990, MODERN HEALTHCA 1015, P24
KENNEDY DV, 1998, HEALTHCARE FIN M AUG, P45
KERR EA, 1995, ANN INTERN MED, V123, P500, DOI 10.7326/0003-4819-123-7-199510010-00004
KILBORN PT, 1998, NY TIMES   0322, pA20
KLEINKE JD, 1994, WALL ST J   1105, pA14
KNUTSON D, 1999, COMMUNICATION   0209
KNUTSON D, 1998, INQUIRY, V35, P177
Knutson DL, 1998, INQUIRY-J HEALTH CAR, V35, P171
LEVIT KR, 1998, HLTH AFF   JAN, P43
LUFT HS, 1995, INQUIRY-J HEALTH CAR, V32, P23
Luft HS, 1996, HEALTH AFFAIR, V15, P23, DOI 10.1377/hlthaff.15.1.23
LUFT HS, 1996, HLTH AFF   SPR, P26
MANNING J, 1998, MINNEAPOLIS STP 0306, P3
MARTINDALE M, 1998, DETROIT NEWS   1006, pD6
MASHOW JI, 1996, ENV DISABILITY INCOM, P29
Maxwell J, 1998, HEALTH AFFAIR, V17, P216, DOI 10.1377/hlthaff.17.3.216
MAXWELL J, 1998, HLTH AFF   MAY, P224
Meyer H, 1998, HOSP HEALTH NETWORK, V72, P22
MEYER H, 1996, HOSP HLTH NETWO 0420, P34
Morreim EH, 1995, BALANCING ACT NEW ME
*NAT COMM CLIN LAB, 1997, REF METH BROTH DIL A, P1
Newhouse JP, 1998, INQUIRY-J HEALTH CAR, V35, P122
Newhouse JP, 1997, HEALTH AFFAIR, V16, P26, DOI 10.1377/hlthaff.16.5.26
NEWHOUSE JP, 1994, HLTH AFFAIRS   SPR, P132
NEWMAN P, 1992, NEW PALGRAVE DICT MO, V1, P683
OGARA N, 1990, HOSPITALS   1205, P64
Overbay A, 1996, AM J LAW MED, V22, P361
PAULY MV, 1986, J ECON LIT, V24, P629
PRIMLEY DW, 1999, HLTH L REP BNA, V8, P173
REINERTSEN JL, 1993, GROUP PRACTICE J JAN, P26
Robinow A L, 1997, Manag Care Q, V5, P61
ROBINOW AL, COMMUNICATION
ROBINOW AL, 1999, COMMUNICATION   0212
ROBINOW AL, 1997, MANAGED CARE Q   SUM, V5, P63
Robinson JC, 1995, HEALTH AFFAIR, V14, P117, DOI 10.1377/hlthaff.14.4.117
ROBINSON JC, 1995, MED CARE, V33, P1161, DOI 10.1097/00005650-199512000-00001
ROBINSON JC, 1996, HLTH AFFAIRS   SPR, P7
ROBINSON JC, 1999, HLTH AFF   MAR, P231
ROCKART JF, 1991, CORPORATION 1990S IN, P189
RODWIN MA, 1993, MED MONEY MORALS PHY, P135
Rogal DL, 1998, INQUIRY-J HEALTH CAR, V35, P115
Rothstein M., 1998, AM JL MED, V24, P401
Rothstein MA, 1998, AM J LAW MED, V24, P399
RUBIN AJ, 1998, LA TIMES   0901, pA1
SALGANIK MW, 1996, BALTIMORE SUN   0426, pC1
SCHULTZ EE, 1994, WALL ST J   0919, pA1

SCHWARTZ PM, 1995, VANDERBILT LAW REV, V48, P304
SCHWARTZ PM, 1995, VANDERBILT LAW REV, V28, P295
SEAVER DJ, 1994, HEALTHCARE FIN M AUG, P20
SHORTELL SM, 1996, REMAKING HLTH CARE A
SINTON P, 1998, SF CHRON   0618, pD1
Smith S, 1998, HEALTH AFFAIR, V17, P128, DOI 10.1377/hlthaff.17.5.128
SOLOVY A, 1996, HOSP HLTH NETWO 0420, P42
SOLOVY A, 1988, HOSPITALS   1120, P52
SOLOVY A, 1998, HOSP HLTH NETWOR AUG, P30
STOUGHTON S, 1999, WASH POST   0208, pA1
SULLIVAN CB, 1991, HLTH AFFAIRS   SUM, P104
SULLIVAN CB, 1991, HLTH AFF   SUM, P114
Summers Lawrence H., 1989, AM ECON REV, V79, P181
SUMMERS LH, 1989, AM ECON REV, V79, P177
TUDOR, 1998, HLTH AFF   MAR, P165
U.S. Department of Justice and Federal Trade Commission, 1996, STAT ANT ENF POL HLT
UNLAND JJ, 1996, J HLTH CARE FIN FAL, P58
UNLAND JJ, 1998, J HLTH CARE FIN WIN, P12
*US DEP JUST FED T, 1999, GUID POL STAT
Van Barneveld EM, 1998, SOC SCI MED, V47, P223, DOI 10.1016/S0277-9536(98)00056-2
VANDEVEN W, 1994, HEALTH AFFAIR, P120
Westin A, 1967, PRIVACY FREEDOM
Wetzell S, 1996, Minn Med, V79, P15
WETZELL S, 1996, MINN MED, V79, P18
WINSLOW R, 1995, WALL STREET J   0721, pB1
WINSLOW R, 1993, WALL ST J   0226, pA9
WISE D, 1995, BUS HLTH   FEB, P22
WISE D, 1993, BUS HLTH   SEP, P53
Witten DJ, 1997, AM J LAW MED, V23, P449
WITTEN DJ, 1997, AM JL MED, V23, P470
WYNGAARDEN JB, 1992, CECIL TXB MED, P332
YASUDA G, 1992, ORLANDO SENTINE 0705, pD1
1998, HOSP HLTH NETWO 1003, P34
1990, BLACKS LAW DICT, P240
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TI Including all voices in international data-sharing governance
SO HUMAN GENOMICS
LA English
DT Article
DE Data sharing; International research; Governance; Public engagement;
   Inclusion; Digital technologies
ID INCREASING VALUE; REDUCING WASTE; POLICY; CHALLENGES; GENOMICS
AB Background: Governments, funding bodies, institutions, and publishers have
developed a number of strategies to encourage researchers to facilitate access
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to datasets. The rationale behind this approach is that this will bring a number of benefits and enable advances in healthcare and medicine by allowing the maximum returns from the investment in research, as well as reducing waste and promoting transparency. As this approach gains momentum, these data-sharing practices have implications for many kinds of research as they become standard practice across the world.

Main text: The governance frameworks that have been developed to support biomedical research are not well equipped to deal with the complexities of international data sharing. This system is nationally based and is dependent upon expert committees for oversight and compliance, which has often led to piece-meal decision-making. This system tends to perpetuate inequalities by obscuring the contributions and the important role of different data providers along the data stream, whether they be low- or middle-income country researchers, patients, research participants, groups, or communities. As research and data-sharing activities are largely publicly funded, there is a strong moral argument for including the people who provide the data in decision-making and to develop governance systems for their continued participation.

Conclusions: We recommend that governance of science becomes more transparent, representative, and responsive to the voices of many constituencies by conducting public consultations about data-sharing addressing issues of access and use; including all data providers in decision-making about the use and sharing of data along the whole of the data stream; and using digital technologies to encourage accessibility, transparency, and accountability. We anticipate that this approach could enhance the legitimacy of the research process, generate insights that may otherwise be overlooked or ignored, and help to bring valuable perspectives into the decision-making around international data sharing.

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CR [Anonymous], 2016, Nature, V534, P435, DOI 10.1038/534435b
Avard D, 2009, J PUBLIC DELIBERATIO, V5, P7
Borry P, 2017, J COMMUNITY GENET
Chalmers I, 2014, LANCET, V383, P156, DOI 10.1016/S0140-6736(13)62229-1
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Coicaud JM, 2014, GLOB POLICY, V5, P135, DOI 10.1111/1758-5899.12118
De Castro Paola, 2013, Acta Inform Med, V21, P291, DOI 10.5455/aim.2013.21.291-292
de Vries J, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-016-0165-6
de Vries J, 2015, TRENDS GENET, V31, P117, DOI 10.1016/j.tig.2014.11.004
de Vries J, 2011, BMC MED ETHICS, V12, DOI 10.1186/1472-6939-12-5
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Goldenberg AJ, 2015, BMC MED ETHICS, V16, DOI 10.1186/s12910-015-0020-1
Haak LL, 2012, LEARN PUBL, V25, P259, DOI 10.1087/20120404
Haug CJ, 2017, NEW ENGL J MED, V376, P2203, DOI 10.1056/NEJMp1704485
Joly Y., 2012, MED LAW INT, V12, P92, DOI [10.1177%2F0968533212458431, DOI 10.1177/0968533212458431]
Kaye J, 2016, BIOPRESERV BIOBANK, V14, P201, DOI 10.1089/bio.2015.0124
Kaye Jane, 2015, Life Sci Soc Policy, V11, P10, DOI 10.1186/s40504-015-0028-9
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Mabile L, 2013, GIGASCIENCE, V2, DOI 10.1186/2047-217X-2-7
Macleod MR, 2014, LANCET, V383, P101, DOI 10.1016/S0140-6736(13)62329-6
Mort M, 2016, HEALTH RISK SOC, V17, P605, DOI 10.1080/13698575.2015.1135234
Murtagh MJ, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-017-0167-z
Murtagh MJ, 2016, BIOPRESERV BIOBANK, V14, P231, DOI 10.1089/bio.2016.0002
Parker M, 2012, J MOB TECHNOL MED, V1, P50, DOI [10.7309/jmtm.23, DOI 10.7309/JMTM.23]
Pizzo E, 2015, HEALTH EXPECT, V18, P1918, DOI 10.1111/hex.12204
Rowhani-Farid Anisa, 2017, Res Integr Peer Rev, V2, P4, DOI 10.1186/s41073-017-0028-9
Shabani M, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002339
Swan M, 2009, INT J ENV RES PUB HE, V6, P492, DOI 10.3390/ijerph6020492
The Wellcome Trust, 2003, SHAR DAT LARG SCAL B
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
Upshur Ross E G, 2007, BMC Med Ethics, V8, P11, DOI 10.1186/1472-6939-8-11
Wilson Rebecca C, 2016, F1000Res, V5, P1307, DOI 10.12688/f1000research.8786.2
Yoshizawa G, 2014, GENOME MED, V6, DOI 10.1186/gm556

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DE BRCA1; BRCA2; breast cancer; data sharing; variant interpretation and
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AB Purpose: The purpose of this study was to develop a national program for Canadian diagnostic laboratories to compare DNA-variant interpretations and resolve discordant-variant classifications using the BRCA1 and BRCA2 genes as a case study.

Methods: BRCA1 and BRCA2 variant data were uploaded and shared through the Canadian Open Genetics Repository (COGR;http://www.openg enetics.ca). A total of 5,554 variant observations were submitted; classification differences were identified and comparison reports were sent to participating laboratories. Each site had the opportunity to reclassify variants. The data were analyzed before and after the comparison report process to track concordantor discordant-variant classifications by three different models.

Results: Variant-discordance rates varied by classification model: 38.9% of variants were discordant when using a five-tier model, 26.7% with a three-tier model, and 5.0% with a two-tier model. After the comparison report process, the proportion of discordant variants dropped to 30.7% with the five-tier model, to 14.2% with the three-tier model, and to 0.9% using the two-tier model.

Conclusion: We present a Canadian interinstitutional quality improvement program for DNA-variant interpretations. Sharing of variant knowledge by clinical diagnostic laboratories will allow clinicians and patients to make more informed decisions and lead to better patient outcomes.

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CR Amendola LM, 2016, AM J HUM GENET, V98, P1067, DOI 10.1016/j.ajhg.2016.03.024
Aronson SJ, 2011, HUM MUTAT, V32, P532, DOI 10.1002/humu.21470
Balmana J, 2016, J CLIN ONCOL, V34, P4071, DOI 10.1200/JCO.2016.68.4316
Burn J, 2016, HUM MUTAT, V37, P505, DOI 10.1002/humu.22986
Carvalho MA, 2007, CANCER RES, V67, P1494, DOI 10.1158/0008-5472.CAN-06-3297
Duzkale H, 2013, CLIN GENET, V84, P453, DOI 10.1111/cge.12257
Eccles DM, 2015, ANN ONCOL, V26, P2057, DOI 10.1093/annonc/mdv278
Fokkema IFAC, 2011, HUM MUTAT, V32, P557, DOI 10.1002/humu.21438
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Landrum MJ, 2016, NUCLEIC ACIDS RES, V44, pD862, DOI 10.1093/nar/gkv1222
Lerner-Ellis J, 2015, J MED GENET, V52, P438, DOI 10.1136/jmedgenet-2014-102933
Narod SA, 2004, NAT REV CANCER, V4, P665, DOI 10.1038/nrc1431
Pepin MG, 2016, GENET MED, V18, P20, DOI 10.1038/gim.2015.31
Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
Richards CS, 2008, GENET MED, V10, P294, DOI 10.1097/GIM.0b013e31816b5cae
Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
Richter S, 2013, ANN ONCOL, V24, P69, DOI 10.1093/annonc/mdt312
Thorogood A, GENET MED
Vail PJ, 2015, J COMMUN GENET, V6, P351, DOI 10.1007/s12687-015-0220-x

```
   Wildeman M, 2008, HUM MUTAT, V29, P6, DOI 10.1002/humu.20654
NR 20
TC 5
Z9 5
U1 1
U2 3
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1098-3600
EI 1530-0366
J9 GENET MED
JI Genet. Med.
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BP 294
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WC Genetics & Heredity
SC Genetics & Heredity
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DA 2019-08-06
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PT J
AU Serwadda, D
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AF Serwadda, David
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   Grabowski, M. Kate
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   Wanyenze, Rhoda K.
TI Open data sharing and the Global South-Who benefits?
SO SCIENCE
LA English
DT Editorial Material
ID PUBLIC-HEALTH RESEARCH; RESEARCH STAKEHOLDERS; VIEWS; EXPERIENCES
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CR Allen L, 2014, NATURE, V508, P312, DOI 10.1038/508312a
```

```
   Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
   Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
   Council for International Organizations of Medical Sciences & World Health
Organization, 2016, INT ETH GUID HLTH RE
   Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
   Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
   Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
NR 7
TC 5
Z9 5
U1 1
U2 12
PU AMER ASSOC ADVANCEMENT SCIENCE
PI WASHINGTON
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DI 10.1126/science.aap8395
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
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PT J
AU Wang, S
   Jiang, XQ
   Tang, HX
   Wang, XF
   Bu, DY
   Carey, K
   Dyke, SOM
   Fox, D
   Jiang, C
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TI A community effort to protect genomic data sharing, collaboration and outsourcing
SO NPJ GENOMIC MEDICINE
LA English
DT Article
ID PRIVACY; QUANTIFICATION
AB The human genome can reveal sensitive information and is potentially re-identifiable, which raises privacy and security concerns about sharing such data on wide scales. In 2016, we organized the third Critical Assessment of Data Privacy and Protection competition as a community effort to bring together biomedical informaticists, computer privacy and security researchers, and scholars in ethical, legal, and social implications (ELSI) to assess the latest advances on privacy-preserving techniques for protecting human genomic data. Teams were asked to develop novel protection methods for emerging genome privacy challenges in three scenarios: Track (1) data sharing through the Beacon service of the Global Alliance for Genomics and Health. Track (2) collaborative discovery of similar genomes between two institutions; and Track (3) data outsourcing to public cloud services. The latter two tracks represent continuing themes from our 2015 competition, while the former was new and a response to a recently established vulnerability. The winning strategy for Track 1 mitigated the privacy risk by hiding approximately 11% of the variation in the database while permitting around 160,000 queries, a significant improvement over the baseline. The winning strategies in Tracks 2 and 3 showed significant progress over the previous competition by achieving multiple orders of magnitude performance improvement in terms of computational runtime and memory requirements. The outcomes suggest that applying highly optimized privacy-preserving and secure computation techniques to safeguard genomic data sharing and analysis is useful. However, the results also indicate that further efforts are needed to refine these techniques into practical solutions.
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CR Al Aziz MM, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0278-x
[Anonymous], 2016, 1000 GENOMES DEEP CA
Aziz Md Momin Al, 2017, BMC Med Genomics, V10, P41, DOI 10.1186/s12920-017-0279-9
Bloss CS, 2013, GENOME MED, V5, DOI 10.1186/gm511
BMC Medical Genomics, 2017, BMC MED GEN SPEC ISS
Bos JW, 2014, J BIOMED INFORM, V50, P234, DOI 10.1016/j.jbi.2014.04.003
Cetin GS, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0276-z
Chen F, 2016, AM MED INF ASS ANN S
Chen F, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0281-2
Chen F, 2017, BIOINFORMATICS, V33, P871, DOI 10.1093/bioinformatics/btw758
Claes P, 2014, PLOS GENET, V10, DOI 10.1371/journal.pgen.1004224
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Constable SD, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S2
Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1
El Emam K., 2014, PAPER COMMISSIONED C
Erlich Y, 2014, NAT REV GENET, V15, P409, DOI 10.1038/nrg3723
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Harmanci A, 2016, NAT METHODS, V13, P251, DOI [10.1038/NMETH.3746, 10.1038/nmeth.3746]
Hayden EC, 2015, NATURE, V519, P400, DOI 10.1038/519400a
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Humbert M, 2013, P 2013 ACM SIGSAC C, P1141, DOI DOI 10.1145/2508859.2516707
Jagadeesh KA, 2017, SCIENCE, V357, P692, DOI 10.1126/science.aam9710
Jiang XQ, 2014, BMC MED INFORM DECIS, V14, DOI 10.1186/1472-6947-14-S1-S1
Kamm L, 2013, BIOINFORMATICS, V29, P886, DOI 10.1093/bioinformatics/btt066
Kim M, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0280-3
Lecroq T, 2013, Yearb Med Inform, V8, P175
McLaren PJ, 2016, GENET MED, V18, P814, DOI 10.1038/gim.2015.167
Naveed M, 2015, ACM COMPUT SURV, V48, DOI 10.1145/2767007
Raisaro JL, 2017, J AM MED INFORM ASSN, V24, P799, DOI 10.1093/jamia/ocw167
Shringarpure SS, 2015, AM J HUM GENET, V97, P631, DOI 10.1016/j.ajhg.2015.09.010
Sousa JS, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0275-0
Sweeney L., 2013, 1304 7605 ARXIV
Tang HX, 2016, BMC MED GENOMICS, V9, DOI 10.1186/s12920-016-0224-3
Thomas U. G., 2016, NEW COMMUNITY CHALLE
Vanderbilt IBM, 2016, MICROSOFT LED TEAMS
Wan ZY, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0282-1
Wan ZY, 2017, AM J HUM GENET, V100, P316, DOI 10.1016/j.ajhg.2016.12.002
Wang R, 2009, P 16 ACM C COMP COMM, P534
WANG S, 2014, BMC MED INFORM DE S1, V14
Wang S, 2016, BIOINFORMATICS, V32, P211, DOI 10.1093/bioinformatics/btv563
Wang XS, 2015, CCS'15: PROCEEDINGS OF THE 22ND ACM SIGSAC CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P492, DOI 10.1145/2810103.2813725
Yu F, 2014, BMC MED INFORM DECIS, V14, DOI 10.1186/1472-6947-14-S1-S3
Zhang YC, 2015, BMC MED INFORM DECIS, V15, DOI [10.1186/1472-6947-15-S5-S5, 10.1186/1472-6947-15-S5-S4]
Ziegeldorf JH, 2017, BMC MED GENOMICS, V10, DOI 10.1186/s12920-017-0277-y

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PT J
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AF Kim, Katherine K.
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TI Factors affecting willingness to share electronic health data among
   California consumers
SO BMC MEDICAL ETHICS
LA English
DT Article
DE Consent; Ethics; Electronic health records; Health information exchange;
   Learning healthcare systems; Distributed research network
ID INFORMATION EXCHANGE; CLINICAL-RESEARCH; INFORMED-CONSENT; PATIENT
   PERSPECTIVES; PATIENTS ATTITUDES; MEDICAL-RESEARCH; PRIMARY-CARE;
   PARTICIPATION; RECORDS; DECISION

AB Background: Robust technology infrastructure is needed to enable learning health care systems to improve quality, access, and cost. Such infrastructure relies on the trust and confidence of individuals to share their health data for healthcare and research. Few studies have addressed consumers' views on electronic data sharing and fewer still have explored the dual purposes of healthcare and research together. The objective of the study is to explore factors that affect consumers' willingness to share electronic health information for healthcare and research.

Methods: This study involved a random-digit dial telephone survey of 800 adult Californians conducted in English and Spanish. Logistic regression was performed using backward selection to test for significant (p-value <= 0.05) associations of each explanatory variable with the outcome variable.

Results: The odds of consent for electronic data sharing for healthcare decreased as Likert scale ratings for EHR impact on privacy worsened, odds ratio (OR) = 0.74, 95% CI [0.60, 0.90]; security, OR = 0.80, 95% CI [0.66, 0.98]; and quality, OR = 0.59, 95% CI [0.46-0.75]. The odds of consent for sharing for research was greater for those who think EHR will improve research quality, OR =

11.26, 95% CI [4.13, 30.73]; those who value research benefit over privacy OR = 2.72, 95% CI [1.55, 4.78]; and those who value control over research benefit OR = 0.49, 95% CI [0.26, 0.94].

Conclusions: Consumers' choices about electronically sharing health information are affected by their attitudes toward EHRs as well as beliefs about research benefit and individual control. Design of person-centered interventions utilizing electronically collected health information, and policies regarding data sharing should address these values of importance to people. Understanding of these perspectives is critical for leveraging health data to support learning health care systems.

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FX The authors were partially funded by grants from AHRQ R01HS019913 (KK), Gordon and Betty Moore Foundation grant to the Betty Irene Moore School of Nursing at UC Davis (KK), and National Center for Advancing Translational Sciences, National Institutes of Health, through grant # UL1 TR000002 (MDW). Funding for the survey was provided by Award # 90HT0029 to California Health and Human Services Agency from Office of the National Coordinator for Health Information Technology (ONC), U.S. Department of Health and Human Services. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of ONC or the State of California. The funders had no role in decisions regarding the data or manuscript.

CR Adler-Milstein J, 2015, HLTH AFF
Agaku IT, 2014, J AM MED INFORM ASSN, V21, P374, DOI 10.1136/amiajnl-2013-002079
Ancker JS, 2015, AM J MANAG CARE, V21, pE487
Ancker JS, 2013, J AM MED INFORM ASSN, V20, P152, DOI 10.1136/amiajnl-2012-001062
Anderson CL, 2011, INFORM SYST RES, V22, P469, DOI 10.1287/isre.1100.0335
Caine K, 2013, J AM MED INFORM ASSN, V20, P7, DOI 10.1136/amiajnl-2012-001023
Campos-Castillo C, 2015, J AM MED INFORM ASSN, V22, pE130, DOI 10.1136/amiajnl-2014-002804
Cho MK, 2015, ANN INTERN MED, V162, P690, DOI 10.7326/M15-0166
Choy A, 2001, EXPOSED ONLINE WHY N
Dhopeshwarkar RV, 2012, ANN FAM MED, V10, P428, DOI 10.1370/afm.1396
Dimitropoulos Linda, 2011, Am J Manag Care, V17, pSP111
Faden RR, 2013, HASTINGS CENT REP, V43, pS16, DOI 10.1002/hast.134
Fiscella K, 2015, BMC MED ETHICS, V16, DOI 10.1186/s12910-015-0056-2
Fox S., 2011, SOCIAL LIFE HLTH INF
Friedman DB, 2015, AM J HEALTH PROMOT, V29, P332, DOI 10.4278/ajhp.130514-QUAL-247
Galea S, 2007, ANN EPIDEMIOL, V17, P643, DOI 10.1016/j.annepidem.2007.03.013
Grande D, 2013, JAMA INTERN MED, V173, P1798, DOI 10.1001/jamainternmed.2013.9166

Harris T, 2005, J EPIDEMIOL COMMUN H, V59, P336, DOI 10.1136/jech.2004.025296
HealthIT.gov, 2014, MEAN CONS OV
Herman B., 2014, EHRS HLTH IT PROJECT
Hill K, 2013, BUILDING METHODOLOGY
Hwang HG, 2012, J MED SYST, V36, P3783, DOI 10.1007/s10916-012-9851-1
Kaplan SH, 2016, EMPIR BIOETH, V7, P116
Keusch F, 2014, BIOL BLOOD MARROW TR, V20, P1604, DOI 10.1016/j.bbmt.2014.06.020
Kim KK, 2015, J AM MED INFORM ASSN, V22, P821, DOI 10.1093/jamia/ocv014
Kim KK, 2014, J AM MED INFORM ASSN, V21, P714, DOI 10.1136/amiajnl-2013-002308
Kuperman GJ, 2013, J GEN INTERN MED, V28, P1663, DOI 10.1007/s11606-012-2313-0
Lieberman L, 1998, J WOMENS HEALTH, V7, P717, DOI 10.1089/jwh.1998.7.717
LLEWELLYNTHOMAS HA, 1991, SOC SCI MED, V32, P35, DOI 10.1016/0277-9536(91)90124-U
McGraw D, 2009, HEALTH AFFAIR, V28, P416, DOI 10.1377/hlthaff.28.2.416
Medford-Davis LN, 2016, HLTH INFORM J
Medical Research Council, 2007, US PERS HLTH INF MED
Mejean C, 2014, J MED INTERNET RES, V16, DOI 10.2196/jmir.3161
Mills EJ, 2006, LANCET ONCOL, V7, P141, DOI 10.1016/S1470-2045(06)70576-9
Page SA, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0130-4
Perera G, 2011, INT J MED INFORM, V80, P94, DOI 10.1016/j.ijmedinf.2010.11.005
Reynolds WW, 2007, SOC SCI MED, V65, P2105, DOI 10.1016/j.socscimed.2007.06.021
Riordan F, 2015, INT J MED INFORM, V84, P237, DOI 10.1016/j.ijmedinf.2015.01.008
Robeznieks A, 2016, GROWING EHR ADOPTION
Sengupta S, 2000, J ACQ IMMUN DEF SYND, V24, P275
Shavers VL, 2001, CANCER, V91, P233, DOI 10.1002/1097-0142(20010101)91:1+<233::AID-CNCR10>3.0.CO;2-8
Shavers-Hornaday V L, 1997, Ethn Health, V2, P31
Simon SR, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1164
Spencer K, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5011
Stevenson F, 2015, BMC HEALTH SERV RES, V15, DOI 10.1186/s12913-015-0783-6
Stevenson F, 2013, FAM PRACT, V30, P227, DOI 10.1093/fampra/cms069
Tait AR, 2003, ANESTHESIOLOGY, V99, P819, DOI 10.1097/00000542-200310000-00012
The Office of the National Coordinator for Health Information Technology (ONC), 2016, REP C UPD AD HLTH IN
Tierney WM, 2015, J GEN INTERN MED, V30, pS31, DOI 10.1007/s11606-014-3053-0
Tikoo M, 2014, EVALUATING CONNECTIC
Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
Wendler D, 2006, PLOS MED, V3, P201, DOI 10.1371/journal.pmed.0030019
Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI 10.1016/j.ijmedinf.2005.08.009
Willison DJ, 2009, BMC MED ETHICS, V10, DOI 10.1186/1472-6939-10-10
NR 54
TC 5
Z9 6
U1 1
U2 13
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1472-6939
J9 BMC MED ETHICS

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JI BMC Med. Ethics
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PG 10
WC Ethics; Medical Ethics; Social Sciences, Biomedical
SC Social Sciences - Other Topics; Medical Ethics; Biomedical Social
   Sciences
GA ES7WQ
UT WOS:000399762500003
PM 28376801
OA DOAJ Gold, Green Published
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PT J
AU Williams, G
   Pigeot, I
AF Williams, Garrath
   Pigeot, Iris
TI Consent and confidentiality in the light of recent demands for data
   sharing
SO BIOMETRICAL JOURNAL
LA English
DT Article
DE Data protection; Ethical review; Informed consent; Privacy; Research
   ethics; Trustworthiness
ID RANDOMIZED CONTROLLED-TRIALS; REPORTING BIAS; MEDICAL-RESEARCH;
   INCREASING VALUE; CLINICAL-TRIALS; REDUCING WASTE; PRIVACY; OUTCOMES;
   CONDUCT; DESIGN
AB Many attempts have been made to formalize ethical requirements for research.
Among the most prominent mechanisms are informed consent requirements and data
protection regimes. These mechanisms, however, sometimes appear as obstacles to
research. In this opinion paper, we critically discuss conventional approaches
to research ethics that emphasize consent and data protection. Several recent
debates have highlighted other important ethical issues and underlined the need
for greater openness in order to uphold the integrity of health-related research.
Some of these measures, such as the sharing of individual-level data, pose
problems for standard understandings of consent and privacy. Here, we argue that
these interpretations tend to be overdemanding: They do not really protect
research subjects and they hinder the research process. Accordingly, we suggest
another way of framing these requirements. Individual consent must be situated
alongside the wider distribution of knowledge created when the actions,
commitments, and procedures of researchers and their institutions are opened to
scrutiny. And instead of simply emphasizing privacy or data protection, we
should understand confidentiality as a principle that facilitates the sharing of
information while upholding important safeguards. Consent and confidentiality
belong to a broader set of safeguards and procedures to uphold the integrity of
the research process.
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CR ALTMAN DG, 1994, BRIT MED J, V308, P283, DOI 10.1136/bmj.308.6924.283
ALTMAN DG, 1980, BRIT MED J, V281, P1336, DOI 10.1136/bmj.281.6251.1336
Baggerly K, 2010, NATURE, V467, P401, DOI 10.1038/467401b
Berlin JA, 2014, CLIN TRIALS, V11, P7, DOI 10.1177/1740774513514497
Capron Alexander Morgan, 1991, Law Med Health Care, V19, P184
Chalmers I, 2005, CLIN TRIALS, V2, P229
Chalmers I, 2013, TRIALS, V14, DOI [10.1186/1745-6215-14-102, 10.1186/1468-6708-14-102]
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Chan AW, 2004, JAMA-J AM MED ASSOC, V291, P2457, DOI 10.1001/jama.291.20.2457
Clayton E. W., 2009, ETHICS EPIDEMIOLOGY
Committee on Civil Liberties Justice and Home Affairs, 2013, REP PROP REG EUR PAR
Council for International Organisations of Medical Sciences (CIOMS) in collaboration with the World Health Organisation (WHO), 2002, INT ETH GUID BIOM RE
Delgado-Rodriguez M, 2004, J EPIDEMIOL COMMUN H, V58, P635, DOI 10.1136/jech.2003.008466
Dwan K, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0066844
Dwork C., 2013, STANFORD LAW REV, V66, P35
Elliott C., 2010, WHITE COAT BLACK HAT
Elliott C., 2010, MOTHER JONES, V35, P54
European Commission, 2012, PROP REG EUR PARL CO
Gigerenzer G., 2004, J SOCIO-ECON, V33, P587, DOI DOI 10.1016/J.SOCEC.2004.09.033
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Graham DJ, 2005, LANCET, V365, P475, DOI 10.1016/S0140-6736(05)17864-7
Habre C, 2014, BMJ-BRIT MED J, V349, DOI 10.1136/bmj.g5219
Halpern SD, 2002, JAMA-J AM MED ASSOC, V288, P358, DOI 10.1001/jama.288.3.358
Healy D, 2009, TRANSCULT PSYCHIATRY, V46, P16, DOI 10.1177/1363461509102285
Ioannidis JPA, 2014, LANCET, V383, P166, DOI 10.1016/S0140-6736(13)62227-8
Ioannidis JPA, 2013, AM J BIOETHICS, V13, P40, DOI 10.1080/15265161.2013.768864
Ioannidis JPA, 2009, NAT GENET, V41, P149, DOI 10.1038/ng.295
Ioannidis JPA, 2005, PLOS MED, V2, P696, DOI 10.1371/journal.pmed.0020124
Jones CW, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f6104
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kelsey T., 2009, PROSPECT
Kirkham JJ, 2010, BMJ-BRIT MED J, V340, DOI 10.1136/bmj.c365
Koenig F, 2015, BIOMETRICAL J, V57, P8, DOI 10.1002/bimj.201300283
Lehman R, 2012, BRIT MED J, V344, DOI 10.1136/bmj.d8158
Lundh A, 2012, COCHRANE DB SYST REV, DOI 10.1002/14651858.MR000033.pub2
Manson NC, 2007, RETHINKING INFORMED CONSENT IN BIOETHICS, P1, DOI 10.1017/CBO9780511814600
McGauran N, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-37
Miller FG, 2008, J LAW MED ETHICS, V36, P560, DOI 10.1111/j.1748-720X.2008.304.x
Neutra RR, 2006, EPIDEMIOLOGY, V17, P335, DOI 10.1097/01.ede.0000209464.97895.bf
O'Neill O., 2002, AUTONOMY TRUST BIOET
Ohm P, 2010, UCLA LAW REV, V57, P1701
Page MJ, 2014, COCHRANE DB SYST REV, V10, DOI DOI 10.10002/14651858.MR000035.PUB2

```
   Parker Michael, 2005, J Health Serv Res Policy, V10, P183, DOI
10.1258/1355819054338960
   Richards NM, 2007, GEORGETOWN LAW J, V96, P123
   RICKHAM PP, 1964, BRIT MED J, V2, P173
   Ross JS, 2012, AM J PUBLIC HEALTH, V102, P72, DOI 10.2105/AJPH.2011.300187
   Rothstein MA, 2013, AM J BIOETHICS, V13, P27, DOI
10.1080/15265161.2013.767955
   Rothstein MA, 2010, AM J BIOETHICS, V10, P3, DOI 10.1080/15265161.2010.494215
   Royal Society, 2012, SCI OPEN ENTERPRISE
   SACKETT DL, 1979, J CHRON DIS, V32, P51, DOI 10.1016/0021-9681(79)90012-2
   Safer DJ, 2002, J NERV MENT DIS, V190, P583, DOI
10.1097/01.NMD.0000030522.74800.0D
   Saini P, 2014, BMJ-BRIT MED J, V349, DOI 10.1136/bmj.g6501
   SIEGLER M, 1982, NEW ENGL J MED, V307, P1518, DOI 10.1056/NEJM198212093072411
   Solove DJ, 2013, HARVARD LAW REV, V126, P1880
   Stamatakis E, 2013, EUR J CLIN INVEST, V43, P469, DOI 10.1111/eci.12074
NR 55
TC 5
Z9 5
U1 0
U2 11
PU WILEY
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PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
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SC Mathematical & Computational Biology; Mathematics
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PT J
AU Doel, T
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   Pratt, R
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   Ourselin, S
AF Doel, Tom
   Shakir, Dzhoshkun I.
   Pratt, Rosalind
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Aertsen, Michael
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   Deprest, Jan
   Vercauteren, Tom
   Ourselin, Sebastien
TI GIFT-Cloud: A data sharing and collaboration platform for medical
   imaging research
SO COMPUTER METHODS AND PROGRAMS IN BIOMEDICINE
LA English
DT Article
DE Data sharing; Biomedical research; Cross-disciplinary research;
   Anonymisation; Deidentification; Fetal surgery
ID DE-IDENTIFICATION; ARCHIVE; INFORMATION; MANAGEMENT; PRIVACY

AB Objectives: Clinical imaging data are essential for developing research software for computer aided diagnosis, treatment planning and image-guided surgery, yet existing systems are poorly suited for data sharing between healthcare and academia: research systems rarely provide an integrated approach for data exchange with clinicians; hospital systems are focused towards clinical patient care with limited access for external researchers; and safe haven environments are not well suited to algorithm development. We have established GIFT-Cloud, a data and medical image sharing platform, to meet the needs of GIFT-Surg, an international research collaboration that is developing novel imaging methods for fetal surgery. GIFT Cloud also has general applicability to other areas of imaging research.

Methods: GIFT-Cloud builds upon well-established cross-platform technologies. The Server provides secure anonymised data storage, direct web-based data access and a REST API for integrating external software. The Uploader provides automated on-site anonymisation, encryption and data upload. Gateways provide a seamless process for uploading medical data from clinical systems to the research server.

Results: GIFT-Cloud has been implemented in a multi-centre study for fetal medicine research. We present a case study of placental segmentation for pre-operative surgical planning, showing how GIFT-Cloud underpins the research and integrates with the clinical workflow.

Conclusions: GIFT-Cloud simplifies the transfer of imaging data from clinical to research institutions, facilitating the development and validation of medical research software and the sharing of results back to the clinical partners. GIFT-Cloud supports collaboration between multiple healthcare and research institutions while satisfying the demands of patient confidentiality, data security and data ownership. (C) 2016 The Authors. Published by Elsevier Ireland Ltd.

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FU Innovative Engineering for Health - Wellcome Trust [WT101957,
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   Council (EPSRC) [NS/A000027/1]; National Institute for Health Research
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CR Archie KA, 2012, J DIGIT IMAGING, V25, P635, DOI 10.1007/s10278-012-9462-x
   Aryanto KYE, 2015, EUR RADIOL, V25, P3685, DOI 10.1007/s00330-015-3794-0
   Bellon E, 2011, EUR J RADIOL, V78, P199, DOI 10.1016/j.ejrad.2010.05.025
   Chalouhi GE, 2013, PRENATAL DIAG, V33, P109, DOI 10.1002/pd.4031
   Clark K, 2013, J DIGIT IMAGING, V26, P1045, DOI 10.1007/s10278-013-9622-7
   Das Samir, 2011, Front Neuroinform, V5, P37, DOI 10.3389/fninf.2011.00037
   Deprest JA, 2010, PRENATAL DIAG, V30, P653, DOI 10.1002/pd.2571
   Fecher B, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0118053
   Fetzer DT, 2008, ACAD RADIOL, V15, P390, DOI 10.1016/j.acra.2007.11.008
   Freymann JB, 2012, J DIGIT IMAGING, V25, P14, DOI 10.1007/s10278-011-9422-x
   Gao Y.R., 2013, MED IMAGING 2013 ADV
   Harrigan RL, 2016, NEUROIMAGE, V124, P1097, DOI
10.1016/j.neuroimage.2015.05.021
   Helmer KG, 2011, J AM MED INFORM ASSN, V18, P416, DOI 10.1136/amiajnl-2010-
000032
   Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
   National Electrical Manufacturers Association, 2016, DIG IM COMM MED DICO
   Ozyurt IB, 2010, NEUROINFORMATICS, V8, P231, DOI 10.1007/s12021-010-9078-6
   Pratt R., 2015, PRENAT DIAGN
   Radiological Society of N. America, 2000 MIRC CLIN TRIAL
   Robinson JD, 2014, AM J ROENTGENOL, V203, pW658, DOI 10.2214/AJR.13.11789
   Scott Adam, 2011, Front Neuroinform, V5, P33, DOI 10.3389/fninf.2011.00033
   Wang G., 2016, MED IMAGE ANAL
NR 21
TC 5
Z9 5
U1 0
U2 9
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
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J9 COMPUT METH PROG BIO
JI Comput. Meth. Programs Biomed.
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WC Computer Science, Interdisciplinary Applications; Computer Science,
   Theory & Methods; Engineering, Biomedical; Medical Informatics
SC Computer Science; Engineering; Medical Informatics
GA EM3NZ
UT WOS:000395223200016
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AU Gazzarata, R
   Giannini, B
   Giacomini, M
AF Gazzarata, R.
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   Giacomini, M.
TI A SOA-Based Platform to Support Clinical Data Sharing
SO JOURNAL OF HEALTHCARE ENGINEERING
LA English
DT Article
ID ELECTRONIC DATA CAPTURE; DATA-MANAGEMENT; WEB SERVICES; TRIALS;
   ARCHITECTURE; SYSTEMS
AB The eSource Data Interchange Group, part of the Clinical Data Interchange
Standards Consortium, proposed five scenarios to guide stakeholders in the
development of solutions for the capture of eSource data. The fifth scenario was
subdivided into four tiers to adapt the functionality of electronic health
records to support clinical research. In order to develop a system belonging to
the "Interoperable" Tier, the authors decided to adopt the service-oriented
architecture paradigm to support technical interoperability, Health Level Seven
Version 3 messages combined with LOINC (Logical Observation Identifiers Names
and Codes) vocabulary to ensure semantic interoperability, and Healthcare
Services Specification Project standards to provide process interoperability.
The developed architecture enhances the integration between patient-care
practice and medical research, allowing clinical data sharing between two
hospital information systems and four clinical data management systems/clinical
registries. The core is formed by a set of standardized cloud services connected
through standardized interfaces, involving client applications. The system was
approved by a medical staff, since it reduces the workload for the management of
clinical trials. Although this architecture can realize the "Interoperable" Tier,
the current solution actually covers the "Connected" Tier, due to local hospital
policy restrictions.
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CR Altman DG, 1990, PRACTICAL STAT MED R
   [Anonymous], 2008, IHE LAB TECHNICAL FR
   [Anonymous], 2009, HL7 ITALIA IMPLEMENT
```

Atalag K., 2012, C 11 ANN HLTH INF NZ

Bonetto M, 2014, 2014 IEEE-EMBS INTERNATIONAL CONFERENCE ON BIOMEDICAL AND HEALTH INFORMATICS (BHI), P346, DOI 10.1109/BHI.2014.6864374

Bonetto M, 2016, IEEE J TRANSL ENG HE, V4, DOI 10.1109/JTEHM.2015.2513043

Boyd AD, 2009, J AM MED INFORM ASSN, V16, P784, DOI 10.1197/jamia.M2985

Bridges Michael W, 2007, Health Manag Technol, V28, P10

Canepa S., 2014, 13 MED C MED BIOL EN, P1314

Clinical Data Interchange Standards Consortium (CDISC), 2006, LEV SOURC DAT INT ES

Curbera F, 2002, IEEE INTERNET COMPUT, V6, P86, DOI 10.1109/4236.991449

Curbera F., 2001, OOPSLA 2001 WORKSH O

dellaSalute M., 2011, SOLE 24ORE SANITA, V7

DiMario M. J., 2006, 2006 IEEE SMC INT C, P6

Dolin RH, 2006, J AM MED INFORM ASSN, V13, P30, DOI 10.1197/jamia.M1888

EHR/CR Functional Profile Working Group, 2008, EHR CR US REQ DOC

EHRCR (Electronic Health Records for Clinical Research) Working Group, 2009, PRACT CONS CLIN TRIA

El Fadly A, 2007, AMIA Annu Symp Proc, P216

El Fadly AbdenNaji, 2011, J Biomed Inform, V44 Suppl 1, pS94, DOI 10.1016/j.jbi.2011.07.007

FAHEY T, 1995, BRIT MED J, V311, P1056, DOI 10.1136/bmj.311.7012.1056

Fraccaro P, 2012, STUD HEALTH TECHNOL, V180, P554, DOI 10.3233/978-1-61499-101-4-554

Fraccaro Paolo, 2013, Med 2 0, V2, pe5, DOI 10.2196/med20.2712

Fraccaro P, 2013, INFORM HEALTH SOC CA, V38, P313, DOI 10.3109/17538157.2013.812648

Gazzarata R., 2016, EUROPEAN J BIOMEDICA, V12

Gazzarata R, 2014, IEEE J BIOMED HEALTH, V18, P1764, DOI 10.1109/JBHI.2014.2334372

Gerritsen M G, 1993, Proc Annu Symp Comput Appl Med Care, P659

Gilbert P., 2013, HL7 VERSION 3 STANDA

Greiner U, 2007, ENTERPRISE INTEROPERABILITY II: NEW CHALLENGES AND APPROACHES, P865, DOI 10.1007/978-1-84628-858-6_93

Guleria P., 2012, INT J ADV RES COMPUT, V1, P18

Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010

Healthinformatics, INT

IEEE, 1991, 610 IEEE, V610, P1, DOI DOI 10.1109/IEEESTD.1991.106963

Kawamoto K, 2007, J AM MED INFORM ASSN, V14, P146, DOI 10.1197/jamia.M2298

Kawamoto K, 2009, J AM MED INFORM ASSN, V16, P874, DOI 10.1197/jamia.M3123

Kilic O, 2009, IEEE T INF TECHNOL B, V13, P467, DOI 10.1109/TITB.2008.904647

Kovalchuk Y, 2013, IEEE CONF WIREL MOB, P297, DOI 10.1109/WiMOB.2013.6673376

Krishnankutty B, 2012, INDIAN J PHARMACOL, V44, P168, DOI 10.4103/0253-7613.93842

Kush R, 2007, J AM MED INFORM ASSN, V14, P662, DOI 10.1197/jamia.M2157

Lotti S., 2012, SERVICE FUNCTIONAL M

Ltd. Milieu and Time.lex, 2014, OV NAT LAWS EL HLTH

Lu ZW, 2010, OPEN ACCESS J CLIN T, V2, P93

Lu ZW, 2010, IEEE ENG MED BIOL, V29, P95, DOI 10.1109/MEMB.2009.935726

Marks RG, 2004, CONTROL CLIN TRIALS, V25, P437, DOI 10.1016/j.cct.2004.07.001

Murphy EC, 2007, INVEST OPHTH VIS SCI, V48, P4383, DOI 10.1167/iovs.07-0345

Mykkanen J, 2007, INT J MED INFORM, V76, P89, DOI 10.1016/j.ijmedinf.2006.10.001

Natis Y. V., 2003, SERVICE ORIENTED ARC

OMG, 2011, ID CROSS REF SERV IX

OMG, 2011, RETR LOC UPD SERV RL

Rico-Villademoros Fernando, 2004, BMC Med Res Methodol, V4, P6, DOI 10.1186/1471-2288-4-6

```
   Rimal Bhaskar Prasad, 2009, Proceedings of the 2009 Fifth International Joint
Conference on INC, IMS and IDC, P44, DOI 10.1109/NCM.2009.218
   Tittle V, 2014, J INT AIDS SOC, V17, P139, DOI 10.7448/IAS.17.4.19712
   Tsagkani C., 2005, P IFIP ACM SIGAPP IN, P23
   Tudoran R, 2014, IEEE ACM INT SYMP, P151, DOI 10.1109/CCGrid.2014.89
   Turisco F, 2005, J INVEST MED, V53, P425, DOI 10.2310/6650.2005.53806
   Vasilescu E, 2006, 1ST TRANSDISCIPLINARY CONFERENCE ON DISTRIBUTED DIAGNOSIS
AND HOME HEALTHCARE, CONFERENCE PROCEEDINGS, P91, DOI 10.1109/DDHH.2006.1624805
   Zhang W, 2009, WISM: 2009 INTERNATIONAL CONFERENCE ON WEB INFORMATION SYSTEMS
AND MINING, PROCEEDINGS, P302, DOI 10.1109/WISM.2009.69
NR 56
TC 5
Z9 5
U1 0
U2 7
PU HINDAWI LTD
PI LONDON
PA ADAM HOUSE, 3RD FLR, 1 FITZROY SQ, LONDON, W1T 5HF, ENGLAND
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J9 J HEALTHC ENG
JI J. Healthc. Eng.
PY 2017
AR 2190679
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WC Health Care Sciences & Services
SC Health Care Sciences & Services
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ER

PT J
AU Riso, B
   Tupasela, A
   Vears, DF
   Felzmann, H
   Cockbain, J
   Loi, M
   Kongsholm, NCH
   Zullo, S
   Rakic, V
AF Riso, Brigida
   Tupasela, Aaro
   Vears, Danya F.
   Felzmann, Heike
   Cockbain, Julian
   Loi, Michele
   Kongsholm, Nana C. H.
   Zullo, Silvia
   Rakic, Vojin
TI Ethical sharing of health data in online Mark platforms - which values
   should be considered?
SO LIFE SCIENCES SOCIETY AND POLICY
LA English
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DT Article

DE Data sharing; Ethical values; Health data; Health research; Information and communication technology platforms; Interoperability

AB Intensified and extensive data production and data storage are characteristics of contemporary western societies. Health data sharing is increasing with the growth of Information and Communication Technology (ICT) platforms devoted to the collection of personal health and genomic data. However, the sensitive and personal nature of health data poses ethical challenges when data is disclosed and shared even if for scientific research purposes.

With this in mind, the Science and Values Working Group of the COST Action CHIP ME 'Citizen's Health through public-private Initiatives: Public health, Market and Ethical perspectives' (IS 1303) identified six core values they considered to be essential for the ethical sharing of health data using ICT platforms. We believe that using this ethical framework will promote respectful scientific practices in order to maintain individuals' trust in research.

We use these values to analyse five ICT platforms and explore how emerging data sharing platforms are reconfiguring the data sharing experience from a range of perspectives. We discuss which types of values, rights and responsibilities they entail and enshrine within their philosophy or outlook on what it means to share personal health information. Through this discussion we address issues of the design and the development process of personal health data and patient-oriented infrastructures, as well as new forms of technologically-mediated empowerment.

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CR [Anonymous], 2013, TALT TIL TERV SAILYV

ARNESON RJ, 1989, PHILOS STUD, V56, P77, DOI 10.1007/BF00646210

Arzberger P, 2004, SCIENCE, V303, P1777, DOI 10.1126/science.1095958

Bansler JP, 2010, COMPUT SUPP COOP W J, V19, P519, DOI 10.1007/s10606-010-9130-y

Bauer S, 2014, SCI CONTEXT, V27, P187, DOI 10.1017/S0269889714000040

Chadwick R, 2001, NAT REV GENET, V2, P318, DOI 10.1038/35066094

COHEN GA, 1989, ETHICS, V99, P906, DOI 10.1086/293126
Corrigan O, 2006, CLIN ETHICS, V1, P101, DOI [10.1258/147775006777254524, DOI 10.1258/147775006777254524]
Dawson A, 2010, BIOETHICS, V24, P218, DOI 10.1111/j.1467-8519.2010.01814.x
Dove Edward S, 2015, Laws, V4, P515
Dunlop L., 2007, SHIDLER J LAW COMMER, V16
European Comission, 2013, DIG SCI HOR 2020
European Commission, 2005, NEW PERSP KNOWL BAS
European Society of Human Genetics (ESHG), 2003, EUROPEAN J HUMAN S2, V11, P8, DOI 10.1038/sj.ejhg.5201115
Felt U., 2007, TAKING EUROPEAN KNOW
Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN H
Global Network of WHO Collaborating Centres for Bioethics, 2015, GLOB HLTH ETH KEY IS
Gottweis H, 2011, NAT REV GENET, V12, P738, DOI 10.1038/nrg3083
Hafen E, 2014, METHOD INFORM MED, V53, P82, DOI 10.3414/ME13-02-0051
Harris JR, 2012, EUR J HUM GENET, V20, P1105, DOI 10.1038/ejhg.2012.96
Heubusch Kevin, 2006, J AHIMA, V77, P26
Hoeyer K, 2016, LAW GOV TECHNOL SER, V29, P73, DOI 10.1007/978-3-319-33525-4_4
Hoffman S, 2010, AM J BIOETHICS, V10, P19, DOI 10.1080/15265161.2010.492894
Kaye J, 2011, BMC, V343
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Keating P., 2003, BIOMEDICAL PLATFORMS
Kelty C, 2014, GENOME MED, V6, DOI 10.1186/gm525
Lakiotaki K, 2014, 2014 IEEE-EMBS INTERNATIONAL CONFERENCE ON BIOMEDICAL AND HEALTH INFORMATICS (BHI), P13, DOI 10.1109/BHI.2014.6864292
Langat P, 2011, PUBLIC HEALTH ETH-UK, V4, P4, DOI 10.1093/phe/phr005
Laurie Graeme, 2004, Eur J Health Law, V11, P87, DOI 10.1163/1571809043230423 80
Leonelli S, 2014, BIG DATA SOC, V1, DOI 10.1177/2053951714534395
Lupton D, 1996, NEW PUBLIC HLTH HLTH
Lupton D, 2014, SOCIOL HEALTH ILL, V36, P856, DOI 10.1111/1467-9566.12109
Mascalzoni D, 2015, EUR J HUM GENET, V23, P721, DOI 10.1038/ejhg.2014.197
Mayer-Schonberger V, 2014, BIG DATA REVOLUTION
Murdoch TB, 2013, JAMA-J AM MED ASSOC, V309, P1351, DOI 10.1001/jama.2013.393
Novas C, 2007, GENET SOC, P11
O'Neill O., 2002, AUTONOMY TRUST BIOET
O'Riordan K, 2013, SCI CULT-UK, V22, P516, DOI 10.1080/14636778.2013.764069
OECD, 2009, BIOEC 2030 DES POL A, DOI [10.1787/9789264056886-en, DOI 10.1787/9789264056886-EN]
OECD, 2013, OECD PRIV FRAM
Osterlund C, 2014, INFORM TECHNOL PEOPL, V27, P390, DOI 10.1108/ITP-09-2014-0193
Patrinos GP, 2012, HUM MUTAT, V33, P1503, DOI 10.1002/humu.22144
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Potamias G, 2014, OPEN BIOL, V4, DOI 10.1098/rsob.140071
Prainsack B, 2017, SOLIDARITY BIOMEDICI
Prainsack B, 2014, THEOR TECH SOC, P147
Prainsack B, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001837
Prainsack B, 2013, MED LAW REV, V21, P71, DOI 10.1093/medlaw/fws040
Rabeharisoa V, 2014, BIOSOCIETIES, V9, P194, DOI 10.1057/biosoc.2014.4
Rawls J., 1971, THEORY JUSTICE
Rippen H., 2000, J MED INTERNET RES, V2, P9, DOI DOI 10.2196/JMIR.2.2.E9
Rodriguez RN, 2013, J AM STAT ASSOC, V108, P1, DOI 10.1080/01621459.2013.771010
SEN A, 1985, J PHILOS, V82, P169, DOI 10.2307/2026184

```
   Sen A., 1995, INEQUALITY REEXAMINE
   Shabani Mahsa, 2015, Life Sci Soc Policy, V11, P3, DOI 10.1186/s40504-014-
0022-7
   Sitra, 2012, TALT OS LIIK
   Solove DJ, 2013, HARVARD LAW REV, V126, P1880
   Sterckx S, 2016, MED HEALTH CARE PHIL, V19, P177, DOI 10.1007/s11019-015-
9661-6
   Tang PC, 2006, J AM MED INFORM ASSN, V13, P121, DOI 10.1197/jamia.M2025
   Tene O., 2012, NW J TECH INTELL PRO, V11, P239
   Thilakanathan D, 2014, FUTURE GENER COMP SY, V35, P102, DOI
10.1016/j.future.2013.09.011
   Titmuss Richard, 1970, GIFT RELATIONSHIP HU
   Van Dijck J, 2016, BIG DATA SOC, V3, DOI 10.1177/2053951716654173
   Vayena E, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001937
   Vayena E, 2013, PLOS MED, V10, DOI 10.1371/journal.pmed.1001402
   Wellcome Trust, 2013, SUMM REP QUAL RES PU
NR 68
TC 5
Z9 5
U1 0
U2 0
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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   Chen, SP
   Nepal, S
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AB Background: Internet-based applications are providing new ways of promoting health and reducing the cost of care. Although data can be kept encrypted in servers, the user does not have the ability to decide whom the data are shared with. Technically this is linked to the problem of who owns the data encryption keys required to decrypt the data. Currently, cloud service providers, rather than users, have full rights to the key. In practical terms this makes the users lose full control over their data. Trust and uptake of these applications can be increased by allowing patients to feel in control of their data, generally stored in cloud-based services.

Objective: This paper addresses this security challenge by providing the user a way of controlling encryption keys independently of the cloud service provider. We provide a secure and usable system that enables a patient to share health information with doctors and specialists.

Methods: We contribute a secure protocol for patients to share their data with doctors and others on the cloud while keeping complete ownership. We developed a simple, stereotypical health application and carried out security tests, performance tests, and usability tests with both students and doctors (N=15).

Results: We developed the health application as an app for Android mobile phones. We carried out the usability tests on potential participants and medical professionals. Of 20 participants, 14 (70%) either agreed or strongly agreed that they felt safer using our system. Using mixed methods, we show that participants agreed that privacy and security of health data are important and that our system addresses these issues.

Conclusions: We presented a security protocol that enables patients to securely share their eHealth data with doctors and nurses and developed a secure and usable system that enables patients to share mental health information with doctors.

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CR Arthur C., 2011, GUARDIAN
Asus, ASUS EEE PAD TRANSF
Blanchet B, 2009, J COMPUT SECUR, V17, P363, DOI 10.3233/JCS-2009-0339
Cavoukian Ann, 2008, Identity in the Information Society, V1, P89, DOI 10.1007/s12394-008-0005-z
Donker T, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2791
EIGamal T., 1984, LECT NOTES COMPUTER, P10, DOI DOI 10.1007/3-540-39568-7_2
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Grajales FJ, 2014, J MED INTERNET RES, V16, DOI 10.2196/jmir.2912
Hilliard ME, 2014, JMIR MHEALTH UHEALTH, V2, DOI 10.2196/mhealth.3599
Huda MN, 2009, J ENG SCI TECHNOL, V4, P154
Iran D.H, 2011, P 8 INT C INF COMM S, P1
Jinhui Yao, 2010, Proceedings 2010 10th IEEE/ACM International Conference on Cluster, Cloud and Grid Computing (CCGrid), P600, DOI 10.1109/CCGRID.2010.17

```
   Karvelas P., 2014, AUSTRALIAN
   Larsson T. I., 1994, User-Centred Requirements for Software Engineering
Environment. Proceedings of the NATO Advanced Research Workshop, P285
   Liang K, 2013, 2013 5 INT C INT NET
   Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
   Lund A.M., 2001, USABILITY INTERFACE, V8, P3, DOI DOI
10.1177/1078087402250360
   Ming Y, 2011, INSTR MEAS COMP COMM, P21
   Nielsen J., 2012, USABILITY 101 INTRO
   Patrizio A, 2007, INTERNETNEWS
   ProVerif, PROVERIF CRYPT PROT
   Pyper C, 2004, MED SCI MONITOR, V10, pSR17
   Regola N, 2013, J MED INTERNET RES, V15, P3, DOI 10.2196/jmir.2076
   Rocha F, 2011, COMPUTER, V44, P44, DOI 10.1109/MC.2011.223
   Rodrigues JJPC, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2494
   Ruotsalainen PS, 2013, JMIR MHEALTH UHEALTH, V1, DOI 10.2196/mhealth.2731
   Sabahi F., 2011, 2011 IEEE 3rd International Conference on Communication
Software and Networks (ICCSN 2011), P245, DOI 10.1109/ICCSN.2011.6014715
   Silva BM, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2498
   Sparks K, 2001, J OCCUP ORGAN PSYCH, V74, P489, DOI 10.1348/096317901167497
   Thilakanathan Danan, 2014, 2014 Second International Conference on Advanced
Cloud and Big Data (CBD), P143, DOI 10.1109/CBD.2014.25
   Thilakanathan D, 2013, SECURITY PRIVACY TRU, P45
   Thilakanathan D, 2014, FUTURE GENER COMP SY, V35, P102, DOI
10.1016/j.future.2013.09.011
   Thilakanathan D, 2013, IEEE INT C COMPUT, P825, DOI 10.1109/CSE.2013.125
   Westin A. F., 1967, PRIVACY FREEDOM
   Zhang GF, 2015, IEEE T COMPUT, V64, P1456, DOI 10.1109/TC.2014.2298013
NR 35
TC 5
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U1 0
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PA 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA
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AF Craig, David W.
TI Understanding the links between privacy and public data sharing
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AB Linking clinical and phenotype variables across data sets will both power
precision medicine studies and introduce new privacy risks
RI Craig, David/K-6961-2019
OI Craig, David/0000-0003-2040-1955
CR Church G, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000665
   Erlich Y, 2014, NAT REV GENET, V15, P409, DOI 10.1038/nrg3723
   Gentry C, 2009, ACM S THEORY COMPUT, P169
   Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
   Harmanci A, 2016, NAT METHODS, V13, P251, DOI [10.1038/NMETH.3746,
10.1038/nmeth.3746]
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Hudson KL, 2015, NEW ENGL J MED, V373, P2293, DOI 10.1056/NEJMp1512205
   Im HK, 2012, AM J HUM GENET, V90, P591, DOI 10.1016/j.ajhg.2012.02.008
   McLaren PJ, 2016, GENET MED, V18, P814, DOI 10.1038/gim.2015.167
   Schadt EE, 2012, NAT GENET, V44, P603, DOI 10.1038/ng.2248
NR 10
TC 5
Z9 5
U1 0
U2 11
PU NATURE PUBLISHING GROUP
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PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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PT S
AU Usman, M
   Jan, MA
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   Nanda, P
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   Jan, Mian Ahmad
   He, Xiangjian
   Nanda, Priyadarsi
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DE Multimedia WSNs; Surveillance; Fire Monitoring; Health-Care; Automation; Streaming; Authentication; Clustering; Error Concealment; PSNR
ID VIDEO CODING HEVC; AUTHENTICATION; SCHEME; AGGREGATION; SYSTEM; CLOUD

AB The use of Multimedia Wireless Sensor Networks (MWSNs) is becoming common nowadays with a rapid growth in communication facilities. Similar to any other WSNs, these networks face various challenges while providing security, trust and privacy for user data. Provisioning of the aforementioned services become an uphill task especially while dealing with real-time streaming data. These networks operates with resource-constrained sensor nodes for days, months and even years depending on the nature of an application. The resource-constrained nature of these networks makes it difficult for the nodes to tackle real-time data in mission-critical applications such as military surveillance, forest fire monitoring, health-care and industrial automation. For a secured MWSN, the transmission and processing of streaming data needs to be explored deeply. The conventional data authentication schemes are not suitable for MWSNs due to the limitations imposed on sensor nodes in terms of battery power, computation, available bandwidth and storage. In this paper, we propose a novel quality-driven clustering-based technique for authenticating streaming data in MWSNs. Nodes with maximum energy are selected as Cluster Heads (CHs). The CHs collect data from member nodes and forward it to the Base Station (BS), thus preventing member nodes with low energy from dying soon and increasing life span of the underlying network. The proposed approach not only authenticates the streaming data but also maintains the quality of transmitted data. The proposed data authentication scheme coupled with an Error Concealment technique provides an energy-efficient and distortion-free real-time data streaming. The proposed scheme is compared with an unsupervised resources scenario. The simulation results demonstrate better network lifetime along with 21.34 dB gain in Peak Signal-to-Noise Ratio (PSNR) of received video data streams.

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CR Akyildiz IF, 2007, COMPUT NETW, V51, P921, DOI 10.1016/j.comnet.2006.10.002
Al-Riyami A., 2016, AD HOC NETWORKS
Benzaid C, 2016, FUTURE GENER COMP SY, V55, P362, DOI 10.1016/j.future.2014.07.006
Boubiche DE, 2015, IEEE COMMUN LETT, V19, P823, DOI 10.1109/LCOMM.2015.2409057
Cheng L., SEAMLESS STREAMING D
Cho K, 2014, IEEE T DEPEND SECURE, V11, P454, DOI 10.1109/TDSC.2013.41
Choi J., LOCATION BASED KEY M
Chu S.-I., AUTHENTICATION PROTO
Das S, 2015, IEEE T DEVICE MAT RE, V15, P24, DOI 10.1109/TDMR.2015.2389038

Dutta T, 2016, J VIS COMMUN IMAGE R, V38, P29, DOI 10.1016/j.jvcir.2015.12.007

Fallahpour M, 2014, IEEE T INSTRUM MEAS, V63, P1057, DOI 10.1109/TIM.2014.2299371

Fenye Bao, 2012, IEEE Transactions on Network and Service Management, V9, P169, DOI 10.1109/TCOMM.2012.031912.110179

Gabrielli A, 2011, IEEE T DEPEND SECURE, V8, P450, DOI 10.1109/TDSC.2009.46

Grover K, 2015, AD HOC NETW, V24, P288, DOI 10.1016/j.adhoc.2014.06.008

Guerrero-Zapata M, 2010, TELECOMMUN SYST, V45, P77, DOI 10.1007/s11235-009-9235-0

Harn L, 2015, IEEE SENS J, V15, P5103, DOI 10.1109/JSEN.2015.2429582

He DJ, 2014, IEEE J BIOMED HEALTH, V18, P316, DOI 10.1109/JBHI.2013.2268897

Jan M. A., 2013, WIRED WIRELESS INTER, P154, DOI DOI 10.1007/978-3-642-38401-1_12

Jan MA, 2016, THESIS

Jan MA, 2014, COMPUT NETW, V74, P92, DOI 10.1016/j.comnet.2014.09.005

Jan MA, 2013, 2013 IEEE 15TH INTERNATIONAL CONFERENCE ON HIGH PERFORMANCE COMPUTING AND COMMUNICATIONS & 2013 IEEE INTERNATIONAL CONFERENCE ON EMBEDDED AND UBIQUITOUS COMPUTING (HPCC_EUC), P1400, DOI 10.1109/HPCC.and.EUC.2013.198

Kim E. P., ERROR RESILIENT ENER

Ko J. H., 2015, MULTISCALE COMPUT SY, V1, P1

Kudeshia A, 2014, IEEE SIGNAL PROC LET, V21, P722, DOI 10.1109/LSP.2014.2313887

Lin C.-Y., 2016, J VISUAL COMMUNICATI

Lin K, 2012, COMPUT COMMUN, V35, P1902, DOI 10.1016/j.comcom.2012.03.010

Merlo A, 2015, PERVASIVE MOB COMPUT, V24, P77, DOI 10.1016/j.pmcj.2015.05.005

Nightingale J, 2014, IEEE T CONSUM ELECTR, V60, P242, DOI 10.1109/TCE.2014.6852000

Ou SH, 2015, IEEE J-STSP, V9, DOI 10.1109/JSTSP.2014.2331916

Rawat P, 2014, J SUPERCOMPUT, V68, P1, DOI 10.1007/s11227-013-1021-9

Rikli NE, 2014, CAN J ELECT COMPUT E, V37, P182, DOI 10.1109/CJECE.2014.2324279

Shim K.-A., SURVEY PUBLIC KEY CR

Shim KA, 2015, IEEE T PARALL DISTR, V26, P2128, DOI 10.1109/TPDS.2014.2346764

Sullivan GJ, 2012, IEEE T CIRC SYST VID, V22, P1649, DOI 10.1109/TCSVT.2012.2221191

Usman M, 2016, IEEE T MULTIMEDIA, V18, P831, DOI 10.1109/TMM.2016.2537200

Usman M, 2015, 2015 PICTURE CODING SYMPOSIUM (PCS) WITH 2015 PACKET VIDEO WORKSHOP (PV), P233, DOI 10.1109/PCS.2015.7170081

Wang W, 2014, IEEE J BIOMED HEALTH, V18, P404, DOI 10.1109/JBHI.2013.2292883

Wu JY, 2014, WIRELESS PERS COMMUN, V75, P1265, DOI 10.1007/s11277-013-1422-3

Xu DW, 2016, J VIS COMMUN IMAGE R, V36, P229, DOI 10.1016/j.jvcir.2016.02.002

Zhou Y, 2015, IEEE SENS J, V15, P1892, DOI 10.1109/JSEN.2014.2366511

Zhu CS, 2015, IEEE T INF FOREN SEC, V10, P118, DOI 10.1109/TIFS.2014.2364679

Zhu XL, 2016, IEEE T INF FOREN SEC, V11, P141, DOI 10.1109/TIFS.2015.2481366

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PT J
AU Krleza-Jeric, K
   Gabelica, M
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   Krnic-Martinic, M
   Pulido, B
   Mahmic-Kaknjo, M
   Reveiz, L
   Simic, J
   Utrobicic, A
   Hrgovic, I
AF Krleza-Jeric, Karmela
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DE clinical trial data sharing; research integrity; IMPACT Observatory
ID INTERNATIONAL-COMMITTEE; REGISTRATION; DECLARATION; STATEMENT
AB Introduction: The opening of research data is emerging thanks to the increasing possibilities of digital technology. The opening of clinical trial (CT) data is a part of this process, expected to have positive scientific, ethical, health, and economic impacts thus contributing to research integrity. The January 2016 proposal by the International Council of Medical Journal Editors triggered ample discussion about CT data sharing and reconfirmed the need for an ongoing assessment of its dynamics. The IMProving Access to Clinical Trials data (IMPACT) Observatory aims to play such a role, and assess the data sharing culture, policies, and practices of key players, the impact of their interventions on CTs, and contribute to a transformation of research. The objective of this paper is to present the IMPACT Observatory as well as share some of its preliminary findings.

   Materials and methods: Methods include a scoping study of research, surveys, interviews, and an environmental scan of research data repositories.

   Results: Our preliminary findings indicate that although opening of CT data has not yet been achieved, its evolution is encouraging. Initiatives by key players contribute to increasing of CT data sharing, and many barriers are shrinking or disappearing.

Conclusions: The major barrier is the lack of data sharing standards, from preparing data for public sharing to its curatorship, findability and access. However, experiences accumulated by sharing CT data according to "upon request" or "open" mechanisms could inform the development of such standards. The Vivli, CORBEL-ECRIN and Open Trials projects are currently working in this direction.

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FU Committee for Publication Ethics (COPE); European Union [291823]; NEWFELPRO project [35]
FX We thank Peter Hughes for comments on earlier versions of this manuscript. We also thank Jasmine Lefebvre for editing the manuscript and Nevena Jeric and Apropo Media for graphic design and illustrations. We thank the Committee for Publication Ethics (COPE) for the initial funding of the environmental scan of repositories through a 2012 grant. The research leading to these results has received funding from the European Union Seventh Framework Programme (FP7 2007-2013) under grant agreement number 291823 Marie Curie FP7-PEOPLE-2011-COFUND (The New International Fellowship Mobility Programme-for Experienced Researchers in Croatia - NEWFELPRO). This article has been prepared as a part of a project "IMPACT Observatory" which has received funding through NEWFELPRO project under the agreement number 35.

CR Bass A., 2008, SIDE EFFECTS PROSECU
Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
Booth A, 2012, SYST REV, V1, DOI 10.1186/2046-4053-1-2
CHALMERS I, 1992, BMJ-BRIT MED J, V305, P786, DOI 10.1136/bmj.305.6857.786
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Cruickshank HC, 2014, BMJ OPEN, V4, DOI 10.1136/bmjopen-2014-005224
DeAngelis CD, 2004, JAMA-J AM MED ASSOC, V292, P1363, DOI 10.1001/jama.292.11.1363
Doshi P., 2013, BMJ OPEN, V3
Doshi P, 2013, JAMA INTERN MED, V173, P380, DOI 10.1001/jamainternmed.2013.3838
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
El Emam K, 2013, GUIDE DEIDENTIFICATI
Goldacre B, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001821
Goodyear MDE, 2007, BRIT MED J, V335, P624, DOI 10.1136/bmj.39339.610000.BE
Hrynaszkiewicz I, 2010, BRIT MED J, V340, DOI 10.1136/bmj.c181
Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Koenig F, 2015, BIOMETRICAL J, V57, P8, DOI 10.1002/bimj.201300283
Krleza-Jeric K, 2005, BRIT MED J, V330, P956, DOI 10.1136/bmj.330.7497.956

```
   Krleza-Jeric K, 2012, CLIN RES INFORM, P389
   Krleza-Jeric K, 2014, PERIOD BIOL, V116, P337
   Krleza-Jeric K, 2011, REV PANAM SALUD PUBL, V30, P87
   Krleza-Jeric K, 2009, CROAT MED J, V50, P105, DOI 10.3325/cmj.2009.50.105
   Levac D, 2010, IMPLEMENT SCI, V5, DOI 10.1186/1748-5908-5-69
   Murray Sally, 2008, Open Med, V2, pe1
   PIGNON JP, 1994, LUNG CANCER-J IASLC, V10, pS135, DOI 10.1016/0169-
5002(94)91675-6
   Remler D. K., 2014, RES METHODS PRACTICE
   SIMES RJ, 1986, J CLIN ONCOL, V4, P1529, DOI 10.1200/JCO.1986.4.10.1529
   Smith CT, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0532-z
   Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
NR 28
TC 5
Z9 6
U1 2
U2 8
PU CROATIAN SOC MEDICAL BIOCHEMISTS
PI ZAGREB
PA DOMAGOJEVA 2, ZAGREB, 10000, CROATIA
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J9 BIOCHEM MEDICA
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SC Medical Laboratory Technology
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ER

PT S
AU Ulrich, H
   Kock, AK
   Duhm-Harbeck, P
   Habermann, JK
   Ingenerf, J
AF Ulrich, Hannes
   Kock, Ann-Kristin
   Duhm-Harbeck, Petra
   Habermann, Jens K.
   Ingenerf, Josef
BE Hoerbst, A
   Hackl, WO
   DeKeizer, N
   Prokosch, HU
   HercigonjaSzekeres, M
   DeLusignan, S
TI Metadata Repository for Improved Data Sharing and Reuse Based on HL7
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FHIR
SO EXPLORING COMPLEXITY IN HEALTH: AN INTERDISCIPLINARY SYSTEMS APPROACH
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT Medical Informatics Europe (MIE) Conference at Conference on Health - Exploring Complexity (HEC) - An Interdisciplinary Systems Approach
CY AUG 28-SEP 02, 2016
CL Munich, GERMANY
DE RDMS; HL7 FHIR; MDR; Data Curation
AB Unreconciled data structures and formats are a common obstacle to the urgently required sharing and reuse of data within healthcare and medical research. Within the North German Tumor Bank of Colorectal Cancer, clinical and sample data, based on a harmonized data set, is collected and can be pooled by using a hospital-integrated Research Data Management System supporting biobank and study management. Adding further partners who are not using the core data set requires manual adaptations and mapping of data elements. Facing this manual intervention and focusing the reuse of heterogeneous healthcare instance data (value level) and data elements (metadata level), a metadata repository has been developed. The metadata repository is an ISO 11179-3 conformant server application built for annotating and mediating data elements. The implemented architecture includes the translation of metadata information about data elements into the FHIR standard using the FHIR Data Element resource with the ISO 11179 Data Element Extensions. The FHIR-based processing allows exchange of data elements with clinical and research IT systems as well as with other metadata systems. With increasingly annotated and harmonized data elements, data quality and integration can be improved for successfully enabling data analytics and decision support.
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CR Choquet R, 2015, J AM MED INFORM ASSN, V22, P76, DOI 10.1136/amiajnl-2014-002794
Dugas M., 2016, METADATA REPOSITORY
Ingenerf J, 2012, STUD HEALTH TECHNOL, V180, P619, DOI 10.3233/978-1-61499-101-4-619
Kopcke F, 2013, INT J MED INFORM, V82, P185, DOI 10.1016/j.ijmedinf.2012.11.008
Oberlander M, 2013, LANGENBECK ARCH SURG, V398, P251, DOI 10.1007/s00423-012-1043-4
Park YR, 2013, STUD HEALTH TECHNOL, V192, P618, DOI 10.3233/978-1-61499-289-9-618
Smits M, 2015, EUROPEAN J BIOMEDICA, p[11, en7]
NR 7
TC 5
Z9 6
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PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
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PT J
AU Meeker, D
   Jiang, XQ
   Matheny, ME
   Farcas, C
   D'Arcy, M
   Pearlman, L
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   Day, ME
   Kim, KK
   Kim, H
   Boxwala, A
   El-Kareh, R
   Kuo, GM
   Resnic, FS
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   Ohno-Machado, L
AF Meeker, Daniella
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TI A system to build distributed multivariate models and manage disparate
   data sharing policies: implementation in the scalable national network
   for effectiveness research
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
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DT Article

DE distributed analytics; federated research network; privacy-preserving network infrastructure; comparative effectiveness research

ID LEARNING HEALTH SYSTEM; INFORMATICS; INFRASTRUCTURE; PCORNET; FOOD

AB Background Centralized and federated models for sharing data in research networks currently exist. To build multivariate data analysis for centralized networks, transfer of patient-level data to a central computation resource is necessary. The authors implemented distributed multivariate models for federated networks in which patient-level data is kept at each site and data exchange policies are managed in a study-centric manner.

Objective The objective was to implement infrastructure that supports the functionality of some existing research networks (e.g., cohort discovery, workflow management, and estimation of multivariate analytic models on centralized data) while adding additional important new features, such as algorithms for distributed iterative multivariate models, a graphical interface for multivariate model specification, synchronous and asynchronous response to network queries, investigator-initiated studies, and study-based control of staff, protocols, and data sharing policies.

Materials and Methods Based on the requirements gathered from statisticians, administrators, and investigators from multiple institutions, the authors developed infrastructure and tools to support multisite comparative effectiveness studies using web services for multivariate statistical estimation in the SCANNER federated network.

Results The authors implemented massively parallel (map-reduce) computation methods and a new policy management system to enable each study initiated by network participants to define the ways in which data may be processed, managed, queried, and shared. The authors illustrated the use of these systems among institutions with highly different policies and operating under different state laws.

Discussion and Conclusion Federated research networks need not limit distributed query functionality to count queries, cohort discovery, or independently estimated analytic models. Multivariate analyses can be efficiently and securely conducted without patient-level data transport, allowing institutions with strict local data storage requirements to participate in sophisticated analyses based on federated research networks.

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CR Adams NM, 1996, STAT COMPUT, V6, P37, DOI 10.1007/BF00161572
Ames MJ, AMIA 2013 SUMM CLIN
Amin W, 2014, J AM MED INFORM ASSN, V21, P633, DOI 10.1136/amiajnl-2014-002759
Avery TR, 2013, PHARMACOEPIDEM DR S, V22, P488, DOI 10.1002/pds.3412
Behilng D, QUALITY DATA MODEL B
Brown JS, 2013, MED CARE, V51, pS22, DOI 10.1097/MLR.0b013e31829b1e2c
Brown JS, 2010, MED CARE, V48, pS45, DOI 10.1097/MLR.0b013e3181d9919f
Byrne CM, 2010, HEALTH AFFAIR, V29, P629, DOI 10.1377/hlthaff.2010.0119
Chu C., 2007, ADV NEURAL INF PROCE, V19, P281, DOI DOI 10.1234/12345678
Devoe JE, 2014, J AM MED INFORM ASSN, V21, P591, DOI 10.1136/amiajnl-2014-002744
Ellisman M, 2005, BIOM INF RES NETW 3
Feldman V, 2012, J COMPUT SYST SCI, V78, P1444, DOI 10.1016/j.jcss.2011.12.024
Fleurence RL, 2014, J AM MED INFORM ASSN, V21, P578, DOI 10.1136/amiajnl-2014-002747
Forrest CB, 2014, HEALTH AFFAIR, V33, P1171, DOI 10.1377/hlthaff.2014.0127
Helmer KG, 2011, J AM MED INFORM ASSN, V18, P416, DOI 10.1136/amiajnl-2010-000032
Holmes JH, 2014, J AM MED INFORM ASSN, V21, P730, DOI 10.1136/amiajnl-2013-002370
Jiang WC, 2013, BIOINFORMATICS, V29, P3238, DOI 10.1093/bioinformatics/btt559
Johnson KA, 2010, ANN PHARMACOTHER, V44, P1877, DOI 10.1345/aph.1P380
Johnson R., 2004, SPRING FRAMEWORK REF, V21
Kahn MG, 2012, MED CARE, V50, pS60, DOI 10.1097/MLR.0b013e318259bff4
Kaushal R, 2014, J AM MED INFORM ASSN, V21, P587, DOI 10.1136/amiajnl-2014-002764
Kho AN, 2014, J AM MED INFORM ASSN, V21, P607, DOI 10.1136/amiajnl-2014-002827
Khurshid A, 2014, J AM MED INFORM ASSN, V21, P612, DOI 10.1136/amiajnl-2014-002740
Kim KK, 2014, J AM MED INFORM ASSN, V21, P714, DOI 10.1136/amiajnl-2013-002308
Kim KK, 2013, MED CARE, V51, pS66, DOI 10.1097/MLR.0b013e31829b1d9f
Mandel AJ, 2012, P 2012 IEEE 2 INT C, P146
Mandl KD, 2014, J AM MED INFORM ASSN, V21, P615, DOI 10.1136/amiajnl-2014-002727
McGlynn EA, 2014, J AM MED INFORM ASSN, V21, P596, DOI 10.1136/amiajnl-2014-002746
McMurry AJ, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0055811
Meeker D, 2014, JAMA INTERN MED, V174, P425, DOI 10.1001/jamainternmed.2013.14191
Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
Oancea B., 2014, ARXIV14074908
Ohmann C, 2009, METHOD INFORM MED, V48, P45, DOI 10.3414/ME9137
Ohno-Machado L, 2014, J AM MED INFORM ASSN, V21, P621, DOI 10.1136/amiajnl-2014-002751
Ohno-Machado L, 2012, SCI TRANSL MED, V4, DOI 10.1126/scitranslmed.3004454
Ohno-Machado L, 2012, J AM MED INFORM ASSN, V19, P196, DOI 10.1136/amiajnl-2011-000538
Orellana F, P2P PAR GRID CLOUD I
Panda B, 2009, PROC VLDB ENDOW, V2, P1426, DOI 10.14778/1687553.1687569
Patient Centered Outcomes Research Institute, 2013, IMPR OUR NAT INFR CO

Payne P, 2011, APPL CLIN INFORM, V2, P331, DOI 10.4338/ACI-2011-02-RA-0014
Platt R, 2012, PHARMACOEPIDEM DR S, V21, P1, DOI 10.1002/pds.2343
Schilling LM, 2013, EGEMS, V1, P11
Shvachko K, 2010 IEEE 26 S 2010
Terry SF, 2011, SCI TRANSL MED, V3, DOI 10.1126/scitranslmed.3001857
Toh S, 2013, JAMA INTERN MED, V173, P817, DOI 10.1001/jamainternmed.2013.3004
von Eschenbach AC, 2006, CANCER INFORM, V2, P22
Waitman LR, 2014, J AM MED INFORM ASSN, V21, P637, DOI 10.1136/amiajnl-2014-002756
Wu Y, 2012, J AM MED INFORM ASSN, V19, P758, DOI 10.1136/amiajnl-2012-000862
Xu M, 1990, DISTR MEM COMP C 199
Zaharia M., 2010, 2 USENIX WORKSH HOT
Zaharia M., 2010, P 2 USENIX C HOT TOP
NR 51
TC 5
Z9 5
U1 1
U2 16
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
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Malin, Bradley A.
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Schneeweiss, Sebastian
TI Ensuring Patient Privacy in Data Sharing for Postapproval Research
SO NEW ENGLAND JOURNAL OF MEDICINE

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LA English
DT Editorial Material
ID CLINICAL-TRIALS; HEALTH DATA; SAFETY; RISK; RULE
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RI Kesselheim, Aaron/R-6793-2017
OI Kesselheim, Aaron/0000-0002-8867-2666
CR [Anonymous], 2009, ENC US RETH PROT DEI
   Arbuckle L, 2013, ANONYMIZING HLTH DAT
   Benitez K, 2010, J AM MED INFORM ASSN, V17, P169, DOI
10.1136/jamia.2009.000026
   Boulos MNK, 2006, J BIOMED INFORM, V39, P160, DOI 10.1016/j.jbi.2005.06.003
   Brownstein JS, 2010, PHARMACOEPIDEM DR S, V19, P627, DOI 10.1002/pds.1939
   Burmester GR, 2014, ARTHRITIS RES THER, V16, DOI 10.1186/ar4452
   Candela S, 2013, VACCINE, V31, P1431, DOI 10.1016/j.vaccine.2012.06.030
   Cohen IG, 2014, HEALTH AFFAIR, V33, P1139, DOI 10.1377/hlthaff.2014.0048
   Darrow JJ, 2014, MINN LAW REV, V98, P805
   Department of Health and Human Services Office of Civil Rights, CAS EX RES
AGR
   Department of Health and Human Services Office of Civil Rights, GUID REG METH
ID PRO
   El Emam K, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0028071
   Evans BJ, 2013, U CAL DAVIS LAW REV, V46, P1175
   Food and Drug Administration, 2013, FED REGISTER, V78, P58786
   Funch D, 2014, DIABETES OBES METAB, V16, P273, DOI 10.1111/dom.12230
   Geller SE, 2011, J WOMENS HEALTH, V20, P315, DOI 10.1089/jwh.2010.2469
   Glovers J, 2004, INT J HEALTH GEOGR, V3, P30
   Ho PM, 2009, JAMA-J AM MED ASSOC, V301, P937, DOI 10.1001/jama.2009.261
   Malin B, 2011, J AM MED INFORM ASSN, V18, P3, DOI 10.1136/jamia.2010.004622
   McGraw D, 2012, PHARMACOEPIDEM DR S, V21, P18, DOI 10.1002/pds.2319
   Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
   Psaty BM, 2014, NEW ENGL J MED, V370, P2165, DOI 10.1056/NEJMp1401664
   Reisz LP, 2012, STATE ATTORNEYS GEN
   Roden DM, 2008, CLIN PHARMACOL THER, V84, P362, DOI 10.1038/clpt.2008.89
   Rosenbaum S, 2007, BNA HLTH CARE POLICY, V15, P1
   Sun LH, 2011, WASHINGTON POST
   US Census Bureau, GEOGR TERMS CONC CEN
   Zulman DM, 2011, J GEN INTERN MED, V26, P783, DOI 10.1007/s11606-010-1629-x
NR 28
TC 5
Z9 5
U1 0
U2 9
PU MASSACHUSETTS MEDICAL SOC
PI WALTHAM
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AU Topa, G
   Alcover, CM
   Moriano, JA
   Depolo, M
AF Topa, Gabriela
   Alcover, Carlos-Maria
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   Depolo, Marco
TI Bridge employment quality and its impact on retirement adjustment: A
   structural equation model with SHARE panel data
SO ECONOMIC AND INDUSTRIAL DEMOCRACY
LA English
DT Article
DE Bridge employment; panel study; retirement; structural equation modeling
ID EARLY OLD-AGE; CONTINUITY THEORY; WORK ATTITUDES; OF-LIFE; HEALTH;
   PARTICIPATION; SATISFACTION; PREDICTORS; TRANSITION; PATTERNS
AB Bridge employment refers to the workforce participation pattern displayed by
older workers between their partial retirement and their complete withdrawal
from the workforce. Based on Shultz's (2003) model of antecedents and
consequences of bridge employment, this article proposes a set of hypotheses,
using SHARE panel data (N = 634) from Wave 1 (2004) and Wave 2 (2006). These
data are analyzed via structural equation modeling (SEM), testing both a direct
effects model and a partial mediation model. Results show that bridge employment
quality partially mediates the influences of T1 antecedents on T2 consequences.
The implications of this study are discussed at both the theoretical and
practical level.
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RI Alcover, Carlos-Maria/C-6303-2011; Moriano, Juan A./L-7607-2014; Topa,
   Gabriela/L-9061-2014
OI Alcover, Carlos-Maria/0000-0001-9632-9107; Moriano, Juan
   A./0000-0002-8332-1314; Topa, Gabriela/0000-0002-9181-8603
CR Adams G, 2004, PERS PSYCHOL, V57, P719, DOI 10.1111/j.1744-6570.2004.00005.x
   Alcover CM, 2012, PERS REV, V41, P380, DOI 10.1108/00483481211212995
```

Alley D., 2007, AGING WORK 21 CENTUR, P7
ATCHLEY RC, 1989, GERONTOLOGIST, V29, P183, DOI 10.1093/geront/29.2.183
Beehr T. A., 2002, WORK CAREERS DEV PER, P214
Beehr T. A., 2008, SAGE HDB ORG BEHAV, P217, DOI [10.4135/9781849200448.n13, DOI 10.4135/9781849200448.N13]
Beehr T. A., 2007, AGING WORK 21 CENTUR, P277
BLANCHET D, 2007, 1 IRDES
Borsch-Supan A, 2009, J EUR SOC POLICY, V19, P341, DOI 10.1177/1350506809341515
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Borsch-Supan A, 2005, SURVEY HLTH AGEING R
Cahill KE, 2011, MON LABOR REV, V134, P34
Davis MA, 2003, J VOCAT BEHAV, V63, P55, DOI 10.1016/S0001-8791(02)00016-7
De Lucca G, 2005, SURVEY HLTH AGEING R
Debrand T, 2007, EC STAT, V403, P19
Dendinger VM, 2005, INT J AGING HUM DEV, V61, P21, DOI 10.2190/K8KU-46LH-DTW5-44TU
Ekerdt DJ, 2010, J GERONTOL B-PSYCHOL, V65, P69, DOI 10.1093/geronb/gbp109
Engelhardt H, 2012, EUR SOCIOL REV, V28, P550, DOI 10.1093/esr/jcr024
FELDMAN D, 2003, HUMAN RESOURCE PLANN, V23, P14
Feldman D. C., 2007, AGING WORK 21 CENTUR, P179
FELDMAN DC, 1994, ACAD MANAGE REV, V19, P285, DOI 10.2307/258706
Giandrea M, 2008, BUREAU LABOR STAT WO
Gobeski KT, 2009, J ORGAN BEHAV, V30, P401, DOI 10.1002/job.547
Higgs P, 2003, SOC POLICY ADMIN, V37, P239, DOI 10.1111/1467-9515.00336
Kim S, 2000, ACAD MANAGE J, V43, P1195, DOI 10.2307/1556345
Kooij DTAM, 2011, J ORGAN BEHAV, V32, P197, DOI 10.1002/job.665
Marmot M, 2006, SOCIAL DETERMINANTS, P97
Munnell AH, 2008, WORKING LONGER: THE SOLUTION TO THE RETIREMENT INCOME CHALLENGE, P1
Ng TWH, 2009, J VOCAT BEHAV, V74, P283, DOI 10.1016/j.jvb.2009.01.004
Pengcharoen C, 2010, INT J MANPOWER, V31, P322, DOI 10.1108/01437721011050602
Pinquart M, 2007, PSYCHOL AGING, V22, P442, DOI 10.1037/0882-7974.22.3.442
Rau BL, 2005, J ORGAN BEHAV, V26, P649, DOI 10.1002/job.330
Raymo JM, 2010, RES AGING, V32, P419, DOI 10.1177/0164027510361462
RHODES SR, 1983, PSYCHOL BULL, V93, P328, DOI 10.1037/0033-2909.93.2.328
Schalk R, 2010, WORKING AGEING EMERG, P114
SCHEIER MF, 1985, HEALTH PSYCHOL, V4, P219, DOI 10.1037/0278-6133.4.3.219
SCHMITT N, 1979, PERS PSYCHOL, V32, P327, DOI 10.1111/j.1744-6570.1979.tb02138.x
Shultz KS, 2007, INT J AGING HUM DEV, V65, P149, DOI 10.2190/AG.65.2.c
Shultz KS, 2003, RETIREMENT: REASONS, PROCESSES, AND RESULTS, P214
Siegrist J, 2004, SOC SCI MED, V58, P1483, DOI 10.1016/S0277-9536(03)00351-4
Siegrist J, 1996, J Occup Health Psychol, V1, P27, DOI 10.1037/1076-8998.1.1.27
Siegrist J, 2009, J EUR SOC POLICY, V19, P317, DOI 10.1177/1350506809341513
Simova Z, 2010, WORKING AGEING EMERG, P169
SINGH J, 1994, J MARKETING RES, V31, P558, DOI 10.2307/3151883
TAYLOR MA, 1995, PSYCHOL AGING, V10, P76, DOI 10.1037/0882-7974.10.1.76
Topa Cantisano G, 2009, PSICOTHEMA, V21, P280
Topa G, 2011, RES AGING, V33, P501, DOI 10.1177/0164027511410549
Ulrich LB, 2005, J EMPLOYMENT COUNS, V42, P159, DOI 10.1002/j.2161-1920.2005.tb01087.x
United Nations, 2011, ESAPWP220
von Bonsdorff ME, 2009, INT J AGING HUM DEV, V69, P79, DOI 10.2190/AG.69.2.a
Wang M, 2008, J APPL PSYCHOL, V93, P818, DOI 10.1037/0021-9010.93.4.818
Wang M, 2007, J APPL PSYCHOL, V92, P455, DOI 10.1037/0021-9010.92.2.455
Wang M, 2010, J MANAGE, V36, P172, DOI 10.1177/0149206309347957

```
   WARR P, 1979, J OCCUP PSYCHOL, V52, P129, DOI 10.1111/j.2044-
8325.1979.tb00448.x
   Weckerle JR, 1999, J OCCUP ORGAN PSYCH, V72, P317, DOI
10.1348/096317999166707
   Zaniboni S, 2010, INT J MANPOWER, V31, P271, DOI 10.1108/01437721011050576
NR 56
TC 5
Z9 5
U1 2
U2 21
PU SAGE PUBLICATIONS LTD
PI LONDON
PA 1 OLIVERS YARD, 55 CITY ROAD, LONDON EC1Y 1SP, ENGLAND
SN 0143-831X
EI 1461-7099
J9 ECON IND DEMOCRACY
JI Econ. Ind. Democr.
PD MAY
PY 2014
VL 35
IS 2
BP 225
EP 244
DI 10.1177/0143831X12475242
PG 20
WC Industrial Relations & Labor
SC Business & Economics
GA AG8FZ
UT WOS:000335655500003
DA 2019-08-06
ER

PT J
AU Saarnak, CFL
   Utzinger, J
   Kristensen, TK
AF Saarnak, Christopher F. L.
   Utzinger, Juerg
   Kristensen, Thomas K.
TI Collection, verification, sharing and dissemination of data: the
   CONTRAST experience
SO ACTA TROPICA
LA English
DT Article
DE CONTRAST; Data curation; Data sampling; Data sharing; Database
   management; Schistosomiasis
ID NEGLECTED TROPICAL DISEASES; SCHISTOSOMA-MANSONI; HELMINTH INFECTION;
   CLIMATE-CHANGE; HEALTH; PRAZIQUANTEL; PREVALENCE; MANAGEMENT; COUNTRIES;
   SYSTEMS
AB The scientific community is charged with growing demands regarding the
management of project data and outputs and the dissemination of key results to
various stakeholders. We discuss experiences and lessons from CONTRAST, a
multidisciplinary alliance that had been funded by the European Commission over
a 4-year period, in order to optimize schistosomiasis control and transmission
surveillance in sub-Saharan Africa. From the start, project partners from Europe
and Africa set out an ambitious goal: to sample data following standard
protocols at all field sites and then sharing the data in a way that would
enable all project partners to have access through a password-protected
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Internet-based data portal. This required anonymous agreement on several common standardized sample forms, ranging from the mundane but important issue of using the same units of measurement to more complex challenges, for instance agreeing on the same protocols for double-treatment of praziquantel in different settings. With the experiences gained by the CONTRAST project, this paper discusses issues of data management and sharing in research projects in the light of the current donor demand, and offers advice and specific suggestions for similar interdisciplinary research projects. (C) 2013 Elsevier B.V. All rights reserved.

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FU EU [032203]
FX The study was supported by the EU grant CONTRAST (FP6 STREP contract no: 032203; http://www.eu-contrast.eu). We thank Fireflower Ltd. for their remarkable contribution to the CONTRAST project. Also, a very big thank you goes to Dr. Charles Lange and Mrs. Agness Okeyo at the National Museums of Kenya for their sterling effort and patience in building the online database.

CR Achimugu P, 2010, STUD HEALTH TECHNOL, V160, P1127, DOI 10.3233/978-1-60750-588-4-1127
Ali M, 2006, BMC PUBLIC HEALTH, V6, DOI 10.1186/1471-2458-6-86
Brooker S, 2010, PLOS NEGLECT TROP D, V4, DOI 10.1371/journal.pntd.0000779
Carraway LN, 2011, AM MIDL NAT, V166, P1, DOI 10.1674/0003-0031-166.1.1
Chammartin F, 2013, LANCET INFECT DIS, V13, P507, DOI 10.1016/S1473-3099(13)70071-9
Colley DG, 2013, AM J TROP MED HYG, V88, P426, DOI 10.4269/ajtmh.12-0639
Costello A, 2009, LANCET, V373, P1693, DOI [10.1016/S0140-6736(09)60935-1, 10.1016/S0140-6736(09)60929-6]
Danso-Appiah A, 2009, PARASITOLOGY, V136, P1837, DOI 10.1017/S0031182009005939
Doumenge JP, 1987, ATLAS GLOBAL DISTRIB
Fireflower Systems Ltd, 2007, US EU CONTRAST SYST
Foley D.H., 2010, INT J HEALTH GEOGR, V9, P1, DOI DOI 10.1186/1476-072X-9-11
Garba A, 2013, ACTA TROP, V128, P334, DOI 10.1016/j.actatropica.2012.08.008
Gray DJ, 2009, PLOS NEGLECT TROP D, V3, DOI 10.1371/journal.pntd.0000413
Hosking J, 2012, ENVIRON HEALTH PERSP, V120, P1076, DOI 10.1289/ehp.1104093
Hurlimann E, 2011, PLOS NEGLECT TROP D, V5, DOI 10.1371/journal.pntd.0001404
KFPE, 2012, GUID TRANSB RES PART
King CH, 2011, PLOS NEGLECT TROP D, V5, DOI 10.1371/journal.pntd.0001321
Ma J, 2008, INT J MED INFORM, V77, P219, DOI 10.1016/j.ijmedinf.2007.02.001
Murray CJL, 2012, LANCET, V380, P2063, DOI 10.1016/S0140-6736(12)61899-6
Picquet M, 1998, T ROY SOC TROP MED H, V92, P90, DOI 10.1016/S0035-9203(98)90971-3
Porcasi X., 2012, GEOSPAT HLTH, V6, P31
Roberts RJ, 2000, STAT MED, V19, P1645
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Schur N, 2013, ACTA TROP, V128, P365, DOI 10.1016/j.actatropica.2011.10.006
Schur N, 2011, PLOS NEGLECT TROP D, V5, DOI 10.1371/journal.pntd.0001194
Science Staff, 2011, SCIENCE, V331, P692, DOI DOI 10.1126/SCIENCE.331.6018.692

Stensgaard AS, 2013, ACTA TROP, V128, P378, DOI
10.1016/j.actatropica.2011.11.010
Stensgaard AS, 2009, GEOSPATIAL HEALTH, V3, P127, DOI 10.4081/gh.2009.216
Tchuente LAT, 2013, ACTA TROP, V128, P275, DOI
10.1016/j.actatropica.2013.06.007
Utzinger J, 2013, ACTA TROP, V128, P182, DOI
10.1016/j.actatropica.2013.08.011
Webster BL, 2013, ACTA TROP, V128, P292, DOI
10.1016/j.actatropica.2012.09.010
Yang K, 2012, GEOSPATIAL HEALTH, V6, P195, DOI 10.4081/gh.2012.137
NR 32
TC 5
Z9 5
U1 0
U2 9
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0001-706X
EI 1873-6254
J9 ACTA TROP
JI Acta Trop.
PD NOV
PY 2013
VL 128
IS 2
SI SI
BP 407
EP 411
DI 10.1016/j.actatropica.2013.05.008
PG 5
WC Parasitology; Tropical Medicine
SC Parasitology; Tropical Medicine
GA 249IW
UT WOS:000326771900025
PM 23707729
DA 2019-08-06
ER

PT J
AU Fegan, G
Moulsdale, M
Todd, J
AF Fegan, Greg
Moulsdale, Michael
Todd, Jim
TI The potential of internet-based technologies for sharing data of public
health importance
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Editorial Material
C1 [Fegan, Greg; Moulsdale, Michael] Kenya Govt Med Res Ctr, Ctr Geog Med Res
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```
OI Fegan, Greg W/0000-0002-2663-2765
CR Almquist ZW, 2010, J STAT SOFTW, V37, P1
   Fegan W, 2008, PLOS MED, V5, P347, DOI 10.1371/journal.pmed.0050006
   Gentleman R, 2007, J COMPUT GRAPH STAT, V16, P1, DOI 10.1198/106186007X178663
   Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
   MAS I, 2010, MOBILE PAYMENTS VIRA
   Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   Seebregts CJ, 2009, INT J MED INFORM, V78, P711, DOI
10.1016/j.ijmedinf.2008.09.005
   SMITH D, 2010, R BLOGGERS      1214
   Tseng D, 2010, LAB CHIP, V10, P1787, DOI 10.1039/c003477k
   Vance Ashlee, 2009, NY TIMES        0106
   Wilkinson L, 2008, TECHNOMETRICS, V50, P418, DOI 10.1198/004017008000000460
NR 11
TC 5
Z9 5
U1 0
U2 6
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
EI 1564-0604
J9 B WORLD HEALTH ORGAN
JI Bull. World Health Organ.
PD FEB
PY 2011
VL 89
IS 2
BP 82
EP 82
DI 10.2471/BLT.11.085910
PG 1
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 725DQ
UT WOS:000287625800001
PM 21346914
OA Bronze, Green Published
DA 2019-08-06
ER

PT J
AU [Anonymous]
AF [Anonymous]
TI Sharing public health data: necessary and now
SO LANCET
LA English
DT Editorial Material
NR 0
TC 5
Z9 5
U1 0
U2 2
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0140-6736
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EI 1474-547X
J9 LANCET
JI Lancet
PD JUN 5
PY 2010
VL 375
IS 9730
BP 1940
EP 1940
PG 1
WC Medicine, General & Internal
SC General & Internal Medicine
GA 609WT
UT WOS:000278689600002
PM 20569822
DA 2019-08-06
ER

PT J
AU Ogden, T
AF Ogden, Trevor
TI Data Sharing, Federal Rule of Evidence 702, and the Lions in the
   Undergrowth
SO ANNALS OF OCCUPATIONAL HYGIENE
LA English
DT Editorial Material
DE data sharing; journals; publication ethics
ID ASBESTOS FIBER CONCENTRATIONS; FORMALDEHYDE RISK-ASSESSMENT; BRAKE
   WORKERS; EXPOSURE; MODEL; LUNGS; STOFFENMANAGER; CHRYSOTILE; CANCER
AB Many concerns would find it useful to have a publicly available database
recording exposures to particular substances, with contextual information. The
European Union's Registration, Evaluations, Authorisation, and restriction of
Chemicals regulation has increased interest in this. It has been suggested that
journals should require detailed publication of exposure data with papers. But
there are problems for researchers, for whom the data are a valuable resource
which has been obtained with effort and often ingenuity. The publication could
also raise problems of confidentiality and liability, and those who have to put
the effort in publication are not those who benefit. Also, there are the
problems of hostile critics misusing the information-for example, industry
reanalysing data to counter any regulatory implications of a study-and this
raises serious wider issues of editorial policy. Two books have recently given
examples of industry misuse of science, 'Doubt is their product' by David
Michaels and 'Defending the indefensible' by McCullogh and Tweedale. Michaels
gives examples of hostile data reanalysis, and among other things, he discusses
the impact on journals of US Federal Rule of Evidence 702, which encourages
expert witnesses to try to get their testimony material into peer-reviewed
journals. This certainly lies behind some submissions to this journal, and
Michaels says that it has led to the creation of peer-reviewed journals which
have strong industry influence. On the other hand, work funded by industry is
not always wrong, papers from other sources are not always free from bias, and
the problem for journals is to continue to apply consistent scientific standards
in a sea of conflicting interests. It does not seem feasible or desirable for
journals to insist on the publication of all the underlying data, although
researchers might be encouraged to form consortia to share data.
C1 British Occupat Hyg Soc, Annals Occupat Hyg, Derby DE24 8LZ, England.
RP Ogden, T (reprint author), British Occupat Hyg Soc, Annals Occupat Hyg, Pride
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```

```
CR Bekelman JE, 2003, JAMA-J AM MED ASSOC, V289, P454, DOI
10.1001/jama.289.4.454
   *BRIT OCC HYG SOC, 2009, COLL EXP DAT SUPP DE
   *BRIT OCC HYG SOC, 1971, ANN OCCUP HYG, V14, P361
   BUSSIERES I, 2009, AMIANTE PARADIS REIT
   Conolly RB, 2009, ANN OCCUP HYG, V53, P181, DOI 10.1093/annhyg/men084
   *CORN, 2008, FED RUL EV
   Crump KS, 2008, ANN OCCUP HYG, V52, P481, DOI 10.1093/annhyg/men038
   Crump KS, 2009, ANN OCCUP HYG, V53, P184, DOI 10.1093/annhyg/men088
   Finkelstein MM, 2008, ANN OCCUP HYG, V52, P455, DOI 10.1093/annhyg/men036
   Finkelstein MM, 2009, ANN OCCUP HYG, V53, P192, DOI 10.1093/annhyg/men080
   GRANT B, 2009, ELSEVIER PUBLISHED 6
   Hodgson JT, 2000, ANN OCCUP HYG, V44, P565, DOI 10.1016/S0003-4878(00)00045-4
   *INT AG RES CANC, 1973, ANN OCCUP HYG, V16, P9
   Liddell FDK, 1997, ANN OCCUP HYG, V41, P3, DOI 10.1016/S0003-4878(96)00177-9
   Marquart H, 2008, ANN OCCUP HYG, V52, P429, DOI 10.1093/annhyg/men032
   Marquart H, 2007, J EXPO SCI ENV EPID, V17, pS16, DOI 10.1038/sj.jes.7500617
   MCCULLOGH J, 2008, DEFENDING INDEFENSIB
   McDonald JC, 1998, ANN OCCUP HYG, V42, P3, DOI 10.1016/S0003-4878(98)00007-6
   Michaels D, 2008, DOUBT IS THEIR PRODU
   OGDEN T, 2000, ANN OCCUP HYG, V44, P654
   Ogden TL, 2009, ANN OCCUP HYG, V53, P307, DOI 10.1093/annhyg/mep031
   Ogden T, 2008, ANN OCCUP HYG, V52, P673, DOI 10.1093/annhyg/men065
   RAAD V, 2008, 58 RGO
   Roggli VL, 2009, ANN OCCUP HYG, V53, P191, DOI 10.1093/annhyg/men079
   Siegel Michael, 2007, Epidemiol Perspect Innov, V4, P12, DOI 10.1186/1742-
5573-4-12
   SMITH R, 2006, TROUBLE MEDICAL JOUR
   Stanton DW, 1997, ANN OCCUP HYG, V41, pR3, DOI 10.1016/S0003-4878(97)87374-7
   Tielemans E, 2008, ANN OCCUP HYG, V52, P577, DOI 10.1093/annhyg/men059
   Tielemans E, 2008, ANN OCCUP HYG, V52, P443, DOI 10.1093/annhyg/men033
   Tweedale G, 2000, MAGIC MINERAL KILLER
   2009, STATEMENT MICHAELHAN
NR 31
TC 5
Z9 5
U1 0
U2 0
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 0003-4878
EI 1475-3162
J9 ANN OCCUP HYG
JI Ann. Occup. Hyg.
PD OCT
PY 2009
VL 53
IS 7
BP 651
EP 655
DI 10.1093/annhyg/mep065
PG 5
WC Public, Environmental & Occupational Health; Toxicology
SC Public, Environmental & Occupational Health; Toxicology
GA 505IA
UT WOS:000270684900001
PM 19736240
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```
OA Bronze
DA 2019-08-06
ER

PT J
AU Buell, JF
   Beebe, TM
   Gross, TG
   Trofe, J
   Hanaway, MJ
   Alloway, RR
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   Woodle, ES
AF Buell, JF
   Beebe, TM
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   Trofe, J
   Hanaway, MJ
   Alloway, RR
   First, MR
   Woodle, ES
TI United network for organ sharing publication on scientific registry of
   transplant recipients central nervous system donor cancer transmission
   data
SO TRANSPLANTATION
LA English
DT Letter
ID TUMOR REGISTRY
C1 Univ Cincinnati, Israeli Penn Int Tranplant Tumor Registry, Cincinnati, OH
45267 USA.
RP Buell, JF (reprint author), Univ Cincinnati, Israeli Penn Int Tranplant Tumor
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RI Woodle, E. Steve/N-8059-2013
OI Woodle, E. Steve/0000-0003-4280-0842
CR Kauffman HM, 2002, TRANSPLANTATION, V74, P358, DOI 10.1097/00007890-
200208150-00011
   Kauffman HM, 2000, TRANSPLANTATION, V70, P1747, DOI 10.1097/00007890-
200012270-00014
   KUAFFMAN HM, 2002, TRANSPLANT REV, V16, P177
   PENN I, 1991, TRANSPLANT P, V23, P2629
NR 4
TC 5
Z9 5
U1 0
U2 0
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA 530 WALNUT ST, PHILADELPHIA, PA 19106-3621 USA
SN 0041-1337
J9 TRANSPLANTATION
JI Transplantation
PD MAR 15
PY 2005
VL 79
IS 5
BP 623
EP 623
DI 10.1097/01.TP.0000148909.25097.67
```

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PG 1
WC Immunology; Surgery; Transplantation
SC Immunology; Surgery; Transplantation
GA 905OZ
UT WOS:000227580000022
PM 15753859
DA 2019-08-06
ER

PT J
AU Phillips, M
AF Phillips, Mark
TI International data-sharing norms: from the OECD to the General Data
   Protection Regulation (GDPR)
SO HUMAN GENETICS
LA English
DT Review
AB The evolution of genomic research and its integration into clinical practice,
as they becomeinternationaleven globalendeavors, has brought us to a place where
scientists and clinicians may now only ignore the rules governing international
data sharing at their own peril. Open data policies, on the one hand,
increasingly require custodians of others' genomic data to make it as widely
available as feasible, including toresearchers in other countries. Data
protection law, on the other, has become a significant hurdle to the sharing of
personal data across jurisdictional borders. The space between these two
competing duties is narrowing. In contrast with the other texts in this volume,
which explore the present and future of data sharing and data protection, this
article's focus is on the past. It centres on the historical development of the
data protection rules regarding theinternational transfer of personal data up to
the present. The article's aim is to bring into focus the underlying objectives
thathave influenced and that will continue to influence the way that data
protection rules are applied to the fields of genomics and health, as well as
future developments in data protection generally. The first part of this article
describes the development of international data-sharing data protection rules
since 1970. The second considers difficulties in applying general data
protection rules to the specific context of genomics and health. The third and
final part compares the options available to comply with the international
transfer restrictions set out in the standard-setting EU General Data Protection
Regulation from a genomics perspective.
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CR [Anonymous], 1981, EUR TREAT SER COUNC
   [Anonymous], 2015, METHODS
   [Anonymous], 2013, 474405 PE
   [Anonymous], 1982, INT LAW GOVERNING CO
   [Anonymous], 2011, APEC CROSS BORD PRIV
   [Anonymous], 2015, SAFE HARBOR FRAMEWOR
   [Anonymous], 2014, APEC CROSS BORDER PR
   [Anonymous], 2009, MADR PRIV DECL
   [Anonymous], 2018, INT STAND PROT PRIV
   [Anonymous], 2016, WHY UN SHOULD BE WOR
   [Anonymous], 2018, AD PROT PERS DAT NON
   [Anonymous], 2015, SAFE HARBOR IS DEAD
   Dove E. S., 2015, MED DATA PRIVACY HDB
   European Union, 2016, OFF J EUR UNION, V49, pL119
```

```
   Evans JP, 2008, GENET MED, V10, P500, DOI [10.1097/GIM.0b013e31817f280a,
10.1097GIM.0b013e31817f280a]
   Kuner C, 2013, TRANSBORDER DATA FLO
   Litton JE, 2017, NATURE, V541, P437, DOI 10.1038/541437a
   Maheu M., 2014, WHICH CLOUD STORAGE
   Marelli L, 2018, SCIENCE, V360, P496, DOI 10.1126/science.aar5419
   Naveed M, 2015, ACM COMPUT SURV, V48, DOI 10.1145/2767007
   OECD, 2013, OECD PRIV FRAM
   Oppenheimer Gerald M, 2009, Virtual Mentor, V11, P988, DOI
10.1001/virtualmentor.2009.11.12.mhst1-0912
   Osborne H., 2018, GUARDIAN
   Rothstein MA, 2018, HASTINGS CENT REP, V48, P5, DOI 10.1002/hast.847
   Stoddart J, 2016, J LAW MED ETHICS, V44, P143, DOI 10.1177/1073110516644205
NR 25
TC 4
Z9 4
U1 3
U2 9
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
EI 1432-1203
J9 HUM GENET
JI Hum. Genet.
PD AUG
PY 2018
VL 137
IS 8
SI SI
BP 575
EP 582
DI 10.1007/s00439-018-1919-7
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PT J
AU Holmes, A
   Dallman, TJ
   Shabaan, S
   Hanson, M
   Allison, L
AF Holmes, Anne
   Dallman, Timothy J.
   Shabaan, Sharif
   Hanson, Mary
   Allison, Lesley
TI Validation of Whole-Genome Sequencing for Identification and
   Characterization of Shiga Toxin-Producing Escherichia coli To Produce
   Standardized Data To Enable Data Sharing
SO JOURNAL OF CLINICAL MICROBIOLOGY
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LA English

DT Article

DE Shiga toxin-producing Escherichia coli; whole-genome sequencing

ID OUTBREAK DETECTION; O157 INFECTION; SURVEILLANCE; CHAIN

AB Whole-genome sequencing (WGS) is rapidly becoming the method of choice for outbreak investigations and public health surveillance of microbial pathogens. The combination of improved cluster resolution and prediction of resistance and virulence phenotypes provided by a single tool is extremely advantageous. However, the data produced are complex, and standard bioinformatics pipelines are required to translate the output into easily interpreted epidemiologically relevant information for public health action. The main aim of this study was to validate the implementation of WGS at the Scottish Escherichia coli O157/STEC Reference Laboratory (SERL) using the Public Health England (PHE) bioinformatics pipeline to produce standardized data to enable interlaboratory comparison of results generated at two national reference laboratories. In addition, we evaluated the BioNumerics whole-genome multilocus sequence typing (wgMLST) and E. coli genotyping plug-in tools using the same data set. A panel of 150 well-characterized isolates of Shiga toxin-producing E. coli (STEC) that had been sequenced and analyzed at PHE using the PHE pipeline and database (SnapperDB) was assembled to provide identification and typing data, including serotype (O: H type), sequence type (ST), virulence genes (eae and Shiga toxin [stx] subtype), and a single-nucleotide polymorphism (SNP) address. To validate the implementation of sequencing at the SERL, DNA was reextracted from the isolates and sequenced and analyzed using the PHE pipeline, which had been installed at the SERL; the output was then compared with the PHE data. The results showed a very high correlation between the data, ranging from 93% to 100%, suggesting that the standardization of WGS between our reference laboratories is possible. We also found excellent correlation between the results obtained using the PHE pipeline and BioNumerics, except for the detection of stx(2a) and stx(2c) when these subtypes are both carried by strains.

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CR AHMED R, 1987, J INFECT DIS, V155, P806, DOI 10.1093/infdis/155.4.806
Ashton PM, 2016, PEERJ, V4, DOI 10.7717/peerj.1752
Ashton PM, 2015, PEERJ, V3, DOI 10.7717/peerj.739
Bankevich A, 2012, J COMPUT BIOL, V19, P455, DOI 10.1089/cmb.2012.0021
Bolger AM, 2014, BIOINFORMATICS, V30, P2114, DOI 10.1093/bioinformatics/btu170
Chattaway MA, 2016, FRONT MICROBIOL, V7, DOI 10.3389/fmicb.2016.00258
Chattaway MA, 2017, J CLIN MICROBIOL, V55, P616, DOI 10.1128/JCM.01790-16
Cowden JM, 2001, EPIDEMIOL INFECT, V126, P335, DOI 10.1017/S0950268801005520
Dallman TJ, 2015, MICROB GENOMICS, V1, DOI 10.1099/mgen.0.000029
Dallman TJ, 2015, CLIN INFECT DIS, V61, P305, DOI 10.1093/cid/civ318
Day M, 2017, J ANTIMICROB CHEMOTH, V72, P145, DOI 10.1093/jac/dkw371
Eppinger M, 2011, P NATL ACAD SCI USA, V108, P20142, DOI 10.1073/pnas.1107176108
Gould LH, 2009, CLIN INFECT DIS, V49, P1480, DOI 10.1086/644621
Holmes A, 2015, EPIDEMIOL INFECT, V143, P104, DOI 10.1017/S0950268814000739

```
   Holmes A, 2015, J CLIN MICROBIOL, V53, P3565, DOI 10.1128/JCM.01066-15
   International Organization for Standardization, 2012, 131362012 ISOTS
   Jenkins C, 2015, APPL ENVIRON MICROB, V81, P3946, DOI 10.1128/AEM.04188-14
   Joensen KG, 2015, J CLIN MICROBIOL, V53, P2410, DOI 10.1128/JCM.00008-15
   Joensen KG, 2014, J CLIN MICROBIOL, V52, P1501, DOI 10.1128/JCM.03617-13
   Kohl TA, 2014, J CLIN MICROBIOL, V52, P2479, DOI 10.1128/JCM.00567-14
   Kozyreva VK, 2017, J CLIN MICROBIOL, V55, P2502, DOI 10.1128/JCM.00361-17
   Langmead B, 2009, GENOME BIOL, V10, DOI 10.1186/gb-2009-10-3-r25
   Law D, 2000, J APPL MICROBIOL, V88, P729, DOI 10.1046/j.1365-
2672.2000.01031.x
   Lindsey RL, 2017, J MICROBIOL METH, V140, P1, DOI 10.1016/j.mimet.2017.06.005
   Lindsey RL, 2016, FRONT MICROBIOL, V7, DOI 10.3389/fmicb.2016.00766
   Locking ME, 2001, EPIDEMIOL INFECT, V127, P215, DOI 10.1017/S0950268801006045
   Lynn RM, 2005, EMERG INFECT DIS, V11, P590, DOI 10.3201/eid1104.040833
   Mellmann A, 2017, J CLIN MICROBIOL, V55, P908, DOI 10.1128/JCM.02242-16
   Nadon C, 2017, EUROSURVEILLANCE, V22, P13, DOI 10.2807/1560-
7917.ES.2017.22.23.30544
   Paton AW, 1998, J CLIN MICROBIOL, V36, P598
   Pollock K, 2005, EUROSURVEILLANCE, V10
   Rusconi B, 2016, FRONT MICROBIOL, V7, DOI 10.3389/fmicb.2016.00985
   Scheutz F, 2012, J CLIN MICROBIOL, V50, P2951, DOI 10.1128/JCM.00860-12
   Sodha SV, 2011, EPIDEMIOL INFECT, V139, P309, DOI 10.1017/S0950268810000920
   Tarr PI, 2005, LANCET, V365, P1073, DOI 10.1016/S0140-6736(05)71144-2
   Tewolde R, 2016, PEERJ, V4, DOI 10.7717/peerj.2308
   Turabelidze G, 2013, J CLIN MICROBIOL, V51, P3950, DOI 10.1128/JCM.01930-13
   Underwood AP, 2013, J CLIN MICROBIOL, V51, P232, DOI 10.1128/JCM.01696-12
   Wood DE, 2014, GENOME BIOL, V15, DOI 10.1186/gb-2014-15-3-r46
NR 39
TC 4
Z9 4
U1 0
U2 9
PU AMER SOC MICROBIOLOGY
PI WASHINGTON
PA 1752 N ST NW, WASHINGTON, DC 20036-2904 USA
SN 0095-1137
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J9 J CLIN MICROBIOL
JI J. Clin. Microbiol.
PD MAR
PY 2018
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IS 3
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WC Microbiology
SC Microbiology
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PT J
AU Rokicki, S
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AF Rokicki, Slawa
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TI Inference With Difference-in-Differences With a Small Number of Groups A
Review, Simulation Study, and Empirical Application Using SHARE Data
SO MEDICAL CARE
LA English
DT Article
DE difference-in-differences; clustered standard errors; inference; Monte
Carlo simulation; GEE
ID GENERALIZED ESTIMATING EQUATIONS; CLUSTER RANDOMIZED-TRIALS;
LONGITUDINAL DATA-ANALYSIS; SMALL-SAMPLE ADJUSTMENTS; EUROPEAN
COUNTRIES; HEALTH; CARE; ESTIMATOR; ROBUST; VARIANCE
AB Background: Difference-in-differences (DID) estimation has become increasingly popular as an approach to evaluate the effect of a group-level policy on individual-level outcomes. Several statistical methodologies have been proposed to correct for the within-group correlation of model errors resulting from the clustering of data. Little is known about how well these corrections perform with the often small number of groups observed in health research using longitudinal data.

Methods: First, we review the most commonly used modeling solutions in DID estimation for panel data, including generalized estimating equations (GEE), permutation tests, clustered standard errors (CSE), wild cluster bootstrapping, and aggregation. Second, we compare the empirical coverage rates and power of these methods using a Monte Carlo simulation study in scenarios in which we vary the degree of error correlation, the group size balance, and the proportion of treated groups. Third, we provide an empirical example using the Survey of Health, Ageing, and Retirement in Europe.

Results: When the number of groups is small, CSE are systematically biased downwards in scenarios when data are unbalanced or when there is a low proportion of treated groups. This can result in over-rejection of the null even when data are composed of up to 50 groups. Aggregation, permutation tests, bias-adjusted GEE, and wild cluster bootstrap produce coverage rates close to the nominal rate for almost all scenarios, though GEE may suffer from low power.

Conclusions: In DID estimation with a small number of groups, analysis using aggregation, permutation tests, wild cluster bootstrap, or bias-adjusted GEE is recommended.

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OI Salomon, Joshua/0000-0003-3929-5515; Salomon, Joshua
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FU European Commission [QLK6-CT-2001-00360, SHARE-I3: RII-CT-2006-062193,
COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812, 211909,

227822, 261982]; German Ministry of Education and Research; Max Planck Society for the Advancement of Science; US National Institute on Aging [U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_BSR06-11, OGHA_04-064, HHSN271201300071C]

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CR Avendano M, 2015, SOC SCI MED, V132, P45, DOI 10.1016/j.socscimed.2015.02.037
Bell Robert, 2002, SURV METHODOL, V28, P169
Bertrand M, 2004, Q J ECON, V119, P249, DOI 10.1162/003355304772839588
Bloom E., 2006, CONTRACTING HLTH EVI
Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
Borsch-Supan A, EASYSHARE RELEASE VE, DOI [10.6103/SHARE.easy.600, DOI 10.6103/SHARE.EASY]
Brewer M, 2013, 2363229 SOC SCI RES
Cameron A.C., 2010, WORKING PAPERS
Cameron AC, 2008, REV ECON STAT, V90, P414, DOI 10.1162/rest.90.3.414
Cameron AC, 2015, J HUM RESOUR, V50, P317
Carter AV, 2017, REV ECON STAT, V99, P698, DOI 10.1162/REST_a_00639
Cohen J, 2010, Q J ECON, V125, P1, DOI 10.1162/qjec.2010.125.1.1
Conley TG, 2011, REV ECON STAT, V93, P113, DOI 10.1162/REST_a_00049
Costa-Font J, 2016, HEALTH ECON, V25, P25, DOI 10.1002/hec.3385
Datar A, 2004, AM J PUBLIC HEALTH, V94, P1501, DOI 10.2105/AJPH.94.9.1501
Dimick JB, 2014, JAMA-J AM MED ASSOC, V312, P2401, DOI 10.1001/jama.2014.16153
Donald SG, 2007, REV ECON STAT, V89, P221, DOI 10.1162/rest.89.2.221
Eldridge SM, 2006, INT J EPIDEMIOL, V35, P1292, DOI 10.1093/ije/dyl129
Ernst MD, 2004, STAT SCI, V19, P676, DOI 10.1214/088342304000000396
Estee S, 2010, MED CARE, V48, P18, DOI 10.1097/MLR.0b013e3181bd498f
Fay MP, 2001, BIOMETRICS, V57, P1198, DOI 10.1111/j.0006-341X.2001.01198.x
Fisher RA, 2002, STAT SCI, V17, P286
Gruber S, 2014, SHARE WORKING PAPER, V17-2014
GUNSOLLEY JC, 1995, COMMUN STAT SIMULAT, V24, P869, DOI 10.1080/03610919508813280
Ho DE, 2006, J AM STAT ASSOC, V101, P888, DOI 10.1198/016214505000001258
Imbens GW, 2016, REV ECON STAT, V98, P701, DOI 10.1162/REST_a_00552
Kalousova L, 2015, HEALTH POLICY PLANN, V30, P423, DOI 10.1093/heapol/czu024
LIANG KY, 1986, BIOMETRIKA, V73, P13, DOI 10.2307/2336267
MacKinnon JG, 2017, J APPL ECONOMET, V32, P233, DOI 10.1002/jae.2508
Mancl LA, 2001, BIOMETRICS, V57, P126, DOI 10.1111/j.0006-341X.2001.00126.x

```
   McCaffrey DF, 2006, STAT MED, V25, P4081, DOI 10.1002/sim.2502
   McGovern ME, 2016, INT J EPIDEMIOL, V45, P2100, DOI 10.1093/ije/dyw122
   Morel JG, 2003, BIOMETRICAL J, V45, P395, DOI 10.1002/bimj.200390021
   Pan W, 2002, STAT MED, V21, P1429, DOI 10.1002/sim.1142
   Peters TJ, 2003, INT J EPIDEMIOL, V32, P840, DOI 10.1093/ije/dyg228
   Rutterford C, 2015, INT J EPIDEMIOL, V44, P1051, DOI 10.1093/ije/dyv113
   Ryan AM, 2015, HEALTH SERV RES, V50, P1211, DOI 10.1111/1475-6773.12270
   Shortell SM, 2009, MED CARE, V47, P932, DOI 10.1097/MLR.0b013e31819a621a
   Webb M.D., 2013, 1315 QUEENS EC DEP
   Werner RM, 2013, MED CARE, V51, P487, DOI 10.1097/MLR.0b013e31828d4d29
   WHITE H, 1980, ECONOMETRICA, V48, P817, DOI 10.2307/1912934
   Wooldridge JM, 2003, AM ECON REV, V93, P133, DOI 10.1257/000282803321946930
   ZEGER SL, 1986, BIOMETRICS, V42, P121, DOI 10.2307/2531248
   Zivin K, 2010, MED CARE, V48, P843, DOI 10.1097/MLR.0b013e3181e5792b
NR 44
TC 4
Z9 4
U1 0
U2 0
PU LIPPINCOTT WILLIAMS & WILKINS
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PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
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EI 1537-1948
J9 MED CARE
JI Med. Care
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VL 56
IS 1
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WC Health Care Sciences & Services; Health Policy & Services; Public,
   Environmental & Occupational Health
SC Health Care Sciences & Services; Public, Environmental & Occupational
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ER

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AU Figueiredo, AS
AF Figueiredo, Ana Sofia
TI Data Sharing: Convert Challenges into Opportunities
SO FRONTIERS IN PUBLIC HEALTH
LA English
DT Review
DE data sharing; data privacy; digital health; big data; FAIR guiding
   principles; open data
ID MARKUP LANGUAGE; REPRESENTATION; STANDARDS; EXCHANGE; PRIVACY; FORMAT
AB Initiatives for sharing research data are opportunities to increase the pace
of knowledge discovery and scientific progress. The reuse of research data has
the potential to avoid the duplication of data sets and to bring new views from
multiple analysis of the same data set. For example, the study of genomic
variations associated with cancer profits from the universal collection of such
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data and helps in selecting the most appropriate therapy for a specific patient. However, data sharing poses challenges to the scientific community. These challenges are of ethical, cultural, legal, financial, or technical nature. This article reviews the impact that data sharing has in science and society and presents guidelines to improve the efficient sharing of research data.

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CR [Anonymous], 2017, OPEN DATA COMMONS LE
[Anonymous], 2017, WE SHARE EVERYONE WI
[Anonymous], 2017, EPIC STRUCTURE PERSI
[Anonymous], 2017, PERSISTENT IDENTIFIE
[Anonymous], 2017, WHAT IS DOCKER
[Anonymous], 2017, DOCKER OVERVIEW
[Anonymous], 2017, SCI DATA
[Anonymous], 2017, OFFICIAL HOME PYTHON
Bastow R, 2010, EMBO REP, V11, P730, DOI 10.1038/embor.2010.145
Beltrame L, 2011, BIOINFORMATICS, V27, P2127, DOI 10.1093/bioinformatics/btr339
Ben-Kiki Oren, 2009, YAML AINT MARKUP LAN
Bender E, 2015, NATURE, V527, pS19, DOI 10.1038/527S19a
bioRxiv.org, 2017, PREPR SERV BIOL
Bourne PE, 2015, NATURE, V527, pS16, DOI 10.1038/527S16a
Bray T., 2014, JAVASCRIPT OBJECT NO
Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
Candela L, 2015, J ASSOC INF SCI TECH, V66, P1747, DOI 10.1002/asi.23358
Chavan V, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-S15-S2
Chelliah Vijayalakshmi, 2013, Methods Mol Biol, V1021, P189, DOI 10.1007/978-1-62703-450-0_10
Demir E, 2010, NAT BIOTECHNOL, V28, P935, DOI 10.1038/nbt.1666
Doran GT, 1981, MANAGE REV, V70, P35, DOI DOI 10.1177/004057368303900411
F1000Research, 2017, F1000RESEARCH INNOVA
Goodman A, 2014, PLOS COMPUT BIOL, V10, DOI 10.1371/journal.pcbi.1003542
Hrynaszkiewicz Iain, 2016, Res Integr Peer Rev, V1, P6, DOI 10.1186/s41073-016-0015-6
Hucka M, 2003, BIOINFORMATICS, V19, P524, DOI 10.1093/bioinformatics/btg015
Joly Y, 2016, CELL, V167, P1150, DOI 10.1016/j.cell.2016.11.004
Kanehisa M, 2017, NUCLEIC ACIDS RES, V45, pD353, DOI 10.1093/nar/gkw1092
Kluyver T, 2016, POSITIONING AND POWER IN ACADEMIC PUBLISHING: PLAYERS, AGENTS AND AGENDAS, P87, DOI 10.3233/978-1-61499-649-1-87
Lubitz T, 2016, BIOINFORMATICS, V32, P2559, DOI 10.1093/bioinformatics/btw179
Lunshof JE, 2008, NAT REV GENET, V9, P406, DOI 10.1038/nrg2360
Markowetz F, 2017, PLOS BIOL, V15, DOI 10.1371/journal.pbio.2002050
McKiernan EC, 2016, ELIFE, V5, DOI 10.7554/eLife.16800
McMurry JA, 2017, PLOS BIOL, V15, DOI 10.1371/journal.pbio.2001414
McQuilton P, 2016, DATABASE-OXFORD, DOI 10.1093/database/baw075

```
   Michener WK, 2015, PLOS COMPUT BIOL, V11, DOI 10.1371/journal.pcbi.1004525
   Modjarrad K, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001935
   Ohno-Machado L, 2017, NAT GENET, V49, P816, DOI 10.1038/ng.3864
   Peach BC, 2017, J CRIT CARE, V38, P259, DOI 10.1016/j.jcrc.2016.11.032
   Perez F, 2007, COMPUT SCI ENG, V9, P21, DOI 10.1109/MCSE.2007.53
   Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
   Piwowar HA, 2013, PEERJ, V1, DOI 10.7717/peerj.175
   Pronk TE, 2015, PEERJ, V3, DOI 10.7717/peerj.1242
   R Core Team, 2017, R LANG ENV STAT COMP
   re3data.org, 2017, REG RES DAT REP
   Rocca-Serra P, 2010, BIOINFORMATICS, V26, P2354, DOI
10.1093/bioinformatics/btq415
   Roche DG, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001779
   Sandve GK, 2013, PLOS COMPUT BIOL, V9, DOI 10.1371/journal.pcbi.1003285
   Suber Peter, 2012, OPEN ACCESS
   Taichman DB, 2016, JAMA-J AM MED ASSOC, V315, P467, DOI
10.1001/jama.2015.18164
   Vines TH, 2013, FASEB J, V27, P1304, DOI 10.1096/fj.12-218164
   Westbrook J, 2005, BIOINFORMATICS, V21, P988, DOI
10.1093/bioinformatics/bti082
   Whyte A, 2015, KEEP RES DATA DCC CH
   Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
   World Health Organization [Internet], 2017, DEV GLOB NORMS SHAR
   Xie Y., 2015, DYNAMIC DOCUMENTS R
NR 55
TC 4
Z9 4
U1 1
U2 7
PU FRONTIERS MEDIA SA
PI LAUSANNE
PA AVENUE DU TRIBUNAL FEDERAL 34, LAUSANNE, CH-1015, SWITZERLAND
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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PT J
AU Majumder, MA
   Guerrini, CJ
   Bollinger, JM
   Cook-Deegan, R
   McGuire, AL
AF Majumder, Mary A.
   Guerrini, Christi J.
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Bollinger, Juli M.
Cook-Deegan, Robert
McGuire, Amy L.
TI Sharing data under the 21st Century Cures Act
SO GENETICS IN MEDICINE
LA English
DT Review
DE 21st Century Cures Act; certificates of confidentiality; data sharing;
HIPAA; privacy
AB On 13 December 2016, President Obama signed the 21st Century Cures Act ("the Act") into law. Many of its provisions support the creation of an "Information Commons," an ecosystem of separate but interconnected initiatives that facilitate open and responsible sharing of genomic and other data for research and clinical purposes. For example, the Act supports the National Institutes of Health in mandating data sharing, provides funding and guidance for the large national cohort program now known as All of Us, expresses congressional support for a global pediatric study network, and strengthens patient access to health information. The Act also addresses potential barriers to data sharing. For example, it makes the issuance of certificates of confidentiality automatic for federally funded research involving identifiable, sensitive" information and strengthens the associated protections. At the same time, the Act exacerbates or neglects several challenges, for example, increasing complexity by adding a new definition of "identifiable" and failing to address the financial sustainability of data sharing and the scope of commercialization. In sum, the Act is a positive step, yet there is still much work to be done before the goals of broad data sharing and utilization can be achieved.
C1 [Majumder, Mary A.; Guerrini, Christi J.; Bollinger, Juli M.; McGuire, Amy L.] Baylor Coll Med, Ctr Med Eth & Hlth Policy, Houston, TX 77030 USA.
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FU National Institutes of Health National Human Genome Research Institute
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Genome Research Institute grant R01 HG008918.
CR ACMG Board of Directors, 2017, GENET MED
Ancker JS, 2016, AM J MANAG CARE, V22, P539
[Anonymous], 2011, PREC MED BUILD KNOWL
Conley John M, 2014, N C J Law Technol, V15, P597
Cook-Deegan R, 2013, EUR J HUM GENET, V21, P585, DOI 10.1038/ejhg.2012.217
Council for International Organizations of Medical Sciences & World Health Organization, 2016, INT ETH GUID HLTH RE
Department of Homeland Security, 2017, Fed Regist, V82, P7149
Evans BJ, 2016, AM J LAW MED, V42, P651, DOI 10.1177/0098858817700245
Evans BJ, 2014, GENET MED, V16, P504, DOI 10.1038/gim.2013.186
Faden RR, 2014, NEW ENGL J MED, V370, P766, DOI 10.1056/NEJMhle1313674
Greenberg A. J., 2016, J RURAL HEALTH, P1
Laakmann AB, 2015, UC IRVINE LAW REV, V5, P1001
Majumder MA, 2016, PLOS BIOL, V14, DOI 10.1371/journal.pbio.2000206
Monegain B., 2015, PRIVACY ADVOCATES BL
NIH, GEN DAT SHAR POL
Popejoy AB, 2016, NATURE, V538, P161, DOI 10.1038/538161a
Ray T, 2016, SUPREME COURT PATENT
Simon BM, 2017, NORTHWEST U LAW REV, V111, P377
US Department of Health and Human Services, 2012, GUID REG METH DEID P

```
NR 19
TC 4
Z9 4
U1 0
U2 0
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
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EI 1530-0366
J9 GENET MED
JI Genet. Med.
PD DEC
PY 2017
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IS 12
BP 1289
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WC Genetics & Heredity
SC Genetics & Heredity
GA FS5RS
UT WOS:000419856500001
PM 28541278
OA Bronze
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ER

PT J
AU Rosenthal, A
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   Engle, E
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   Tuzikov, A
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AF Rosenthal, Alex
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   Snezhko, Eduard
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   Astrovko, Andrei
   Skrahina, Alena
   Taaffe, Jessica
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   Long, Alyssa
   Wollenberg, Kurt
   Akhundova, Irada
   Ismayilova, Sharafat
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   Gadirova, Hagigat
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   Tuzikov, Alexander
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TI The TB Portals: an Open-Access, Web-Based Platform for Global
   Drug-Resistant-Tuberculosis Data Sharing and Analysis
SO JOURNAL OF CLINICAL MICROBIOLOGY
LA English
DT Article
DE tuberculosis; digital health; interactive portals; MDR-TB; Mycobacterium
   tuberculosis; query; XDR-TB; drug-resistant TB
ID MYCOBACTERIUM-TUBERCULOSIS; GENOMIC ANALYSIS; EVOLUTION
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AB The TB Portals program is an international consortium of physicians, radiologists, and microbiologists from countries with a heavy burden of drug-resistant tuberculosis working with data scientists and information technology professionals. Together, we have built the TB Portals, a repository of socioeconomic/geographic, clinical, laboratory, radiological, and genomic data from patient cases of drug-resistant tuberculosis backed by shareable, physical samples. Currently, there are 1,299 total cases from five country sites (Azerbaijan, Belarus, Moldova, Georgia, and Romania), 976 (75.1%) of which are multidrug or extensively drug resistant and 38.2%, 51.9%, and 36.3% of which contain X-ray, computed tomography (CT) scan, and genomic data, respectively. The top Mycobacterium tuberculosis lineages represented among collected samples are Beijing, T1, and H3, and single nucleotide polymorphisms (SNPs) that confer resistance to isoniazid, rifampin, ofloxacin, and moxifloxacin occur the most frequently. These data and samples have promoted drug discovery efforts and research into genomics and quantitative image analysis to improve diagnostics while also serving as a valuable resource for researchers and clinical providers. The TB Portals database and associated projects are continually growing, and we invite new partners and collaborations to our initiative. The TB Portals data and their associated analytical and statistical tools are freely available at https://tbportals.niaid.nih.gov/.

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CR Casali N, 2014, NAT GENET, V46, P279, DOI 10.1038/ng.2878
CHEN RY, 2014, SCI TRANSL MED, V6
Cohen KA, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001880
Desjardins CA, 2016, NAT GENET, V48, P544, DOI 10.1038/ng.3548
Detjen AK, 2015, LANCET RESP MED, V3, P451, DOI 10.1016/S2213-2600(15)00095-8
Farhat MR, 2013, NAT GENET, V45, P1183, DOI 10.1038/ng.2747
Ioerger TR, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007778
Jaeger S, 2014, IEEE T MED IMAGING, V33, P233, DOI 10.1109/TMI.2013.2284099
Kim JY, 2003, TUBERCULOSIS CONTROL, P54
Kovalev V, 2013, INT J COMPUT ASSIST, V8, pS18

```
   Kovalev V, 2015, INT J COMPUT ASSI S1, V10, P1
   Li H, 2010, BIOINFORMATICS, V26, P589, DOI 10.1093/bioinformatics/btp698
   Manson AL, 2017, NAT GENET, V49, P395, DOI 10.1038/ng.3767
   Sharma A, 2017, LANCET INFECT DIS
   Vitol I, 2006, INFECT GENET EVOL, V6, P491, DOI 10.1016/j.meegid.2006.03.003
   Walker BJ, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0112963
   WHO, 2006, THE STOP TB STRAT
   WHO, 2015, THE END TB STRAT
   Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
   Wollenberg KR, 2017, J CLIN MICROBIOL, V55, P457, DOI 10.1128/JCM.02116-16
   World Health Organization, 2016, GLOB TUB REP
   World Health Organization, 2014, DEF REP FRAM TUB 201
   World Health Organization, 2016, US HIGH BURD COUNTR
   World Health Organization, 2016, MULT RES TUB MDR TB
   World Health Organization (WHO), 2017, TUBERCULOSIS
   Yerlikaya S, 2017, INT J INFECT DIS, V56, P253, DOI
10.1016/j.ijid.2017.01.025
   Zhang HT, 2013, NAT GENET, V45, P1255, DOI 10.1038/ng.2735
NR 27
TC 4
Z9 4
U1 0
U2 4
PU AMER SOC MICROBIOLOGY
PI WASHINGTON
PA 1752 N ST NW, WASHINGTON, DC 20036-2904 USA
SN 0095-1137
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J9 J CLIN MICROBIOL
JI J. Clin. Microbiol.
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WC Microbiology
SC Microbiology
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PT J
AU Takai-Igarashi, T
   Kinoshita, K
   Nagasaki, M
   Ogishima, S
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   Nagase, S
   Nagaie, S
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   Nagami, F
   Minegishi, N
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Suzuki, Y
Suzuki, K
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AF Takai-Igarashi, Takako
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Suzuki, Yoichi
Suzuki, Kichiya
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Kuriyama, Shinichi
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Yamamoto, Masayuki
TI Security controls in an integrated Biobank to protect privacy in data sharing: rationale and study design
SO BMC MEDICAL INFORMATICS AND DECISION MAKING
LA English
DT Article
DE Personalized healthcare; Biobank; Privacy violation risk; Personal genome data; Personal health data; Data sharing policy; Security policy; Remote access
ID ELECTRONIC HEALTH RECORDS; GENOME-WIDE ASSOCIATION; GENETIC EXCEPTIONALISM; HOMOMORPHIC ENCRYPTION; PERSONALIZED MEDICINE; EMERGE CONSORTIUM; CHALLENGES; HIPAA; TESTS; LEGAL

AB Background: With the goal of realizing genome-based personalized healthcare, we have developed a biobank that integrates personal health, genome, and omics data along with biospecimens donated by volunteers of 150,000. Such a large-scale of data integration involves obvious risks of privacy violation. The research use of personal genome and health information is a topic of global discussion with regard to the protection of privacy while promoting scientific advancement. The present paper reports on our plans, current attempts, and accomplishments in addressing security problems involved in data sharing to ensure donor privacy while promoting scientific advancement.

Methods: Biospecimens and data have been collected in prospective cohort studies with the comprehensive agreement. The sample size of 150,000 participants was required for multiple researches including genome-wide screening of gene by environment interactions, haplotype phasing, and parametric linkage analysis.

Results: We established the Tohoku Medical Megabank (TMM) data sharing policy: a privacy protection rule that requires physical, personnel, and technological safeguards against privacy violation regarding the use and sharing of data. The proposed policy refers to that of NCBI and that of the Sanger Institute. The proposed policy classifies shared data according to the strength of re-identification risks. Local committees organized by TMM evaluate re-identification risk and assign a security category to a dataset. Every dataset is stored in an assigned segment of a supercomputer in accordance with its security category. A security manager should be designated to handle all security problems at individual data use locations. The proposed policy requires closed networks and IP-VPN remote connections.

Conclusion: The mission of the biobank is to distribute biological resources most productively. This mission motivated us to collect biospecimens and health data and simultaneously analyze genome/omics data in-house. The biobank also has the mission of improving the quality and quantity of the contents of the biobank. This motivated us to request users to share the results of their research as feedback to the biobank. The TMM data sharing policy has tackled every security problem originating with the missions. We believe our current implementation to be the best way to protect privacy in data sharing.

C1 [Takai-Igarashi, Takako; Kinoshita, Kengo; Nagasaki, Masao; Ogishima, Soichi; Nakamura, Naoki; Nagase, Sachiko; Nagaie, Satoshi; Saito, Tomo; Nagami, Fuji; Minegishi, Naoko; Suzuki, Yoichi; Suzuki, Kichiya; Hashizume, Hiroaki; Kuriyama, Shinichi; Hozawa, Atsushi; Yaegashi, Nobuo; Kure, Shigeo; Tamiya, Gen; Kawaguchi, Yoshio; Tanaka, Hiroshi; Yamamoto, Masayuki] Tohoku Univ, Tohoku Med Megabank Org, Aoba Ku, 2-1 Seiryo Machi, Sendai, Miyagi, Japan.

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FU Tohoku Medical Megabank Project from Japan Agency for Medical Research and Development (AMED); Ministry of Education, Culture, Sports, Science and Technology (MEXT)

FX The present work was supported in part by the Tohoku Medical Megabank Project from the Japan Agency for Medical Research and Development (AMED) and the Ministry of Education, Culture, Sports, Science and Technology (MEXT).

CR Atreya RV, 2013, J AM MED INFORM ASSN, V20, P95, DOI 10.1136/amiajnl-2012-001026
Ball MP, 2012, P NATL ACAD SCI USA, V109, P11920, DOI 10.1073/pnas.1201904109
Burke W, 2001, AM J MED GENET, V106, P233, DOI 10.1002/ajmg.10011
Clayton EW, 2010, GENET MED, V12, P616, DOI 10.1097/GIM.0b013e3181efdbd0
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Constable SD, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S2
den Dunnen JT, 2015, HUM MUTAT, V36, P657, DOI 10.1002/humu.22810
Elliott P, 2008, INT J EPIDEMIOL, V37, P234, DOI 10.1093/ije/dym276
Green MJ, 2003, ANN INTERN MED, V138, P571, DOI 10.7326/0003-4819-138-7-200304010-00013
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hafen E, 2014, METHOD INFORM MED, V53, P82, DOI 10.3414/ME13-02-0051

Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Jiang XQ, 2013, MED CARE, V51, pS58, DOI 10.1097/MLR.0b013e31829b1d10
Kim M, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S3
Kinkorova J, 2016, EPMA J, V7, DOI 10.1186/s13167-016-0053-7
Koshiba S, 2016, SCI REP-UK, V6, DOI 10.1038/srep31463
Kostkova P, 2016, FRONT PUBLIC HEALTH, V4, DOI 10.3389/fpubh.2016.00007
Kuriyama S, 2016, J EPIDEMIOL, V26, P493, DOI 10.2188/jea.JE20150268
Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
Lu WJ, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S1
Malin B, 2000, J AM MED INFORM ASSN, P537
Malin B, 2011, HUM GENET, V130, P383, DOI 10.1007/s00439-011-1042-5
Malin B, 2011, J AM MED INFORM ASSN, V18, P3, DOI 10.1136/jamia.2010.004622
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
McGuire AL, 2008, GENET MED, V10, P495, DOI [10.1097GIM.0b013e31817a8aaa, 10.1097/GIM.0b013e31817a8aaa]
McGuire AL, 2011, GENOME RES, V21, P1001, DOI 10.1101/gr.120329.111
Nagasaki M, 2015, NAT COMMUN, V6, DOI 10.1038/ncomms9018
Naveed M, 2015, ACM COMPUT SURV, V48, DOI 10.1145/2767007
Nishimura Adam A, 2014, Curr Genet Med Rep, V2, P201
Parks A, 2009, TIME, V173
Roden DM, 2008, CLIN PHARMACOL THER, V84, P362, DOI 10.1038/clpt.2008.89
Ross LF, 2001, J LAW MED ETHICS, V29, P141
Rothstein MA, 2007, J LAW MED ETHICS, V35, P59, DOI 10.1111/j.1748-720X.2007.00154.x
Saigusa D, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0160555
Sengupta S, 2008, J AM MED INFORM ASSN, V15, P569, DOI 10.1197/jamia.M2207
Shoenbill K, 2014, J AM MED INFORM ASSN, V21, P171, DOI 10.1136/amiajnl-2013-001694
Sweeney L, 1998, NEW ENGL J MED, V338, P1077
Wendler D, 2012, ANN INTERN MED, V156, P596, DOI 10.7326/0003-4819-156-8-201204170-00008
Zhang YH, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S4
Zhang YC, 2015, BMC MED INFORM DECIS, V15, DOI [10.1186/1472-6947-15-S5-S5, 10.1186/1472-6947-15-S5-S4]
NR 40
TC 4
Z9 4
U1 1
U2 24
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1472-6947
J9 BMC MED INFORM DECIS
JI BMC Med. Inform. Decis. Mak.
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WC Medical Informatics
SC Medical Informatics
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PT J
AU Hofman, CS
   Lutomski, JE
   Boter, H
   Buurman, BM
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   Donders, R
   Rikkert, MGMO
   Makai, P
   Melis, RAJF
AF Hofman, Cynthia S.
   Lutomski, Jennifer E.
   Boter, Han
   Buurman, Bianca M.
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   Donders, Rogier
   Rikkert, Marcel G. M. Olde
   Makai, Peter
   Melis, Rene A. J. F.
CA TOPICS-MDS Res Consortium
TI Examining the construct and known-group validity of a composite endpoint
   for The Older Persons and Informal Caregivers Survey Minimum Data Set
   (TOPICS-MDS); A large-scale data sharing initiative
SO PLOS ONE
LA English
DT Article
ID QUALITY-OF-LIFE; HEALTH-STATUS; PATIENT GROUPS; CARE; ADULTS
AB Background
   Preference-weighted multi-faceted endpoints have the potential to facilitate
comparative effectiveness research that incorporates patient preferences. The
Older Persons and Informal Caregivers Survey-Composite endpoint (TOPICS-CEP) is
potentially a valuable outcome measure for evaluating interventions in geriatric
care as it combines multiple outcomes relevant to older persons in a single
metric. The objective of this study was to validate TOPICS-CEP across different
study settings (general population, primary care and hospital).
   Methods
   Data were extracted from TOPICS Minimum Dataset (MDS), a pooled public-access
national database with information on older persons throughout the Netherlands.
Data of 17,603 older persons were used. Meta-correlations were performed between
TOPICS-CEP indexed scores, EuroQol5-D utility scores and Cantril's ladder life
satisfaction scores. Mixed linear regression analyses were performed to compare
TOPICS-CEP indexed scores between known groups, e.g. persons with versus without
depression.
   Results
   In the complete sample and when stratified by study setting TOPICS-CEP and
Cantril's ladder were moderately correlated, whereas TOPICS-CEP and EQ-5D were
highly correlated. Higher mean TOPICS-CEP scores were found in persons who were:
married, lived independently and had an education at university level. Moreover,
higher mean TOPICS-CEP scores were found in persons without dementia, depression,
and dizziness with falls, respectively. Similar results were found when
stratified by subgroup.
   Conclusion
   This study supports that TOPICS-CEP is a robust measure which can potentially
be used in broad settings to identify the effect of intervention or of
prevention in elderly care.
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RI Olde Rikkert, Marcel/D-9773-2012; Melis, Rene/J-5943-2012; Rikkert, M.G.M. Olde/H-8078-2014; Donders, A.R.T./L-4277-2015
OI Melis, Rene/0000-0002-7863-4738; Rikkert, M.G.M. Olde/0000-0003-1397-1677; Donders, A.R.T./0000-0002-0484-1419
FU Dutch National Care for the Elderly Programme - ZonMw, organization for health research and development, The Netherlands [60-61900-98-302]
FX This work was supported by The Dutch National Care for the Elderly Programme, coordinated and sponsored by ZonMw, organization for health research and development, The Netherlands [Grant number: 60-61900-98-302]. The funder had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.
CR BAUMEISTER RF, 1995, PSYCHOL BULL, V117, P497, DOI 10.1037/0033-2909.117.3.497
Brazier J, 2004, HEALTH ECON, V13, P873, DOI 10.1002/hec.866
Cantril H, 1965, PATTERN HUMAN CONCER
COHEN J, 1988, APPL PSYCH MEAS, V12, P425, DOI 10.1177/014662168801200410
Crooks VC, 2008, AM J PUBLIC HEALTH, V98, P1221, DOI 10.2105/AJPH.2007.115923
DONABEDIAN A, 1966, MILBANK FUND Q, V44, P166, DOI 10.2307/3348969
ERICKSON P, 1989, MED CARE, V27, pS66, DOI 10.1097/00005650-198903001-00006
Faes MC, 2010, AGING MENT HEALTH, V14, P834, DOI 10.1080/13607861003781825
Fortin Martin, 2004, Health Qual Life Outcomes, V2, P51, DOI 10.1186/1477-7525-2-51
Fried LP, 2004, J GERONTOL A-BIOL, V59, P255
Han KT, 2014, HEALTH QUAL LIFE OUT, V12, DOI 10.1186/s12955-014-0109-0
Hofman CS, OLDER PERSONS INFORM
Hofman CS, 2014, BMC GERIATR, V14, DOI 10.1186/1471-2318-14-51
Janssen MF, 2013, QUAL LIFE RES, V22, P1717, DOI 10.1007/s11136-012-0322-4
Kovner CT, 2002, HEALTH AFFAIR, V21, P78, DOI 10.1377/hlthaff.21.5.78
Krabbe PFM, 1999, J CLIN EPIDEMIOL, V52, P293, DOI 10.1016/S0895-4356(98)00163-2
Lutomski JE, 2015, QUAL LIFE RES, V24, P1281, DOI 10.1007/s11136-014-0841-2
Lutomski JE, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0081673
Malhotra R, 2014, ARCH GERONTOL GERIAT, V58, P269, DOI 10.1016/j.archger.2013.10.004
Park NS, 2009, J APPL GERONTOL, V28, P461, DOI 10.1177/0733464808328606
PATRICK DL, 1989, MED CARE, V27, pS217, DOI 10.1097/00005650-198903001-00018
Schwarzer G., 2010, META METAANALYSIS R
SZENDE AGOTA, 2007, EQ 5D VALUE SETS INV

```
   Terwee CB, 2007, J CLIN EPIDEMIOL, V60, P34, DOI
10.1016/j.jclinepi.2006.03.012
   van der Zee KI, 1996, INT J BEHAV MED, V3, P104, DOI
10.1207/s15327558ijbm0302_2
   WEINBERGER M, 1992, J AM GERIATR SOC, V40, P585, DOI 10.1111/j.1532-
5415.1992.tb02107.x
   Woolhead G, 2004, AGE AGEING, V33, P165, DOI 10.1093/ageing/afh045
NR 27
TC 4
Z9 4
U1 0
U2 10
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
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PY 2017
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AR e0173081
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA EN9HQ
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PT J
AU McKinstry, B
   Sullivan, FM
   Vasishta, S
   Armstrong, R
   Hanley, J
   Haughney, J
   Philip, S
   Smith, BH
   Wood, A
   Palmer, CNA
AF McKinstry, Brian
   Sullivan, Frank M.
   Vasishta, Shobna
   Armstrong, Roma
   Hanley, Janet
   Haughney, John
   Philip, Sam
   Smith, Blair H.
   Wood, Amanda
   Palmer, Colin N. A.
TI Cohort profile: the Scottish Research register SHARE. A register of
   people interested in research participation linked to NHS data sets
SO BMJ OPEN
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LA English

DT Article

ID CLINICAL-RESEARCH; RECRUITMENT

AB Purpose: Recruitment to trials is often difficult. Many trials fail to meet recruitment targets resulting in underpowered studies which waste resources and the time of those who participated. While there is evidence that many people are willing to take part in research, particularly if it involves a condition from which they suffer, researchers are unable to easily contact such people often relying on busy clinicians to identify them. Many clinicians perceive themselves as too busy to take part in research activities. The Scottish Health Research Register SHARE adopts an approach which asks the public to consent to their data held in National Health Service databases to be used to determine their suitability for research projects. Additionally, participants can consent for spare blood, left after routine venepuncture to be automatically identified in the laboratory and stored for future research studies.

Participants: Anyone over the age of 16 years in Scotland can participate. Participants are approached through a range of methods including directly at outpatient clinics and general practitioners practices, leaflets with hospital letters and personal email from employers.

Findings to date: SHARE has recruited around 130 000 people. SHARE has demonstrated that it can quickly and efficiently recruit to studies, over 20 until now. In addition, it can be used to administer questionnaire studies by email and recruit to patient and public involvement groups.

Future plans: SHARE continues to steadily recruit with the ambition of eventually achieving 1 000 000 people in Scotland. We are steadily increasing the number of data sets we use for identifying participants. We are adding a mobile app which will facilitate dissemination about research and allow the collection of physiological and activity data if desired. We anticipate that SHARE will soon become the main source of health research recruitment in Scotland.

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RI Palmer, Colin/M-9773-2019; Palmer, Colin/C-7053-2008; Sullivan, Frank/L-8286-2019

OI Palmer, Colin/0000-0002-6415-6560; Palmer, Colin/0000-0002-6415-6560; Sullivan, Frank/0000-0002-6623-4964; Philip, Sam/0000-0001-6164-211X; Hanley, Janet/0000-0003-1728-0136

FU Chief Scientists Office of the Scottish Government; Wellcome Trust Biomedical Resource Award [099177/Z/12/Z]; Medical Research Council [MC_PC_13040, MR/K007017/1]

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```
   Additional funding and initiation of the spare blood retention in
   Tayside was supported by The Wellcome Trust Biomedical Resource Award
   Number 099177/Z/12/Z.
CR [Anonymous], 2014, HEALTH TECHNOL ASSES, V18, P1, DOI 10.3310/hta18430
   BMA, CAR DAT CONF CONC CA
   Chalmers I, 2009, OBSTET GYNECOL, V114, P1341, DOI
10.1097/AOG.0b013e3181c3020d
   Chief Scientist Office, 2015, EL FUND
   de Lusignan S, 2011, Yearb Med Inform, V6, P112
   Doran T, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d3590
   Grant A, 2013, BMC HEALTH SERV RES, V13, DOI 10.1186/1472-6963-13-422
   Harris PA, 2005, J AM MED INFORM ASSN, V12, P608, DOI 10.1197/jamia.M1722
   Harris PA, 2012, ACAD MED, V87, P66, DOI 10.1097/ACM.0b013e31823ab7d2
   Kendrick Stephen, 1993, Health Bulletin (Edinburgh), V51, P72
   National Services Scotland, SCOTT PRIM CAR INF R
   NIHR CRN, 2014, WHAT DO PEOPL THINK
   Sully BGO, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-166
   Thomas N, 2015, TRIALS, V16, DOI 10.1186/s13063-015-1115-1
   Treweek S, 2013, BMJ OPEN, V3, DOI 10.1136/bmjopen-2012-002360
NR 15
TC 4
Z9 4
U1 0
U2 6
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 2044-6055
J9 BMJ OPEN
JI BMJ Open
PD FEB
PY 2017
VL 7
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SC General & Internal Medicine
GA EQ2BD
UT WOS:000397872400066
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ER

PT J
AU Gouvalas, A
   Igoumenidis, M
   Theodorou, M
   Athanasakis, K
AF Gouvalas, Athanasios
   Igoumenidis, Michael
   Theodorou, Mamas
   Athanasakis, Kostas
TI Cost-Sharing Rates Increase During Deep Recession: Preliminary Data From
   Greece
SO INTERNATIONAL JOURNAL OF HEALTH POLICY AND MANAGEMENT
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LA English

DT Article

DE Cost-Sharing; Patient Participation; Prescription Drugs; Out-of-Pocket (OOP) Expenses

ID CYPRUS; MEDICINES; PAYMENT; ACCESS; CRISIS; CARE

AB Background: Measures taken over the past four years in Greece to reduce pharmaceutical expenditure have led to significant price reductions for medicines, but have also changed patient cost-sharing rates for prescription drugs. This study attempts to capture the resulting increase in patients' out-of-pocket (OOP) expenses for prescription drugs during the 2011-2014 period.

Methods: The authors conducted a retrospective review of financial data derived from 39 883 prescriptions, dispensed at three randomly chosen pharmacies located in Lamia, central Greece.

Results: The study recorded an average contribution rate per prescription as follows: 11.28% for 2011 (95% CI: 10.76-11.80), 14.10% for 2012, 19.97% for 2013, and 29.08% for 2014. Correspondingly, the mean patient charge per prescription for 2011 was (sic)6.58 (95% CI: 6.22-6.94), (sic)8.28 for 2012, (Sic)8.35 for 2013, and (sic)10.87 for 2014. During the 2011-2014 period, mean percentage rate of patient contribution increased by 157.75%, while average patient charge per prescription in current prices increased by 65.22%. The use of a newly introduced internal reference price (IRP) system increased the level of prescription charge at a rate of 2.41% for 2012 (100% surcharge on patients), 26.24% for 2013 (49.95% on patients and 50.04% on the appropriate health insurance funds), and 47.72% for 2014 (85.06% on patients and 14.94% on funds).

Conclusion: Increased cost-sharing rates for prescription drugs can reduce public pharmaceutical expenditure, but international experience shows that rising OOP expenses can compromise patients' ability to pay, particularly when it comes to chronic diseases and vulnerable populations. Various suggestions could be effective in refining the cost-sharing approach by giving greater consideration to chronic patients, and to the poor and elderly.

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CR Carone G., 2012, COST CONTAINMENT POL
Cohn J, 2014, MILBANK Q, V92, P418, DOI 10.1111/1468-0009.12066
Cutler DM, 2010, NEW ENGL J MED, V362, P1553, DOI 10.1056/NEJMp1002305
Frouzi E, 2013, INT J PHARM SCI RES, V4, P125
Gatwood J, 2014, J MANAG CARE SPEC PH, V20, P1102, DOI 10.18553/jmcp.2014.20.11.1102
Hynd A, 2008, PHARMACOEPIDEM DR S, V17, P1091, DOI 10.1002/pds.1670
Lambrelli D, 2011, HEALTH POLICY, V101, P162, DOI 10.1016/j.healthpol.2010.08.023
Lesen E, 2014, EUR J PUBLIC HEALTH, V24, P85, DOI 10.1093/eurpub/ckt062
Luiza VL, 2015, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD007017.pub2
Mann BS, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0089168
OECD, 2011, PHARM EXP HLTH GLANC, DOI 10.1787/health_glance-2011-63-en
OECD, 2014, OECD HLTH STAT 2014
Olga Siskou Ch, 2014, Value Health Reg Issues, V4, P107, DOI 10.1016/j.vhri.2014.07.003
Organisation for Economic Cooperation and Development (OECD)/ European Union, 2014, HLTH GLANC EUR 2014
Page Robert Lee 2nd, 2008, Consult Pharm, V23, P44

```
   Pappa E, 2011, EUR J CLIN PHARMACOL, V67, P185, DOI 10.1007/s00228-010-0940-0
   Petrou P, 2015, J MED ECON, V18, P805, DOI 10.3111/13696998.2015.1049179
   Petrou P, 2014, HEALTH POLICY TECHN, V3, P167, DOI 10.1016/j.hlpt.2014.04.003
   Petrou P, 2015, HEALTH POLICY, V119, P563, DOI
10.1016/j.healthpol.2015.03.004
   Puig-Junoy J, 2014, APPL HEALTH ECON HEA, V12, P279, DOI 10.1007/s40258-014-
0097-6
   Riggs KR, 2014, JAMA INTERN MED, V174, P849, DOI
10.1001/jamainternmed.2014.853
   Sinnott SJ, 2016, PHARMACOEPIDEM DR S, V25, P695, DOI 10.1002/pds.3917
   Sinnott SJ, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0064914
   Skroumpelos A, 2014, DISEASES, V2, P93, DOI [10.3390/diseases2020093, DOI
10.3390/DISEASES2020093]
   Souliotis Kyriakos, 2015, Front Public Health, V3, P203, DOI
10.3389/fpubh.2015.00203
   Soumerai SB, 2004, HEALTH AFFAIR, V23, P135, DOI 10.1377/hlthaff.23.1.135
   Spillane S, 2015, J PHARM POLICY PR S1, V8, pO10
   Tamblyn R, 2001, JAMA-J AM MED ASSOC, V285, P421, DOI 10.1001/jama.285.4.421
   Terraneo M, 2014, INT J HEALTH SERV, V44, P761, DOI 10.2190/HS.44.4.e
   The Pharmaceutical Market in Greece, 2013, PHARM MARK GREEC ANN
   Tordrup D, 2013, APPL HEALTH ECON HEA, V11, P639, DOI 10.1007/s40258-013-
0056-7
   Tsiligianni I, 2015, QUAL PRIM CARE, V22, P38
   Vogler Sabine, 2011, South Med Rev, V4, P69, DOI 10.5655/smr.v4i2.1004
   World Health Organization (WHO), HLTH EXP SER
   Wouters OJ, 2015, B WORLD HEALTH ORGAN, V93, P606, DOI 10.2471/BLT.14.148742
   Zare H, 2013, HEALTH POLICY, V112, P35, DOI 10.1016/j.healthpol.2013.05.020
NR 36
TC 4
Z9 4
U1 0
U2 1
PU KERMAN UNIV MEDICAL SCIENCES
PI KERMAN
PA JAHAD BLVD, KERMAN, 7619813159, IRAN
SN 2322-5939
J9 INT J HEALTH POLICY
JI Int. J. Health Policy Manag.
PD DEC
PY 2016
VL 5
IS 12
BP 687
EP 692
DI 10.15171/ijhpm.2016.62
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WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
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PT J
AU Belloni, M
   Brugiavini, A
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Meschi, E
Tijdens, K
AF Belloni, Michele
Brugiavini, Agar
Meschi, Elena
Tijdens, Kea
TI Measuring and Detecting Errors in Occupational Coding: an Analysis of SHARE Data
SO JOURNAL OF OFFICIAL STATISTICS
LA English
DT Article
DE ISCO; coding software; coding error; cognitive functioning; education
ID POLARIZATION; WORK

AB This article studies coding errors in occupational data, as the quality of this data is important but often neglected. In particular, we recoded open-ended questions on occupation for last and current job in the Dutch sample of the "Survey of Health, Ageing and Retirement in Europe" (SHARE) using a high-quality software program for ex-post coding (CASCOT software). Taking CASCOT coding as our benchmark, our results suggest that the incidence of coding errors in SHARE is high, even when the comparison is made at the level of one-digit occupational codes (28% for last job and 30% for current job). This finding highlights the complexity of occupational coding and suggests that processing errors due to miscoding should be taken into account when undertaking statistical analyses or writing econometric models. Our analysis suggests strategies to alleviate such coding errors, and we propose a set of equations that can predict error. These equations may complement coding software and improve the quality of occupational coding.

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OI Meschi, Elena/0000-0002-0314-9965

FU EU [283646]; European Commission [312691, QLK6-CT-2001-00360, RII-CT-2006-062193, CIT5-CT-2005-028857, CIT4-CT2006-028812, 211909, 227822, 261982]; U.S. National Institute on Aging [U01 AG09740-13S2, P01 AG005842, P01 AG08291, P30 AG12815, R21 AG025169, Y1-AG-4553-01, IAG BSR06-11, OGHA 04-064]; German Ministry of Education and Research
FX This article builds on research carried out for the DASISH project (Data Service Infrastructure for Social Sciences and Humanities, funded by EU-FP7, Contract no. 283646) and the SHARE project (Survey of Health, Ageing and Retirement in Europe). The authors are grateful to researchers at CentERdata in the Netherlands for their efforts in coding Dutch job titles. The authors would like to thank Eric Balster, Peter Elias, Eric Harrison, Maurice Martens, Sue Westerman, and all participants of the "CASCOT: Occupational Coding in Multi-national Surveys" Workshop in Venice (10-11 April 2014) for helpful suggestions on earlier draft of this work. The research leading to these results has received support under the European Commission's 7th Framework Programme (FP7/2013-2017) under grant agreement no312691, InGRID - Inclusive Growth Research Infrastructure Diffusion. The last author would like to acknowledge the contribution of WEBDATANET [COST Action IS1004]. This paper uses data from SHARE wave 1 release 2.5.0, as of 23 August 2011. The SHARE data collection has been primarily funded by the European Commission through the 5th Framework Programme (project

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CR Autor DH, 2013, J LABOUR MARK RES, V46, P185, DOI 10.1007/s12651-013-0128-z
Autor DH, 2006, AM ECON REV, V96, P189, DOI 10.1257/000282806777212620
Autor DH, 2003, Q J ECON, V118, P1279, DOI 10.1162/003355303322552801
Bethmann A., 2014, TRADITIONAL SURVEY T
BIEMER PP, 2003, INTRO SURVEY QUALITY
CBS (Statistics Netherlands), 2012, COD TOOL IMPL 2012 C
Christelis D, 2010, EUR ECON REV, V54, P18, DOI 10.1016/j.euroecorev.2009.04.001
Day J., 2014, FED EC STAT ADV COMM
DESA, 2010, STUD METH F, V82
ELIAS P, 1993, COMPUTER ASSISTED ST
Elias P, 1997, OECD LABOUR MARKET S, V20
Ellison R., 2014, CASCOT OCC COD MULT
Feenstra RC, 1996, AM ECON REV, V86, P240
Fletcher JM, 2011, HEALTH ECON, V20, P553, DOI 10.1002/hec.1616
Ganzeboom H., 2008, OCCUPATION CODING DO
Goos M, 2007, REV ECON STAT, V89, P118, DOI 10.1162/rest.89.1.118
Hartog J, 2000, ECON EDUC REV, V19, P131, DOI 10.1016/S0272-7757(99)00050-3
Hoffmann E., 1995, 951 ILO
ILO, 2010, STUD METH SER F, V102
ILO, 2012, INT STAND CLASS OCC, V1
International Labor Organization (ILO), 2014, ISCO INT STAND CLASS
Jackle A, 2008, J OFF STAT, V24, P411
Jones R., 2004, CASCOT COMPUTER ASSI
Leist AK, 2013, ANN EPIDEMIOL, V23, P455, DOI 10.1016/j.annepidem.2013.05.014
Leuven E, 2011, HBK ECON, V4, P283
MANHEIM RESEARCH INSTITUTE FOR THE ECONOMICS OF AGING (MEA), 2013, SHARE REL GUID 2 6 0
Moscarini G, 2007, SCAND J ECON, V109, P807, DOI 10.1111/j.1467-9442.2007.00510.x
Perales F, 2014, LONGITUD LIFE COURSE, V5, P299, DOI 10.14301/llcs.v5i3.295
Ravesteijn B., 2013, 13143 TINB I
Rose D, 2007, EUR SOC, V9, P459, DOI 10.1080/14616690701336518
Tijdens K. G., 2014, 149 AIAS U AMST
Tijdens K, 2014, J OFF STAT, V30, P23, DOI 10.2478/jos-2014-0002
United Nations, 2007, UPD INT STAND CLASS
United Nations (UN), 2014, NAT CLASS
Westerman S., 2014, CASCOT OCC COD MULT
WILCOXON F, 1945, BIOMETRICS BULL, V1, P80, DOI 10.2307/3001968
Wooldridge JM, 2010, ECONOMETRIC ANALYSIS OF CROSS SECTION AND PANEL DATA, 2ND EDITION, P1

NR 37
TC 4
Z9 4
U1 1
U2 4
PU SCIENDO

PI WARSAW
PA DE GRUYTER POLAND SP Z O O, BOGUMILA ZUGA 32A STR, 01-811 WARSAW, POLAND
SN 0282-423X
J9 J OFF STAT
JI J. Off. Stat.
PD DEC
PY 2016
VL 32
IS 4
BP 917
EP 945
DI 10.1515/JOS-2016-0049
PG 29
WC Social Sciences, Mathematical Methods; Statistics & Probability
SC Mathematical Methods In Social Sciences; Mathematics
GA EE5UU
UT WOS:000389674100010
OA Other Gold
DA 2019-08-06
ER

PT J
AU Haraty, RA
Zbib, M
Masud, M
AF Haraty, Ramzi A.
Zbib, Mirna
Masud, Mehedi
TI Data damage assessment and recovery algorithm from malicious attacks in healthcare data sharing systems
SO PEER-TO-PEER NETWORKING AND APPLICATIONS
LA English
DT Article
DE Data security; Data exchange; Healthcare data protection; Healthcare data tampering
AB In a data sharing system in a cloud computing environment, such as health care system, peers or data sources execute transactions on-the-fly in response to user queries without any centralized control. In this case confidential data might be intercepted or read by hackers. We cannot consider any centralized control for securing data since we cannot assume any central third party security infrastructure (e.g., PKI) to protect confidential data in a data sharing system. Securing health information from malicious attacks has become a major concern. However, securing the data from attacks sometimes fail and attackers succeed in inserting malicious data. Hence, this presents a need for fast and efficient damage assessment and recovery algorithms. In this paper, we present an efficient data damage assessment and recovery algorithm to delete malicious transactions and recover affected transactions in a data source in a health care system based on the concept of the matrix. We compare our algorithm with other approaches and show the performance results.
C1 [Haraty, Ramzi A.; Zbib, Mirna] Lebanese Amer Univ, Dept Comp Sci & Math, Beirut, Lebanon.
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OI Haraty, Ramzi/0000-0002-6978-3627
CR Ammann P, 2002, IEEE T KNOWL DATA EN, V14, P1167, DOI 10.1109/TKDE.2002.1033782

Bernstein P., 1987, CONCURRENCY CONTROL
Chakraborty A, 2010, INT J INF SECUR, V9, P51, DOI 10.1007/s10207-009-0095-0
Chu J, 2012, P 15 INT C RES ATT I
Fu G, 2008, 3 AS PAC TRUST INFR
Haeni R., 1997, INFORM WARFARE INTRO
Haraty R., 2007, ISESCO SCI TECHNOLOG, V3, P43
Hua D, 2011, DBKDA 2011 3 INT C A
Hutchinson W., 2006, Informing Science, V9, P213
Kim T., 2010, P 9 USENIX S OP SYST, P89
Kurra K, 2015, P 48 HAW INT C SYST
Lala C, 2001, IEEE T SYST MAN CY A, V31, P300, DOI 10.1109/3468.935047
Libicki M., 1995, WHAT IS INFORM WARFA
Liu P, 2011, COMPUT STAND INTER, V33, P96, DOI 10.1016/j.csi.2010.03.009
Lomet D., 2006, SIGMOD
Megan B, 1999, INFORM WARFARE WHAT
Microsoft Corporation, 2015, NORTHW PUBS SAMPL DA
Ning P., 2004, INTERNET ENCY, V2, P355
Panda B, 2003, SEVENTH INTERNATIONAL DATABASE ENGINEERING AND APPLICATIONS SYMPOSIUM, PROCEEDINGS, P336, DOI 10.1109/IDEAS.2003.1214947
Panda B., 1994, P S APPL COMP PHOEN, P363
Panda B, 1998, P IFIP TC11 WG 11 3
Panda B, 2002, P 2002 ACM S APPL CO, P445
Ragothaman P., 2002, P 16 ANN IFPI WG 11, P121
Ray I, 2004, LECT NOTES COMPUT SC, V3112, P106
Reuter A, 1993, T PROCESSING CONCEPT
Xie MY, 2008, FCST: 2008 JAPAN-CHINA JOINT WORKSHOP ON FRONTIER OF COMPUTER SCIENCE AND TECHNOLOGY, PROCEEDINGS, P36, DOI 10.1109/FCST.2008.25
Zhou J, 2005, Proceedings from the Sixth Annual IEEE Systems, Man and Cybernetics Information Assurance Workshop, P302, DOI 10.1109/IAW.2005.1495967
Zhou J, 2004, DISTRIB COMPUT, P111
NR 28
TC 4
Z9 4
U1 0
U2 9
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 1936-6442
EI 1936-6450
J9 PEER PEER NETW APPL
JI Peer Peer Netw. Appl.
PD SEP
PY 2016
VL 9
IS 5
SI SI
BP 812
EP 823
DI 10.1007/s12083-015-0361-z
PG 12
WC Computer Science, Information Systems; Telecommunications
SC Computer Science; Telecommunications
GA DQ6VR
UT WOS:000379344100002
DA 2019-08-06
ER

PT J
AU Stuver, SO
McNiff, K
Fraile, B
Odejide, O
Abel, GA
Dodek, A
Jacobson, JO
AF Stuver, Sherri O.
McNiff, Kristen
Fraile, Belen
Odejide, Oreofe
Abel, Gregory A.
Dodek, Anton
Jacobson, Joseph O.
TI Novel Data Sharing Between a Comprehensive Cancer Center and a Private Payer to Better Understand Care at the End of Life
SO JOURNAL OF PAIN AND SYMPTOM MANAGEMENT
LA English
DT Article
DE End-of-life care; claims data; oncology patients; quality improvement
ID POPULATION-BASED INDICATORS; OF-LIFE; MEDICARE BENEFICIARIES; ADMINISTRATIVE DATA; MENTAL-HEALTH; LAST YEAR; QUALITY; DEATH; AGGRESSIVENESS; INTENSITY

AB Context. Understanding end-of-life (EOL) care patterns is a prerequisite to improving the experience for cancer patients. EOL measures endorsed by the National Quality Forum (NQF) have been examined in older patients using Medicare claims.

Objectives. To evaluate EOL care for patients treated at a comprehensive cancer center, using private payer claims data.

Methods. A retrospective cohort study was conducted of Dana-Farber Cancer Institute (DFCI) patients who died between July 2010 and December 2012, and were insured by Blue Cross Blue Shield of Massachusetts. Primary data sources included Blue Cross Blue Shield of Massachusetts claims information and DFCI administrative data. We assessed NQF-endorsed measures of EOL care related to emergency department visits, hospitalizations, and intensive care unit admissions in the last 30 days, chemotherapy in the last 14 days, hospice stay, and death in an acute care setting. Patterns of care by cancer type and service location were determined.

Results. Among 674 patients (mean age 58 years), event rates for NQF-endorsed EOL measures were similar to those reported using Medicare claims. Decedents with hematologic malignancies received significantly more intensive care and were less likely to have enrolled in hospice, compared to decedents with solid tumors. Thirty to 45% of EOL events occurred outside of DFCI and its affiliated hospitals.

Conclusion. Data sharing between a private payer and a large cancer center proved feasible and informative. High rates of hospital service use outside of our sites of care were unexpected. The findings suggest opportunities to better manage care at the end of life. (C) 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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```
   Bach PB, 2004, JAMA-J AM MED ASSOC, V292, P2765, DOI 10.1001/jama.292.22.2765
   Barbera L, 2006, J PALLIATIVE CARE, V22, P12, DOI 10.1177/082585970602200103
   Bernacki R, 2015, BMJ OPEN, V5, DOI 10.1136/bmjopen-2015-009032
   Blayney DW, 2012, HEALTH AFFAIR, V31, P718, DOI 10.1377/hlthaff.2011.1295
   Brooks GA, 2014, HEALTH AFFAIR, V33, P1793, DOI 10.1377/hlthaff.2014.0280
   Campion FX, 2011, J ONCOL PRACT, V7, p31S, DOI 10.1200/JOP.2011.000313
   Chastek B, 2012, J ONCOL PRACT, V8, p75S, DOI 10.1200/JOP.2011.000469
   Dartmouth Atlas of Health Care, 2015, CARE OF CHRONIC ILLN
   Earle CC, 2005, INT J QUAL HEALTH C, V17, P505, DOI 10.1093/intqhc/mzi061
   Earle CC, 2003, J CLIN ONCOL, V21, P1133, DOI 10.1200/JCO.2003.03.059
   Earle CC, 2004, J CLIN ONCOL, V22, P315, DOI 10.1200/JCO.2004.08.036
   Earle CC, 2008, J CLIN ONCOL, V26, P3860, DOI 10.1200/JCO.2007.15.8253
   Emanuel EJ, 2002, ARCH INTERN MED, V162, P1722, DOI
10.1001/archinte.162.15.1722
   Goodman DC, QUALITY OF END OF LI
   Grunfeld E, 2008, CANCER, V112, P2301, DOI 10.1002/cncr.23428
   Grunfeld E, 2006, PALLIATIVE MED, V20, P769, DOI 10.1177/0269216306072553
   Hassett MJ, 2014, J ONCOL PRACT, V10, pE160, DOI 10.1200/JOP.2013.001240
   Ho TH, 2011, J CLIN ONCOL, V29, P1587, DOI 10.1200/JCO.2010.31.9897
   Hui D, 2014, CANCER-AM CANCER SOC, V120, P1572, DOI 10.1002/cncr.28614
   Jacobson JO, 2008, J CLIN ONCOL, V26, P1893, DOI 10.1200/JCO.2007.14.2992
   Jang RW, 2015, JNCI-J NATL CANCER I, V107, P1, DOI DOI 10.1093/JNCI/DJU424
   Kolodziej M, 2011, J ONCOL PRACT, V7, P301, DOI 10.1200/JOP.2011.000394
   Krzyzanowska MK, 2011, INT J QUAL HEALTH C, V23, P554, DOI
10.1093/intqhc/mzr043
   Kwok AC, 2011, LANCET, V378, P1408, DOI 10.1016/S0140-6736(11)61268-3
   Langton JM, 2014, PALLIATIVE MED, V28, P1167, DOI 10.1177/0269216314533813
   Liu TW, 2009, ONCOLOGIST, V14, P1232, DOI 10.1634/theoncologist.2009-0095
   Miesfeldt S, 2012, J PALLIAT MED, V15, P548, DOI 10.1089/jpm.2011.0310
   Morden NE, 2012, HEALTH AFFAIR, V31, P786, DOI 10.1377/hlthaff.2011.0650
   Murphy Sherry L, 2013, Natl Vital Stat Rep, V61, P1
   Obermeyer Z, 2014, JAMA-J AM MED ASSOC, V312, P1888, DOI
10.1001/jama.2014.14950
   Odejide OO, 2014, J ONCOL PRACT, V10, pE396, DOI 10.1200/JOP.2014.001537
   Pyenson B, 2004, J PAIN SYMPTOM MANAG, V28, P200, DOI
10.1016/j.jpainsymman.2004.05.003
   Rosenwax LK, 2011, MED J AUSTRALIA, V194, P570
   Setoguchi S, 2008, J CLIN ONCOL, V26, P5671, DOI 10.1200/JCO.2008.16.3956
   Sheffield KM, 2011, CANCER-AM CANCER SOC, V117, P5003, DOI 10.1002/cncr.26115
   Teno JM, 2013, JAMA-J AM MED ASSOC, V309, P470, DOI 10.1001/jama.2012.207624
   Warren JL, 2011, J NATL CANCER I, V103, P853, DOI 10.1093/jnci/djr145
   Wright AA, 2008, JAMA-J AM MED ASSOC, V300, P1665, DOI
10.1001/jama.300.14.1665
   Wright AA, 2010, J CLIN ONCOL, V28, P4457, DOI 10.1200/JCO.2009.26.3863
   Zerillo JA, 2015, J ONCOL PRACT, V11, P372, DOI 10.1200/JOP.2015.003921
NR 41
TC 4
Z9 4
U1 0
U2 5
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0885-3924
EI 1873-6513
J9 J PAIN SYMPTOM MANAG
JI J. Pain Symptom Manage.
PD AUG
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PY 2016
VL 52
IS 2
BP 161
EP 169
DI 10.1016/j.jpainsymman.2016.02.004
PG 9
WC Health Care Sciences & Services; Medicine, General & Internal; Clinical
   Neurology
SC Health Care Sciences & Services; General & Internal Medicine;
   Neurosciences & Neurology
GA DT7RD
UT WOS:000381683000004
PM 27033156
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ER

PT J
AU Lord, PA
   Willis, TA
   Carder, P
   West, RM
   Foy, R
AF Lord, Paul A.
   Willis, Thomas A.
   Carder, Paul
   West, Robert M.
   Foy, Robbie
TI Optimizing primary care research participation: a comparison of three
   recruitment methods in data-sharing studies
SO FAMILY PRACTICE
LA English
DT Article
DE Electronic health records; family practice; primary health care; quality
   improvement; research design; research subject recruitment
ID QUALITY-OF-CARE; GENERAL-PRACTICE; EXPERIENCE; OUTCOMES; TIME
AB Recruitment of representative samples in primary care research is essential
to ensure high-quality, generalizable results. This is particularly important
for research using routinely recorded patient data to examine the delivery of
care. Yet little is known about how different recruitment strategies influence
the characteristics of the practices included in research.
   We describe three approaches for recruiting practices to data-sharing studies,
examining differences in recruitment levels and practice representativeness.
   We examined three studies that included varying populations of practices from
West Yorkshire, UK. All used anonymized patient data to explore aspects of
clinical practice. Recruitment strategies were 'opt-in', 'mixed opt-in and opt-
out' and 'opt-out'. We compared aggregated practice data between recruited and
not-recruited practices for practice list size, deprivation, chronic disease
management, patient experience and rates of unplanned hospital admission.
   The opt-out strategy had the highest recruitment (80%), followed by mixed
(70%) and opt-in (58%). Practices opting-in were larger (median 7153 versus 4722
patients, >P = 0.03) than practices that declined to opt-in. Practices recruited
by mixed approach were larger (median 7091 versus 5857 patients, >P = 0.04) and
had differences in the clinical quality measure (58.4% versus 53.9% of diabetic
patients with HbA1c a parts per thousand currency sign 59 mmol/mol, >P < 0.01).
We found no differences between practices recruited and not recruited using the
opt-out strategy for any demographic or quality of care measures.
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Opt-out recruitment appears to be a relatively efficient approach to ensuring participation of typical general practices. Researchers should, with appropriate ethical safeguards, consider opt-out recruitment of practices for studies involving anonymized patient data sharing.

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FU National Institute for Health Research (NIHR) under Research for Patient Benefit (RfPB) Programme [PB-PG-0110-21046, PB-PG-101-23041]; National Institute for Health Research (NIHR) [RP-PG-1209-10040]; National Institute for Health Research [RP-PG-1209-10040]
FX National Institute for Health Research (NIHR) [under its Research for Patient Benefit (RfPB) Programme (Grant Reference Numbers PB-PG-0110-21046 and PB-PG-101-23041) and its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1209-10040)].

CR [Anonymous], 2014, HEALTH TECHNOL ASSES, V18, P1, DOI 10.3310/hta18430
[Anonymous], 2013, HOSP EPISODE STAT AD
Ashworth M, 2014, BRIT J GEN PRACT, V64, pE168, DOI 10.3399/bjgp14X677545
Beaulieu MD, 2013, CAN MED ASSOC J, V185, pE590, DOI 10.1503/cmaj.121802
Borgiel A, 1997, CAN FAM PHYSICIAN, V43, P1699
Borgiel A, 1997, CAN FAM PHYSICIAN, V43, P1703
Campbell MK, 2007, HEALTH TECHNOL ASSES, V11
Campbell SM, 2001, BRIT MED J, V323, P784, DOI 10.1136/bmj.323.7316.784
Down L, 2009, J CLIN EPIDEMIOL, V62, P67, DOI 10.1016/j.jclinepi.2008.02.014
Foy R, 2003, FAM PRACT, V20, P83, DOI 10.1093/fampra/20.1.83
Gielen AC, 2008, HLTH BEHAV HLTH ED T, P407
Grant C, 2002, BRIT MED J, V324, P1556, DOI 10.1136/bmj.324.7353.1556
Green ME, 2012, BMC HEALTH SERV RES, V12, DOI 10.1186/1472-6963-12-214
Guthrie B, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d3514
Hamilton W, 2013, BRIT J GEN PRACT, V63, DOI 10.3399/bjgp13X660751
Health and Social Care Information Centre, NAT DIAB AUD 2012 13
McLintock K, 2014, BMJ OPEN, V4, DOI 10.1136/bmjopen-2014-005178
Ng CWL, 2013, BRIT J GEN PRACT, V63, pE604, DOI 10.3399/bjgp13X671588
NHS England, 2013, GP PAT SURV WEIGHT P
Public Health England, NAT GEN PRACT PROF
Reid FDA, 1999, BRIT MED J, V319, P98, DOI 10.1136/bmj.319.7202.98
Rendell JM, 2007, COCHRANE DB SYST REV, V2, P21, DOI DOI 10.1002/14651858.MR000021.PUB3
Rushforth B, 2015, BMC FAM PRACT, V16, DOI 10.1186/s12875-015-0350-6
Serumaga B, 2011, BMJ-BRIT MED J, V342, DOI 10.1136/bmj.d108
Sheather J, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f7042
Starfield B, 2001, BRIT J GEN PRACT, V51, P303
van den Hombergh P, 2013, BMC FAM PRACT, V14, DOI 10.1186/1471-2296-14-23
NR 27
TC 4
Z9 4
U1 1
U2 1
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND

SN 0263-2136
EI 1460-2229
J9 FAM PRACT
JI Fam. Pr.
PD APR
PY 2016
VL 33
IS 2
BP 200
EP 204
DI 10.1093/fampra/cmw003
PG 5
WC Primary Health Care; Medicine, General & Internal
SC General & Internal Medicine
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UT WOS:000374475200014
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OA Bronze, Green Published
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PT J
AU Blevins, M
   Wehbe, FH
   Rebeiro, PF
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   McGowan, CC
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AF Blevins, Meridith
   Wehbe, Firas H.
   Rebeiro, Peter F.
   Caro-Vega, Yanink
   McGowan, Catherine C.
   Shepherd, Bryan E.
CA Caribbean Cent South Amer Network
TI Interactive Data Visualization for HIV Cohorts: Leveraging Data Exchange
   Standards to Share and Reuse Research Tools
SO PLOS ONE
LA English
DT Article
ID INFORMATION-SYSTEMS; PUBLIC-HEALTH
AB Objective
   To develop and disseminate tools for interactive visualization of HIV cohort data.
   Design and Methods
   If a picture is worth a thousand words, then an interactive video, composed of a long string of pictures, can produce an even richer presentation of HIV population dynamics. We developed an HIV cohort data visualization tool using open-source software (R statistical language). The tool requires that the data structure conform to the HIV Cohort Data Exchange Protocol (HICDEP), and our implementation utilized Caribbean, Central and South America network (CCASAnet) data.
   Results
   This tool currently presents patient-level data in three classes of plots: (1) Longitudinal plots showing changes in measurements viewed alongside event probability curves allowing for simultaneous inspection of outcomes by relevant patient classes. (2) Bubble plots showing changes in indicators over time allowing for observation of group level dynamics. (3) Heat maps of levels of

indicators changing over time allowing for observation of spatial-temporal dynamics. Examples of each class of plot are given using CCASAnet data investigating trends in CD4 count and AIDS at antiretroviral therapy (ART) initiation, CD4 trajectories after ART initiation, and mortality.

Conclusions

We invite researchers interested in this data visualization effort to use these tools and to suggest new classes of data visualization. We aim to contribute additional shareable tools in the spirit of open scientific collaboration and hope that these tools further the participation in open data standards like HICDEP by the HIV research community.

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FU National Institute of Allergy and Infectious Diseases (NIAID) as part of the International Epidemiologic Databases to Evaluate AIDS (IeDEA) [U01 AI069923]; TN-CFAR [P30 AI110527, R01 AI093234]
FX This work was supported by the National Institute of Allergy and Infectious Diseases (NIAID) as part of the International Epidemiologic Databases to Evaluate AIDS (IeDEA): U01 AI069923. Partial support was provided by TN-CFAR P30 AI110527 and R01 AI093234.

CR Bastian M., 2009, P INT AAAI C WEBL SO, V8, P361, DOI DOI 10.1136/QSHC.2004.010033
Carriquiry G, 2015, JIAS IN PRESS
Carroll LN, 2014, J BIOMED INFORM, V51, P287, DOI 10.1016/j.jbi.2014.04.006
CLEVELAND WS, 1981, AM STAT, V35, P54, DOI 10.2307/2683591
Corbett EL, 2003, ARCH INTERN MED, V163, P1009, DOI 10.1001/archinte.163.9.1009
Diggle P. J, 2002, ANAL LONGITUDINAL DA
Edwards JK, 2015, CLIN INFECT DIS
Egger M, 2002, LANCET, V360, P119, DOI 10.1016/S0140-6736(02)09411-4
Fauci AS, 1996, ANN INTERN MED, V124, P654, DOI 10.7326/0003-4819-124-7-199604010-00006
Freifeld CC, 2008, J AM MED INFORM ASSN, V15, P150, DOI 10.1197/jamia.M2544
Gao S, 2008, INT J HEALTH GEOGR, V7, DOI 10.1186/1476-072X-7-8
Gentleman RC, 2004, GENOME BIOL, V5, DOI 10.1186/gb-2004-5-10-r80
Harger JR, 2012, COMP OPEN SOURCE VIS
Harrell FE, 2015, SPRINGER SER STAT, DOI 10.1007/978-3-319-19425-7
KAPLAN EL, 1958, J AM STAT ASSOC, V53, P457, DOI 10.2307/2281868
Kjaer J, 2004, ANTIVIR THER, V9, P631
Luz PM, 2015, CD4 RESPONS IN PRESS
Mathers C, 2008, GLOBAL BURDEN OF DISEASE: 2004 UPDATE, P1
McGowan CC, 2007, INT J EPIDEMIOL, V36, P969, DOI 10.1093/ije/dym073
Richards TB, 1999, PUBLIC HEALTH REP, V114, P359, DOI 10.1093/phr/114.4.359
Robinson AC, 2011, HEALTH INFORM J, V17, P191, DOI 10.1177/1460458211409718
Rosling H, 2011, J EPIDEMIOL GLOB HEA, V1, P11, DOI 10.1016/j.jegh.2011.07.001
Silverman B. W, 1986, DENSITY ESTIMATION S
Snow J., 1855, MODE COMMUNICATION C
Tukey J. W., 1977, EXPLORATORY DATA ANA
Weidmann NB, 2010, INT INTERACT, V36, P86, DOI 10.1080/03050620903554614

```
   Yi Q, 2008, INT J HEALTH GEOGR, V7, DOI 10.1186/1476-072X-7-29
NR 28
TC 4
Z9 4
U1 0
U2 5
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD MAR 10
PY 2016
VL 11
IS 3
AR e0151201
DI 10.1371/journal.pone.0151201
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA DG3TL
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PT J
AU Darquy, S
   Moutel, G
   Lapointe, AS
   D'Audiffret, D
   Champagnat, J
   Guerroui, S
   Vendeville, ML
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   Boespflug-Tanguy, Odile
   Duchange, Nathalie
TI Patient/family views on data sharing in rare diseases: study in the
   European LeukoTreat project
SO EUROPEAN JOURNAL OF HUMAN GENETICS
LA English
DT Article
ID BIOBANK RESEARCH; CONSENT; HEALTH; LEUKODYSTROPHIES; PARTICIPATION;
   PERSPECTIVE; REGISTRY
AB The purpose of this study was to explore patient and family views on the
sharing of their medical data in the context of compiling a European
leukodystrophies database. A survey questionnaire was delivered with help from
referral centers and the European Leukodystrophies Association, and the
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questionnaires returned were both quantitatively and qualitatively analyzed. This study found that patients/families were strongly in favor of participating. Patients/families hold great hope and trust in the development of this type of research. They have a strong need for information and transparency on database governance, the conditions framing access to data, all research conducted, partnerships with the pharmaceutical industry, and they also need access to results. Our findings bring ethics-driven arguments for a process combining initial broad consent with ongoing information. On both, we propose key item-deliverables to database participants.

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FU EU [241622]; Institut National de la Sante et de la Recherche Medical (Inserm)
FX This work was given EU FP7 program funding under Leukotreat Grant Agreement No. 241622. We thank the European Leukodystrophies Association (ELA) and its European network (Faveaux P, Duran MJ, Blondeau MC, Priamo P, Gosalbez Garcia A, Machiels C, de Miomandre G, Forstner G, Romano S). The authors are grateful to patients and their families who answered the questionnaire. We also thank the LeukoTreat Ethics Committee and the LeukoTreat referral-center partners. N Duchange and S Darquy are supported by the Institut National de la Sante et de la Recherche Medical (Inserm) as researchers.

CR Almeida AM, 2014, LEUKEMIA RES, V38, P421, DOI 10.1016/j.leukres.2014.01.015
[Anonymous], 2013, EURORDIS POLICY FACT
Ayme S, 2014, ORPHANET J RARE DIS, V9, DOI 10.1186/1750-1172-9-30
Bladen CL, 2013, HUM MUTAT, V34, P1449, DOI 10.1002/humu.22390
Boespflug-Tanguy O, 2008, CURR NEUROL NEUROSCI, V8, P217, DOI 10.1007/s11910-008-0034-x
Caulfield T, 2002, NAT REV GENET, V3, P577
Curran WJ, 1971, J PUBLIC HLTH, V61, P1245
Duchange N, 2014, EUR J PAEDIATR NEURO, V18, P97
European Commission, 2004, GUIDELINES
Farmer A, 2013, BMC PEDIATR, V13, DOI 10.1186/1471-2431-13-130
Gaskell G, 2013, EUR J HUM GENET, V21, P14, DOI 10.1038/ejhg.2012.104
Godard B, 2003, EUR J HUM GENET, V11, pS88, DOI 10.1038/sj.ejhg.5201114
Grady C, 2011, CONTEMP CLIN TRIALS, V33, P3
Griggs RC, 2009, MOL GENET METAB, V96, P20, DOI 10.1016/j.ymgme.2008.10.003

```
   Hansson MG, 2005, J MED ETHICS, V31, P415, DOI 10.1136/jme.2004.009456
   Hansson MG, 2010, METHOD MOL BIOL, V675, P39
   Hansson MG, 2008, BRIT J CANCER, V100, P8
   Kaye J, 2014, EUR J HUM GENET, V23, P1
   Kohlschutter A, 2011, EXPERT REV NEUROTHER, V11, P1485, DOI
[10.1586/ern.11.135, 10.1586/ERN.11.135]
   Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
   Mascalzoni D, 2014, EUR J HUM GENET, V23, P721
   Mascalzoni D., 2008, PLOS MED, V5, P192, DOI DOI 10.1371/J0URNAL.PMED.0050192
   Master Z, 2012, NAT METHODS, V9, P885, DOI 10.1038/nmeth.2142
   McCormack P, 2013, PLOS CURR, V10, P5
   Moutel G, 2005, EUR J HUM GENET, V13, P1055, DOI 10.1038/sj.ejhg.5201450
   OECD, 2007, PRINC GUID ACC RES D
   Peppercorn J, 2012, CANCER-AM CANCER SOC, V118, P5060, DOI 10.1002/cncr.27515
   RE Gliklich, 2014, REGISTRIES EVALUATIN
   Steinsbekk KS, 2013, EUR J HUM GENET, V21, P897, DOI 10.1038/ejhg.2012.282
   Strobl J, 2000, BRIT MED J, V321, P890, DOI 10.1136/bmj.321.7265.890
   Thornton H, 2009, INT J SURG, V7, P501, DOI 10.1016/j.ijsu.2009.09.001
   Trinidad Susan Brown, 2012, AJOB Prim Res, V3, P3
   Vandenbroucke JP, 1998, BRIT MED J, V316, P1331, DOI
10.1136/bmj.316.7141.1331
   Wendler D, 2006, ARCH INTERN MED, V166, P1449, DOI
10.1001/archinte.166.14.1449
NR 34
TC 4
Z9 4
U1 0
U2 6
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1018-4813
EI 1476-5438
J9 EUR J HUM GENET
JI Eur. J. Hum. Genet.
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WC Biochemistry & Molecular Biology; Genetics & Heredity
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PT J
AU Gotze, F
   Mann, S
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AF Gotze, Franziska
Mann, Stefan
Ferjani, Ali
Kohler, Andreas
Heckelei, Thomas
TI Explaining market shares of organic food: evidence from Swiss household data
SO BRITISH FOOD JOURNAL
LA English
DT Article
DE Consumer behaviour; Switzerland; Organic food; Generalized Linear Model
ID CONSUMER PERCEPTIONS; CONSUMPTION; HEALTH; DEMAND; GLOBALIZATION;
DETERMINANTS; ATTITUDES; PRODUCTS; WELFARE; NORWAY

AB Purpose - The purpose of this paper is to identify those product characteristics that are of importance to consumers of organic food in Switzerland.

Design/methodology/approach - In order to identify important organic product characteristics, this study applies a Generalized Linear Model using a six-year sample of Swiss household data distinguishing between organic and conventional products at the product level.

Findings - The analysis reveals three product-related dimensions of importance. First, Swiss consumers prefer unprocessed organic products over highly processed ones suggesting that communicating potential benefits of organic food is more promising for unprocessed products. Second, organic consumers are reluctant to buy products with high price premiums. Third, Swiss consumers prefer domestically produced organic products over imported ones.

Practical implications - The results imply that supporting organic agriculture in Switzerland is still promising from a policy and a marketing perspective as long as the organic price premium is not too high.

Originality/value - This paper presents results regarding the determinants of the organic market share in Switzerland. They give a first understanding of which product characteristics determine organic market shares. From a policy as well as from a marketing perspective a further investigation at the household level is promising in order to understand and respond to the needs and expectations of Swiss consumers.

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OI Heckelei, Thomas/0000-0002-6251-3480; Kohler, Andreas/0000-0003-2756-8512

CR Andersen LM, 2011, J AGR ECON, V62, P565, DOI 10.1111/j.1477-9552.2011.00310.x
Baker BP, 2002, FOOD ADDIT CONTAM, V19, P427, DOI 10.1080/02652030110113799
Banati D, 2011, TRENDS FOOD SCI TECH, V22, P56, DOI 10.1016/j.tifs.2010.12.007
Batte MT, 2007, FOOD POLICY, V32, P145, DOI 10.1016/j.foodpol.2006.05.003
Baum CF, 2008, STATA J, V8, P299, DOI 10.1177/1536867X0800800212
Bio Suisse, 2015, BIO ZAHLEN BIO SUISS
Goetzke B, 2014, APPETITE, V77, P94, DOI 10.1016/j.appet.2014.02.012
Greenhalgh L.A., 1997, NUTR FOOD SCI, V99, P336
Guerrero L, 2009, APPETITE, V52, P345, DOI 10.1016/j.appet.2008.11.008

Harper G. C., 2002, British Food Journal, V104, P287, DOI 10.1108/00070700210425723
Haumann Barbara Fitch, 2014, WORLD ORGANIC AGR ST, P241
Hauser M, 2011, APPETITE, V57, P329, DOI 10.1016/j.appet.2011.05.322
HBS, 2013, HOUS BUDG SURV
Hughner R., 2007, J CONSUM BEHAV, V6, P1, DOI DOI 10.1002/CB.210
Kilcher L., 2011, ORGANIC MARKET EUROP
Lee HJ, 2015, FOOD QUAL PREFER, V39, P259, DOI 10.1016/j.foodqual.2014.06.002
Lockie S, 2004, APPETITE, V43, P135, DOI 10.1016/j.appet.2004.02.004
Magnusson M. K., 2001, British Food Journal, V103, P209, DOI 10.1108/00070700110386755
Mellor M., 1989, SCI CULTURE, V1, P17
Michelsen J., 1999, ORGANIC FARMING EURO, V7
Mohamad SS, 2014, PROCD SOC BEHV, V130, P509, DOI 10.1016/j.sbspro.2014.04.059
Nygard B, 1998, SOCIOL RURALIS, V38, P35, DOI 10.1111/1467-9523.00062
Oberholtzer L., 2006, ORGANIC POULTRY EGGS, P1
Oberholtzer L., 2005, PRICE PREMIUMS HOLD, P1
Papke LE, 1996, J APPL ECONOM, V11, P619, DOI 10.1002/(SICI)1099-1255(199611)11:6<619::AID-JAE418>3.0.CO;2-1
Park TA, 1996, AM J AGR ECON, V78, P647, DOI 10.2307/1243282
Povey R, 1998, HEALTH EDUC RES, V13, P171, DOI 10.1093/her/13.2.171
Sotos JR, 2015, NURS EDUC TODAY, V35, P132, DOI 10.1016/j.nedt.2014.08.004
Raynolds LT, 2004, WORLD DEV, V32, P725, DOI 10.1016/j.worlddev.2003.11.008
Sahota A., 2010, WORLD ORGANIC AGR ST, P53
Schifferstein HNJ, 1998, FOOD QUAL PREFER, V9, P119, DOI 10.1016/S0950-3293(97)00044-X
Schrock R, 2013, ANAL PRICE ELASTICIT, V148, P1
SFSO, 2014, ORG FARM PLANTS PLAN
SFU, 2013, DOM PROD PERC TERMS
Shafie FA, 2012, PROCD SOC BEHV, V49, P360, DOI 10.1016/j.sbspro.2012.07.034
Thompson GD, 1998, AM J AGR ECON, V80, P1113, DOI 10.2307/1244214
Torjusen H, 2001, FOOD QUAL PREFER, V12, P207, DOI 10.1016/S0950-3293(00)00047-1
Vermeir I, 2006, J AGR ENVIRON ETHIC, V19, P169, DOI 10.1007/s10806-005-5485-3
von Borell E, 2004, LIVEST PROD SCI, V90, P3, DOI 10.1016/j.livprodsci.2004.07.003
Wier M, 2008, FOOD POLICY, V33, P406, DOI 10.1016/j.foodpol.2008.01.002
Willer H., 2014, BIOFACH 2014
NR 41
TC 4
Z9 4
U1 1
U2 14
PU EMERALD GROUP PUBLISHING LTD
PI BINGLEY
PA HOWARD HOUSE, WAGON LANE, BINGLEY BD16 1WA, W YORKSHIRE, ENGLAND
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JI Br. Food J.
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WC Food Science & Technology
SC Food Science & Technology
GA DJ3WG
UT WOS:000374136800012
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PT J
AU Kim, Y
   Kim, S
AF Kim, Youngseek
   Kim, Sujin
TI Institutional, Motivational, and Resource Factors Influencing Health
   Scientists' Data-Sharing Behaviours
SO JOURNAL OF SCHOLARLY PUBLISHING
LA English
DT Article
DE Data sharing; health scientists; institutional theory; theory of planned
   behaviour; structural equation modelling
ID GENOMICS
AB This study proposes a composite model of data sharing to examine what determines health scientists' behaviours drawing on institutional, motivational, and resource perspectives. The proposed model was developed considering institutional theory and the theory of planned behaviour. In addition, resource utilization measures were also combined into the research model. Using a national researcher pool, the Community of Scientists' Scholar Database, the analysis included a total of 207 survey responses. Partial least-squares structural equation modelling was performed to evaluate the causal relationship among the data sharing study measures. Findings suggest that regulative pressure by journal publishers and the availability of data repositories was found to be significantly related to data-sharing behaviour. Three motivational factorsperceived career benefit, perceived career risk, and perceived effortwere also found to have a significant influence on attitude toward data sharing, which has a significant relationship with data-sharing behaviour.
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RP Kim, Y (reprint author), Univ Kentucky, Sch Lib & Informat Sci, Lexington, KY 40506 USA.
CR AJZEN I, 1991, ORGAN BEHAV HUM DEC, V50, P179, DOI 10.1016/0749-5978(91)90020-T
   Ajzen I., 2005, HDB ATTITUDES ATTITU
   ANDERSON JC, 1988, PSYCHOL BULL, V103, P411, DOI 10.1037/0033-2909.103.3.411
   Brown C, 2003, J AM SOC INF SCI TEC, V54, P926, DOI 10.1002/asi.10289
   Campbell E.G., 2002, AM SCI, V287, P473
   Campbell EG, 2000, RES POLICY, V29, P303, DOI 10.1016/S0048-7333(99)00068-2
   Campbell Eric G, 2003, J Health Care Law Policy, V6, P241
   Centers for Disease Control and Prevention, SPEC REP
   Chin WW, 1998, QUANT METH SER, P295
   DIMAGGIO PJ, 1983, AM SOCIOL REV, V48, P147, DOI 10.2307/2095101
   Faniel I. M., 2011, INT J DIGITAL CURATI, V6, P58, DOI [10.2218/ijdc.v6i1.172, DOI 10.2218/IJDC.V6I1.172]
   Fennema-Notestine C, 2009, METHODS MOL BIOL, V569, P25, DOI 10.1007/978-1-59745-524-4_2
   Fishbein M., 1975, BELIEF ATTITUDE INTE
   FORNELL C, 1981, J MARKETING RES, V18, P39, DOI 10.2307/3151312
   Foster N.F., 2005, D LIB MAGAZINE, V11, p[1, 1]

Hair J., 2006, MULTIVARIATE DATA AN
Horsburgh JS, 2011, COMPUT GEOSCI-UK, V37, P207, DOI 10.1016/j.cageo.2010.07.003
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Kim J., 2007, J DIGITAL INFORM, V8, p[2, 1]
Kim Y, 2012, J COMPUTATIONAL SCI, V3, P47, DOI DOI 10.22369/ISSN.2153-4136/3/1/6
Kim YS, 2015, J SPECTROSC, P1, DOI 10.1155/2015/462140
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
National Institute of Health, NIH DAT SHAR POL IMP
National Institute of Health (NIH), DAT SHAR WORKB
National Science Foundation, FIELD SCI ENG COD DE
Noor MAF, 2006, PLOS BIOL, V4, P1113, DOI 10.1371/journal.pbio.0040228
Nunnally J. C., 1994, PSYCHOMETRIC THEORY
Piwowar H. A., 2008, INT C EL PUBL
Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
Reidpath DD, 2001, BIOETHICS, V15, P125, DOI 10.1111/1467-8519.00220
Ringle CM, SMARTPLS 2 0 M3 BETA
Rogelberg SG, 2007, ORGAN RES METHODS, V10, P195, DOI 10.1177/1094428106294693
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Scott Brandt D., 2007, COLL RES LIB NEWS, V68, P365
Scott W. R., 2001, I ORG
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
TOLBERT PS, 1983, ADMIN SCI QUART, V28, P22, DOI 10.2307/2392383
TOLBERT PS, 1985, ADMIN SCI QUART, V30, P1, DOI 10.2307/2392808
University of Essex, UK DAT ARCH
University of Washington Health Science Library, DAT RES HLTH SCI
Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
NR 42
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Z9 5
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PA JOURNALS DIVISION, 5201 DUFFERIN ST, DOWNSVIEW, TORONTO, ON M3H 5T8, CANADA
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JI J. Sch. Publ.
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WC Humanities, Multidisciplinary; Information Science & Library Science
SC Arts & Humanities - Other Topics; Information Science & Library Science
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PT S
AU Eze, B
   Peyton, L
AF Eze, Benjamin
   Peyton, Liam
BE Shakshuki, E
TI Systematic Literature Review on the Anonymization of High Dimensional
   Streaming Datasets for Health Data Sharing
SO 6TH INTERNATIONAL CONFERENCE ON EMERGING UBIQUITOUS SYSTEMS AND
   PERVASIVE NETWORKS (EUSPN 2015)/THE 5TH INTERNATIONAL CONFERENCE ON
   CURRENT AND FUTURE TRENDS OF INFORMATION AND COMMUNICATION TECHNOLOGIES
   IN HEALTHCARE (ICTH-2015)
SE Procedia Computer Science
LA English
DT Proceedings Paper
CT 6th International Conference on Emerging Ubiquitous Systems and
   Pervasive Networks (EUSPN) / 5th International Conference on Current and
   Future Trends of Information and Communication Technologies in
   Healthcare (ICTH)
CY SEP 27-30, 2015
CL Berlin, GERMANY
DE privacy; personal health information; high-dimensional datasets;
   streaming databases; data sharing
ID K-ANONYMITY; PRIVACY
AB One of the biggest challenges to health data sharing is regulations that
prohibit the transmission and distribution of Personal Health Information (PHI)
even among collaborating organizations. This impedes research and reduces the
utility of these datasets. Anonymization can address this issue by hiding PHI
while maintaining the analytical utility of the data. Much research has focused
on data that is static, independent and complete. Unfortunately, this is not
typical of health data. Instead of static, independent tables, health data is in
relational databases with multiple high-dimensional tables that are
transactional and constantly changing. Data recipients usually receive multiple
versions of the database over time. This study reviews literature on
anonymization methodologies for large and fast changing high-dimensional
datasets, especially health data. Relevant papers are analyzed, categorized and
compared in terms of scope, and contributions. Finally, we used the extracted
details from our analysis to outline possible research direction for developing
a realistic anonymization framework for health data sharing. (c) 2015 The
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CR Abdalaal A, 2013, COMPUT SECUR, V37, P143, DOI 10.1016/j.cose.2013.03.008
   Aggarwal CC, 2008, ADV DATABASE SYST, V34, P433
   Byun JW, 2006, LECT NOTES COMPUT SC, V4165, P48
   Cao JN, 2011, IEEE T DEPEND SECURE, V8, P337, DOI 10.1109/TDSC.2009.47
   Chung KL, 2007, INFORM SCIENCES, V177, P2130, DOI 10.1016/j.ins.2006.12.003
   El Emam K, 2008, J AM MED INFORM ASSN, V15, P627, DOI 10.1197/jamia.M2716
   El Emam K, 2009, J AM MED INFORM ASSN, V16, P670, DOI 10.1197/jamia.M3144
   Eze Benjamin, 2010, J. theor. appl. electron. commer. res., V5, P56, DOI
10.4067/S0718-18762010000100006
   Fung BCM, 2012, IEEE T SERV COMPUT, V5, P373, DOI 10.1109/TSC.2011.13
   Fung BCM, 2010, ACM COMPUT SURV, V42, DOI 10.1145/1749603.1749605
   Gal TS, 2014, J BIOMED INFORM, V50, P32, DOI 10.1016/j.jbi.2014.01.001
   Ghinita G., 2007, P 33 INT C VER LARG, P758
   Ghinita G, 2008, PROC INT CONF DATA, P715, DOI 10.1109/ICDE.2008.4497480
```

```
   Gkoulalas-Divanis A, 2014, J BIOMED INFORM, V50, P4, DOI
10.1016/j.jbi.2014.06.002
   Guo K, 2013, KNOWL-BASED SYST, V46, P95, DOI 10.1016/j.knosys.2013.03.007
   Hay M, 2010, VLDB J, V19, P797, DOI 10.1007/s00778-010-0210-x
   Jandel M, 2014, COMPUT SECUR, V46, P48, DOI 10.1016/j.cose.2014.07.001
   Keele S, 2007, GUIDELINES PERFORMIN
   Kim S, 2014, J BIOMED INFORM, V50, P95, DOI 10.1016/j.jbi.2014.03.015
   Kohlmayer F, 2012, P ASE IEEE INT C PRI
   Kohlmayer F, 2014, J BIOMED INFORM, V50, P62, DOI 10.1016/j.jbi.2013.12.002
   LeFevre K, 2005, SIGMOD, P49, DOI DOI 10.1145/1066157.1066164
   Li JY, 2008, IEEE T KNOWL DATA EN, V20, P1181, DOI 10.1109/TKDE.2008.52
   Li N, 2007, INT CONF NANO MICRO, P692
   Machanavajjhala A, P INT C DAT ENG, V2006
   Mohammed N, 2010, ACM T KNOWL DISCOV D, V4, DOI 10.1145/1857947.1857950
   Mortazavi R, 2014, KNOWL-BASED SYST, V67, P195, DOI
10.1016/j.knosys.2014.05.011
   Narayanan A, 2008, P IEEE S SECUR PRIV, P111, DOI 10.1109/SP.2008.33
   Nergiz ME, 2014, COMPUT SECUR, V44, P51, DOI 10.1016/j.cose.2014.03.006
   Nergiz ME, 2009, IEEE T KNOWL DATA EN, V21, P1104, DOI 10.1109/TKDE.2008.210
   Okoli C., 2010, SPROUTS WORKING PAPE, V10, P1, DOI DOI 10.2139/SSRN.1954824
   Pei J, 2007, P INT C SCI STAT DAT, DOI [10.1109/SSDBM.2007.16, DOI
10.1109/SSDBM.2007.16]
   Samarati P., 1998, P IEEE S RES SEC PRI, P384
   Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI
10.1142/S0218488502001648
   Tamersoy A, 2012, IEEE T INF TECHNOL B, V16, P413, DOI
10.1109/TITB.2012.2185850
   Vatsalan D, 2013, INFORM SYST, V38, P946, DOI 10.1016/j.is.2012.11.005
   Xu J., 2006, P 12 ACM SIGKDD INT, P785, DOI DOI 10.1145/1150402.1150504
   Yingjie Wu, 2009, 2009 WRI World Congress on Computer Science and Information
Engineering, CSIE, P53, DOI 10.1109/CSIE.2009.549
NR 38
TC 4
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U1 0
U2 2
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PA SARA BURGERHARTSTRAAT 25, PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
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J9 PROCEDIA COMPUT SCI
PY 2015
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BP 348
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   Interdisciplinary Applications; Computer Science, Theory & Methods;
   Health Care Sciences & Services
SC Computer Science; Health Care Sciences & Services
GA BE6BX
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OA Other Gold
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AU Bredenoord, AL
Mostert, M
Isasi, R
Knoppers, BM
AF Bredenoord, Annelien L.
Mostert, Menno
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Knoppers, Bartha M.
TI Data sharing in stem cell translational science: policy statement by the International Stem Cell Forum Ethics Working Party
SO REGENERATIVE MEDICINE
LA English
DT Article
DE data sharing; ethics; policy; stem cells; translational science

AB Data and sample sharing constitute a scientific and ethical imperative but need to be conducted in a responsible manner in order to protect individual interests as well as maintain public trust. In 2014, the Global Alliance for Genomics and Health (GA4GH) adopted a common Framework for Responsible Sharing of Genomic and Health-Related Data. The GA4GH Framework is applicable to data sharing in the stem cell field, however, interpretation is required so as to provide guidance for this specific context. In this paper, the International Stem Cell Forum Ethics Working Party discusses those principles that are specific to translational stem cell science, including engagement, data quality and safety, privacy, security and confidentiality, risk-benefit analysis and sustainability.

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FU Stem Cell Network of Canada; International Stem Cell Forum; EUCelLEX;
ZonMw - The Netherlands Organization for Health Research and Development
FX The authors gratefully acknowledge funding from the Stem Cell Network of Canada, the International Stem Cell Forum, EUCelLEX and ZonMw - The Netherlands Organization for Health Research and Development. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.

CR Andrews PW, 2015, REGEN MED S2, V10, pS1
Boers SN, 2015, AM J BIOETHICS, V15, P53, DOI 10.1080/15265161.2015.1062165
Bredenoord A. L., 2011, HUM MUTAT, V32, P1
Gogel S, 2010, GENE THER, V18, P1
Habets MGJL, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-66
Isasi R, 2014, CELL STEM CELL, V14, P427, DOI 10.1016/j.stem.2014.03.014
Isasi R, 2012, REGEN MED, V7, P439, DOI [10.2217/rme.12.23, 10.2217/RME.12.23]
Knoppers BM, 2010, REGEN MED, V5, P5, DOI 10.2217/RME.09.84
Matthews DJH, 2011, SCIENCE, V331, P725
Niemansburg SL, 2014, TISSUE ENG PT A, V20, P2567, DOI [10.1089/ten.tea.2013.0332, 10.1089/ten.TEA.2013.0332]
Takahashi K, 2007, CELL, V131, P861, DOI 10.1016/j.cell.2007.11.019
Takahashi K, 2006, CELL, V126, P663, DOI 10.1016/j.cell.2006.07.024
Thomson JA, 1998, SCIENCE, V282, P1145, DOI 10.1126/science.282.5391.1145

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TC 4
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PU FUTURE MEDICINE LTD
PI LONDON
PA UNITEC HOUSE, 3RD FLOOR, 2 ALBERT PLACE, FINCHLEY CENTRAL, LONDON, N3
   1QB, ENGLAND
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WC Cell & Tissue Engineering; Engineering, Biomedical
SC Cell Biology; Engineering
GA CX4LW
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AU Sabitha, S
   Rajasree, MS
AF Sabitha, S.
   Rajasree, M. S.
BE Pinho, LM
   Karl, W
   Cohen, A
   Brinkschulte, U
TI Anonymous-CPABE: Privacy Preserved Content Disclosure for Data Sharing
   in Cloud
SO ARCHITECTURE OF COMPUTING SYSTEMS - ARCS 2015
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
CT 28th International Conference on Architecture of Computing Systems
   (ARCS)
CY MAR 24-27, 2015
CL Inst Super Engn Porto, CISTER Res Ctr, Porto, PORTUGAL
SP Gesell Informatic e V, Special Interest Grp Architecture Comp Syst,
Informationstechnische Gesell VDE
HO Inst Super Engn Porto, CISTER Res Ctr
DE Cloud computing; Ciphertext-policy attribute-based encryption;
   Re-encryption; Anonymization
ID ATTRIBUTE-BASED ENCRYPTION; CIPHERTEXT
AB Healthcare Providers are widely using Cloud Computing to securely share Electronic Health Record(EHR). Entire EHR data cannot be disclosed to all the users with different privilege level, since it is more privacy sensitive. So Healthcare Provider has to enforce a privacy preserved access control mechanism to efficiently share EHR. Privacy preserved secure data sharing is one of the most challenging issues in cloud environment. Existing access control mechanisms for data sharing do not consider the privacy of individuals, who are the subjects of data which is being shared while preventing user revocation problem.

To address these problems, we are proposing a novel idea in which, users whose attributes satisfy the access policy and access rights are effective in access time can recover the corresponding data. Proposed scheme is able to ensure security, integrity, privacy preserved fine-grained access control and prevent data mining attacks on shared data. Even though this paper focuses on EHR sharing, it can be generalized to privacy preserved data sharing.

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CR Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
   Boneh D, 2005, LECT NOTES COMPUT SC, V3494, P440
   Fung BCM, 2010, ACM COMPUT SURV, V42, DOI 10.1145/1749603.1749605
   Gentry C, 2002, LECT NOTES COMPUT SC, V2501, P548
   Goh E.J., 2003, NDSS, V3, P131
   Goyal V., 2006, ACM C COMP COMM SEC, P89
   Green M, 2007, LECT NOTES COMPUT SC, V4521, P288
   Jansen Wayne, 2011, NIST SPECIAL PUBLICA
   Kallahalla M., 2003, FAST, V3, P29
   Liu Q, 2014, INFORM SCIENCES, V258, P355, DOI 10.1016/j.ins.2012.09.034
   Ostrovsky R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P195
   Sedayao J., 2012, ENHANCING CLOUD SECU
   Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
   Wang CJ, 2012, PROCEEDINGS OF THE 2012 EIGHTH INTERNATIONAL CONFERENCE ON COMPUTATIONAL INTELLIGENCE AND SECURITY (CIS 2012), P447, DOI 10.1109/CIS.2012.106
   Wang G., 2010, ACM C COMP COMM SEC, P735
   Wang GJ, 2011, COMPUT SECUR, V30, P320, DOI 10.1016/j.cose.2011.05.006
NR 16
TC 4
Z9 4
U1 1
U2 5
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
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J9 LECT NOTES COMPUT SC
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WC Computer Science, Information Systems; Computer Science, Software Engineering; Computer Science, Theory & Methods
SC Computer Science
GA BD6RG
UT WOS:000362516500012
DA 2019-08-06
ER

PT S
AU Azarm-Daigle, M

Kuziemsky, C
Peyton, L
AF Azarm-Daigle, Mana
Kuziemsky, Craig
Peyton, Liam
BE Shakshuki, E
TI A Review of Cross Organizational Healthcare Data Sharing
SO 6TH INTERNATIONAL CONFERENCE ON EMERGING UBIQUITOUS SYSTEMS AND PERVASIVE NETWORKS (EUSPN 2015)/THE 5TH INTERNATIONAL CONFERENCE ON CURRENT AND FUTURE TRENDS OF INFORMATION AND COMMUNICATION TECHNOLOGIES IN HEALTHCARE (ICTH-2015)
SE Procedia Computer Science
LA English
DT Proceedings Paper
CT 6th International Conference on Emerging Ubiquitous Systems and Pervasive Networks (EUSPN) / 5th International Conference on Current and Future Trends of Information and Communication Technologies in Healthcare (ICTH)
CY SEP 27-30, 2015
CL Berlin, GERMANY
DE Cross-organizational healthcare data sharing; patient privacy; literature review; quality of care; technology adoption; interoperability
ID INFORMATION EXCHANGE; SYSTEM

AB Increasingly, healthcare is provided by a team of care providers from different organizations. Cross-organizational healthcare data sharing is a major issue in interoperable healthcare organizations. Studies have shown that quality of care can be put at risk when patients are transferred from one organization to another, while the need for protecting patient privacy is sometimes an inhibitor to providing information computing technology (ICT) solutions. This paper presents a systematic literature review of cross-organizational healthcare data sharing. The review includes research related to laws and regulations as well as proposed methodological and ICT solutions. Our methodology for querying, filtering and selecting relevant papers from scientific, academic and general repositories is explained and the selected papers are categorized and compared in terms of scope, contributions, and future directions. Based on this analysis, we outline a possible research direction for developing ICT solutions that healthcare providers and regulators would be willing to adopt. Based on our review, we concluded that inspite of the liberal regulations around data sharing among authorized healthcare providers, these organizations are utterly reluctant to collaborate on patient information. Fear of a breech of personal health information, and the shortage of technological facilitators that are compatible with the existing health information systems, are the main causes of the cross-organizational interoperability problems in the healthcare sector. The existing collaborative technologies require considerable initial investments that the current healthcare system is not willing to spend funds on. (c) 2015 The Authors. Published by Elsevier B.V.

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CR Abernethy A., 2011, AJPM, V40, P217
Beardwood J., 2005, HEALTHCARE Q, P76
Campos-Castillo C., 2014, JAMIA
Cars T, 2013, BASIC CLIN PHARMACOL, V112, P392, DOI 10.1111/bcpt.12055

```
   Cavoukian A, GUIDE PERSONAL HLTH
   Coleman EA, 2003, J AM GERIATR SOC, V51, P549, DOI 10.1046/j.1532-
5415.2003.51185.x
   El Emam K, 2010, JMIR, V8, P4
   El Emam K, 2010, J AM MED INFORM ASSN, V17, P2
   El Emam K, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0028071
   Haux Reinhold, 2006, NTERNATIONAL J MED I, V75, P268
   Hincapie A, 2011, APPL CLIN INFORM, V2, P499, DOI 10.4338/ACI-2011-05-R-0027
   HNHB LHIN, 2011, INT HNHB LHIN
   Kitchenham B, 2009, INFORM SOFTWARE TECH, V51, P7, DOI
10.1016/j.infsof.2008.09.009
   Korst LM, 2008, J AM MED INFORM ASSN, V15, P195, DOI 10.1197/j.jamia.M2475
   Kuziemsky C., 2013, INTEROPERABILITY HEA
   Leonard K, 2000, Healthc Manage Forum, V13, P45
   Local Health Integration Network, ONL PAT REC ENH CAR
   Luchenski S, 2013, JMIR, V15, p,8
   Mouttham A., 2012, JISF, V14, P1
   Okoli C., GUIDE CONDUCTING SYS
   Peyton L., 2010, IJAMC, V4, P3
   Pietro P., 2014, IS, V39, P22
   Rozenblum R., 2011, QUALITATIVE STUDY CA, V183, P281
   Software Engineering Group, 2007, GUID PERF SYST LIT R, P1
   Tu K, 2010, BMC MED INFORM DECIS, V10, DOI 10.1186/1472-6947-10-35
   Vest JR, 2014, APPL CLIN INFORM, V5, P219, DOI 10.4338/ACI-2013-10-RA-0083
   Webster P., 2013, CANADIAN MED ASS J C, V185
NR 27
TC 4
Z9 4
U1 0
U2 6
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA SARA BURGERHARTSTRAAT 25, PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 1877-0509
J9 PROCEDIA COMPUT SCI
PY 2015
VL 63
BP 425
EP 432
DI 10.1016/j.procs.2015.08.363
PG 8
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Computer Science, Theory & Methods;
   Health Care Sciences & Services
SC Computer Science; Health Care Sciences & Services
GA BE6BX
UT WOS:000373842900055
OA Other Gold
DA 2019-08-06
ER

PT J
AU Njagi, EN
   Molenberghs, G
   Kenward, MG
   Verbeke, G
   Rizopoulos, D
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Kenward, Michael G.
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Rizopoulos, Dimitris
TI A characterization of missingness at random in a generalized shared-parameter joint modeling framework for longitudinal and time-to-event data, and sensitivity analysis
SO BIOMETRICAL JOURNAL
LA English
DT Article
DE Censoring; Coarsening; Missing at Random; Missingness; Missing not at Random; Pattern-mixture model; Selection model; Shared-parameter model
ID PROSTATE-CANCER; MIXTURE-MODELS; CD4 COUNTS; SURVIVAL; AIDS; CURE; PROGRESSION; MARKER

AB We consider a conceptual correspondence between the missing data setting, and joint modeling of longitudinal and time-to-event outcomes. Based on this, we formulate an extended shared random effects joint model. Based on this, we provide a characterization of missing at random, which is in line with that in the missing data setting. The ideas are illustrated using data from a study on liver cirrhosis, contrasting the new framework with conventional joint models.

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FU IAP research Network of the Belgian Government (Belgian Science Policy) [P7/06]
FX We gratefully acknowledge support from IAP research Network P7/06 of the Belgian Government (Belgian Science Policy). We also thank the referees for their helpful comments.

CR Andersen PK, 1993, STAT MODELS BASED CO
Creemers A, 2011, STAT MODEL, V11, P279, DOI 10.1177/1471082X1001100401
Creemers A, 2010, BIOMETRICAL J, V52, P111, DOI 10.1002/bimj.200800235
DEGRUTTOLA V, 1994, BIOMETRICS, V50, P1003
Duchateau L, 2008, STAT BIOL HEALTH, P1
Faucett CL, 1996, STAT MED, V15, P1663, DOI 10.1002/(SICI)1097-0258(19960815)15:15<1663::AID-SIM294>3.0.CO;2-1
Henderson R, 2000, Biostatistics, V1, P465, DOI 10.1093/biostatistics/1.4.465
Hogan J W, 1998, Stat Methods Med Res, V7, P28
Hogan JW, 1997, STAT MED, V16, P239
Klein J., 1997, SURVIVAL ANAL TECHNI
Lavalley MP, 1996, STAT MED, V15, P2289, DOI 10.1002/(SICI)1097-0258(19961115)15:21<2289::AID-SIM449>3.0.CO;2-I
Law NJ, 2002, BIOSTATISTICS, V3, P547, DOI 10.1093/biostatistics/3.4.547
Little R., 2002, STAT ANAL MISSING DA
Molenberghs G, 2004, STAT SINICA, V14, P989
Molenberghs G, 1998, STAT NEERL, V52, P153, DOI 10.1111/1467-9574.00075
Molenberghs G, 2005, MODELS DISCRETE LONG
Molenberghs G, 2007, MISSING DATA CLIN ST

```
   Molenberghs G., 2012, INT J STAT MED RES, V1, P16
   Molenberghs G, 2008, J ROY STAT SOC B, V70, P371, DOI 10.1111/j.1467-
9868.2007.00640.x
   Molenberghs G, 2011, STAT PROBABIL LETT, V81, P892, DOI
10.1016/j.spl.2011.01.012
   Njagi E. N., 2013, STAT METHOD IN PRESS
   PAWITAN Y, 1993, J AM STAT ASSOC, V88, P719, DOI 10.2307/2290756
   Rizopoulos D, 2012, CH CRC BIOSTAT SER, P1, DOI 10.1201/b12208
   Rizopoulos D, 2011, BIOMETRICS, V67, P819, DOI 10.1111/j.1541-
0420.2010.01546.x
   Rizopoulos D, 2009, J ROY STAT SOC B, V71, P637, DOI 10.1111/j.1467-
9868.2008.00704.x
   RUBIN DB, 1976, BIOMETRIKA, V63, P581, DOI 10.2307/2335739
   TAYLOR JMG, 1994, J AM STAT ASSOC, V89, P727
   TSIATIS A, 1975, P NATL ACAD SCI USA, V72, P20, DOI 10.1073/pnas.72.1.20
   TSIATIS AA, 1995, J AM STAT ASSOC, V90, P27, DOI 10.2307/2291126
   Tsiatis AA, 2004, STAT SINICA, V14, P809
   Verbeke G, 2000, LINEAR MIXED MODELS
   Verbeke G, 2010, STAT MODEL, V10, P391, DOI 10.1177/1471082X0901000403
   Verbeke G, 2010, LONGITUDINAL RESEARCH WITH LATENT VARIABLES, P37, DOI
10.1007/978-3-642-11760-2_2
   Xu J, 2001, J ROY STAT SOC C-APP, V50, P375, DOI 10.1111/1467-9876.00241
   Yu MG, 2008, J AM STAT ASSOC, V103, P178, DOI 10.1198/016214507000000400
   Yu MG, 2004, STAT SINICA, V14, P835
NR 36
TC 4
Z9 4
U1 0
U2 9
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0323-3847
EI 1521-4036
J9 BIOMETRICAL J
JI Biom. J.
PD NOV
PY 2014
VL 56
IS 6
BP 1001
EP 1015
DI 10.1002/bimj.201300028
PG 15
WC Mathematical & Computational Biology; Statistics & Probability
SC Mathematical & Computational Biology; Mathematics
GA AS3LE
UT WOS:000344178400008
PM 24947904
DA 2019-08-06
ER

PT J
AU Ardini, MA
   Pan, HQ
   Qin, Y
   Cooley, PC
AF Ardini, Mary-Anne
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Pan, Huaqin
Qin, Ying
Cooley, Philip C.
TI Sample and data sharing: Observations from a central data repository
SO CLINICAL BIOCHEMISTRY
LA English
DT Article
DE Clinical data repository; Biobank; NIDDK

AB Objectives: From 2003 to 2013, RTI International served as the data repository for the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK). RTI worked closely with two sample repository partners to build and maintain the Central Repository (CR) that made data and samples available to approved requestors. In this paper, we recap aspects of establishing the mechanism; detail the challenges and limitations of data and sample sharing, and explore the future of resource sharing in light of the evolving environment of research funding.

Design and methods: Effective maintenance required the system to be flexible and dynamic while at the same time compliant with established data standards.

Results: Our years serving as the CR for NIDDK have yielded a number of observations about the difficulties of running a repository, an operation that is by definition dependent on many outside parties whose degree of expertise and efficiency have a direct impact on repository functioning.

Conclusion: The bio-banking industry will likely continue to become more globally centralized for studying specific genetic diseases and monitoring the health of our environment. The dynamic relationship between emerging technologies and the infrastructure will be needed to support future research that requires the ability of organizations providing support to remain flexible even while following established standards. (C) 2013 The Canadian Society of Clinical Chemists. Published by Elsevier Inc. All rights reserved.

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FU National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), Bethesda, MD, USA [HHSN267200800016C]
FX This work was supported by National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), Bethesda, MD 29892, USA, contract number HHSN267200800016C.

CR [Anonymous], 2003, NIH DAT SHAR POL IMP
Blackman G, BIOBANKING SAVING FU
Cami J, PROMISING FUTURE BIO
Florian Heinemann & Sven Kolber GbR, DBCOPY DAT TOOL
Frey M, FUTURE BIOBANKING
Horn L, 2012, MARKETING YOUR BIOBA
Landy DC, 2012, GENET MED, V14, P223, DOI [10.1038/GIM.0b013e3182310ba0, 10.1038/gim.0b013e3182310ba0]
Manolio TA, 2012, AM J EPIDEMIOL, V175, P859, DOI 10.1093/aje/kwr453
National Institutes of Health, TRANSNIH BIOMEDICAL
Pan HQ, 2013, DATABASE-OXFORD, DOI 10.1093/database/bas058
Stephanie Baum, 2012, FDA GIVES GO AHEAD P

NR 11
TC 4
Z9 4
U1 0
U2 9
PU PERGAMON-ELSEVIER SCIENCE LTD

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PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, ENGLAND
SN 0009-9120
EI 1873-2933
J9 CLIN BIOCHEM
JI Clin. Biochem.
PD MAR
PY 2014
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IS 4-5
BP 252
EP 257
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WC Medical Laboratory Technology
SC Medical Laboratory Technology
GA AD2IT
UT WOS:000333058900004
PM 24291049
OA Green Accepted
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PT J
AU Erickson, BJ
   Fajnwaks, P
   Langer, SG
   Perry, J
AF Erickson, Bradley J.
   Fajnwaks, Patricio
   Langer, Steve G.
   Perry, John
TI Multisite Image Data Collection and Management Using the RSNA Image
   Sharing Network
SO TRANSLATIONAL ONCOLOGY
LA English
DT Article
AB The execution of a multisite trial frequently includes image collection. The
Clinical Trials Processor (CTP) makes removal of protected health information
highly reliable. It also provides reliable transfer of images to a central
review site. Trials using central review of imaging should consider using CTP
for handling image data when a multisite trial is being designed.
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CR Clark K, 2013, J DIGIT IMAGING, V26, P1045, DOI 10.1007/s10278-013-9622-7
   Erickson BJ, 2014, J DIGIT IMAGING
   Erickson BJ, 2012, J DIGIT IMAGING, V25, P449, DOI 10.1007/s10278-012-9490-6
   Ford R, 2009, EUR J CANCER, V45, P268, DOI 10.1016/j.ejca.2008.10.031
   Mortamet B, 2009, MAGN RESON MED, V62, P365, DOI 10.1002/mrm.21992
   Rhodes C, 2010, IEEE ENG MED BIO, P3475, DOI 10.1109/IEMBS.2010.5627838
NR 6
TC 4
Z9 4
U1 0
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U2 1
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
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EI 1936-5233
J9 TRANSL ONCOL
JI Transl. Oncol.
PD FEB
PY 2014
VL 7
IS 1
BP 36
EP 39
DI 10.1593/tlo.13799
PG 4
WC Oncology
SC Oncology
GA AQ3ID
UT WOS:000342684300005
PM 24772205
OA DOAJ Gold, Green Published
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ER

PT J
AU Shmueli-Blumberg, D
   Hu, L
   Allen, C
   Frasketi, M
   Wu, LT
   VanVeldhuisen, P
AF Shmueli-Blumberg, Dikla
   Hu, Lian
   Allen, Colleen
   Frasketi, Michael
   Wu, Li-Tzy
   VanVeldhuisen, Paul
TI The National Drug Abuse Treatment Clinical Trials Network Data Share
   project: Website design, usage, challenges, and future directions
SO CLINICAL TRIALS
LA English
DT Article
ID SUBSTANCE USE DISORDERS; ITEM RESPONSE THEORY; QUALITY-OF-LIFE; HIV
   RISK; RACIAL/ETHNIC DIFFERENCES; ADDICTION SEVERITY; BRIEF SCREENERS;
   GENDER; DEPENDENCE; ALCOHOL
AB Background There are many benefits of data sharing, including the promotion
of new research from effective use of existing data, replication of findings
through re-analysis of pooled data files, meta-analysis using individual patient
data, and reinforcement of open scientific inquiry. A randomized controlled
trial is considered as the gold standard' for establishing treatment
effectiveness, but clinical trial research is very costly, and sharing data is
an opportunity to expand the investment of the clinical trial beyond its
original goals at minimal costs.
   Purpose We describe the goals, developments, and usage of the Data Share
website (http://www.ctndatashare.org) for the National Drug Abuse Treatment
Clinical Trials Network (CTN) in the United States, including lessons learned,
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limitations, and major revisions, and considerations for future directions to improve data sharing.

Methods Data management and programming procedures were conducted to produce uniform and Health Insurance Portability and Accountability Act (HIPAA)-compliant de-identified research data files from the completed trials of the CTN for archiving, managing, and sharing on the Data Share website.

Results Since its inception in 2006 and through October 2012, nearly 1700 downloads from 27 clinical trials have been accessed from the Data Share website, with the use increasing over the years. Individuals from 31 countries have downloaded data from the website, and there have been at least 13 publications derived from analyzing data through the public Data Share website.

Limitations Minimal control over data requests and usage has resulted in little information and lack of control regarding how the data from the website are used. Lack of uniformity in data elements collected across CTN trials has limited cross-study analyses.

Conclusions The Data Share website offers researchers easy access to de-identified data files with the goal to promote additional research and identify new findings from completed CTN studies. To maximize the utility of the website, ongoing collaborative efforts are needed to standardize the core measures used for data collection in the CTN studies with the goal to increase their comparability and to facilitate the ability to pool data files for cross-study analyses.

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FU US National Institute on Drug Abuse (NIDA) of the National Institutes of Health [HHSN271200900034C, HSN271200522071C]; NIDA [R33DA027503, R01DA019623]

FX The work for the National Drug Abuse Treatment Clinical Trials Network (CTN) Data Share website is made possible by the US National Institute on Drug Abuse (NIDA) of the National Institutes of Health (grant number HHSN271200900034C to The EMMES Corporation, and grant number HSN271200522071C to Duke University). Li-Tzy Wu has received research funding from NIDA (R33DA027503, R01DA019623).

CR Brooks A, 2010, SUBST USE MISUSE, V45, P2444, DOI 10.3109/10826084.2010.490928
Burlew AK, 2011, AM J DRUG ALCOHOL AB, V37, P324, DOI 10.3109/00952990.2011.596973
Estabrooks C A, 1995, Can J Nurs Res, V27, P77
Fienberg S. E., 1985, SHARING RES DATA
Greenfield SF, 2011, AM J DRUG ALCOHOL AB, V37, P301, DOI 10.3109/00952990.2011.596875
Hartzler B, 2011, AM J DRUG ALCOHOL AB, V37, P460, DOI 10.3109/00952990.2011.602995
Hartzler B, 2010, J SUBST ABUSE TREAT, V39, P114, DOI 10.1016/j.jsat.2010.05.008
Hernan MA, 2009, EPIDEMIOLOGY, V20, P167, DOI 10.1097/EDE.0b013e318196784a
Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
Insel TR, 2003, PLOS BIOL, V1, P9, DOI 10.1371/journal.pbio.0000017
Korte JE, 2011, SUBST ABUSE REHABIL, V2, P205, DOI 10.2147/SAR.S23796
Korte JE, 2011, AM J DRUG ALCOHOL AB, V37, P358, DOI 10.3109/00952990.2011.602997

```
   Lindblad R, 2011, AM J DRUG ALCOHOL AB, V37, P440, DOI
10.3109/00952990.2011.602996
   NORMAN C, 1985, SCIENCE, V229, P632, DOI 10.1126/science.229.4714.632
   Pilowsky DJ, 2011, SUBST ABUSE REHABIL, V2, P133, DOI 10.2147/SAR.S20895
   Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   Rosa C, 2012, SUBST ABUSE REHABIL, V3, P81, DOI 10.2147/SAR.S31836
   Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI
10.1161/CIRCOUTCOMES.112.965798
   Tai B, 2010, J SUBST ABUSE TREAT, V38, pS4, DOI 10.1016/j.jsat.2010.01.011
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   Thomson Reuters, 2012, COLL SCI ESS
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wu LT, 2008, AM J ADDICTION, V17, P304, DOI 10.1080/10550490802138913
   Wu LT, 2013, GEN HOSP PSYCHIAT, V35, P74, DOI
10.1016/j.genhosppsych.2012.06.014
   Wu LT, 2012, J PSYCHIATR RES, V46, P360, DOI 10.1016/j.jpsychires.2011.12.002
   Wu LT, 2010, SUBST ABUSE REHABIL, V1, P13, DOI 10.2147/SAR.S15151
   Wu LT, 2011, DRUG ALCOHOL DEPEN, V118, P186, DOI
10.1016/j.drugalcdep.2011.03.018
   Wu LT, 2010, J SUBST ABUSE TREAT, V38, pS70, DOI 10.1016/j.jsat.2009.12.011
   Wu LT, 2009, AM J ADDICTION, V18, P206, DOI 10.1080/10550490902787031
   Wu LT, 2009, DRUG ALCOHOL DEPEN, V103, P114, DOI
10.1016/j.drugalcdep.2009.01.018
   Wu LT, 2009, J STUD ALCOHOL DRUGS, V70, P414, DOI 10.15288/jsad.2009.70.414
NR 31
TC 4
Z9 4
U1 0
U2 9
PU SAGE PUBLICATIONS LTD
PI LONDON
PA 1 OLIVERS YARD, 55 CITY ROAD, LONDON EC1Y 1SP, ENGLAND
SN 1740-7745
EI 1740-7753
J9 CLIN TRIALS
JI Clin. Trials
PD DEC
PY 2013
VL 10
IS 6
BP 977
EP 986
DI 10.1177/1740774513503522
PG 10
WC Medicine, Research & Experimental
SC Research & Experimental Medicine
GA 275LB
UT WOS:000328676700016
PM 24085772
OA Green Accepted
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ER

PT J
AU Tully, MP
   Kettis, A
   Hoglund, AT
   Morlin, C
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Schwan, A
Ljungberg, C
AF Tully, Mary P.
Kettis, Asa
Hoglund, Anna T.
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TI Transfer of data or re-creation of knowledge - Experiences of a shared electronic patient medical records system
SO RESEARCH IN SOCIAL & ADMINISTRATIVE PHARMACY
LA English
DT Article
DE Health informatics; Prescribing; Primary care; Secondary care; Electronic medical record
ID HEALTH-CARE; INFORMATION; WISDOM; ERRORS

AB Background: A shared electronic medical record (EMR) can improve communication between primary and secondary care. A consideration of the contents using Data-Information-Knowledge-Wisdom (DIKW) hierarchy could help inform further development of such systems regarding communication about prescribed medication.

Objectives: To investigate primary and secondary care doctors' experiences of the shared EMR in Uppsala, Sweden, focusing on the creation, use and cross-sector transfer of data, information, knowledge and wisdom about individual patients' prescribed medication.

Method: Nine focus groups were held with hospital doctors, of different grades and medical specialties, working at a single large teaching hospital in Uppsala, Sweden and primary care doctors worked in the same geographical area, in urban and rural primary care centers. The transcribed data were analyzed used the constant comparative method, based on data from the participants and application of the DIKW hierarchy.

Results: The doctors were very positive about accessing and using the shared EMR. Data and information in the system were efficiently retrieved and combined with newly collected data and information to create further knowledge. However, they also described a data and information overload, where it was difficult to get a general overview of what had happened over time, coupled with the frequent lack of knowledge being created and shared by other healthcare providers. Doctors were, instead, either explicitly asked or implicitly expected to read and interpret all available data and information and recreate knowledge themselves.

Conclusions: This study highlighted the differences between access to data and information and access to knowledge in a shared EMR. In rolling out such a system, an increased availability of data and information should not be at the expense of a reduced availability of knowledge. (C) 2013 Elsevier Inc. All rights reserved.

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CR Ackoff R.L., 1989, J APPL SYSTEMS ANAL, V16, P3, DOI DOI 10.1002/9781444303179.CH3

Ahmed A, 2011, CRIT CARE MED, V39, P1626, DOI 10.1097/CCM.0b013e31821858a0
Barbour R., 2007, DOING FOCUS GROUPS
Bellinger G, SYSTEMS THINKING
Berg M, 1996, SOCIOL HEALTH ILL, V18, P499, DOI 10.1111/1467-9566.ep10939100
CAYTON H, 2003, J HLTH SERV RES P S1, V8, P33
Gajic O, 2010, AM J RESP CRIT CARE, V182, P585, DOI 10.1164/rccm.201004-0677ED
Jha AK, 2008, INT J MED INFORM, V77, P848, DOI 10.1016/j.ijmedinf.2008.06.007
Kalvemark S, 2004, SOC SCI MED, V58, P1075, DOI 10.1016/S0277-9536(03)00279-X
Kripalani S, 2007, JAMA-J AM MED ASSOC, V297, P831, DOI 10.1001/jama.297.8.831
Kukafka R, 2007, J BIOMED INFORM, V40, P398, DOI 10.1016/j.jbi.2007.07.001
Maenpaa T, 2009, INT J MED INFORM, V78, P757, DOI 10.1016/j.ijmedinf.2009.07.001
Midlov P, 2005, PHARM WORLD SCI, V27, P116, DOI 10.1007/s11096-004-3705-y
Moore P, 2011, J PATIENT SAF, V7, P148, DOI 10.1097/PTS.0b013e31822c5bf9
Motamedi SM, 2011, BMJ QUAL SAF, V20, P403, DOI 10.1136/bmjqs.2009.034587
Murphy DR, 2012, ARCH INTERN MED, V172, P283, DOI 10.1001/archinternmed.2011.740
Rowley J, 2006, J DOC, V62, P251, DOI 10.1108/00220410610653325
Rowley J, 2007, J INF SCI, V33, P163, DOI 10.1177/0165551506070706
Royal Pharmaceutical Society, 2012, KEEP PAT SAF THEY TR
Saleem JJ, 2011, P HUM FACT ERG SOC A, V55, P660
Simon SR, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1164
Strauss A, 1999, BASICS QUALITATIVE R
Tully MP, 2005, J EVAL CLIN PRACT, V11, P430, DOI 10.1111/j.1365-2753.2005.00553.x
Wyatt JC, 2001, J ROY SOC MED, V94, P6, DOI 10.1177/014107680109400102
NR 24
TC 4
Z9 4
U1 0
U2 20
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
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J9 RES SOC ADMIN PHARM
JI Res. Soc. Adm. Pharm.
PD NOV-DEC
PY 2013
VL 9
IS 6
BP 965
EP 974
DI 10.1016/j.sapharm.2013.02.004
PG 10
WC Public, Environmental & Occupational Health; Pharmacology & Pharmacy
SC Public, Environmental & Occupational Health; Pharmacology & Pharmacy
GA 255PN
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DA 2019-08-06
ER

PT J
AU Sivarajasingam, V

```
   Shepherd, JP
   Newcombe, RG
AF Sivarajasingam, V.
   Shepherd, J. P.
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TI Data sharing to reduce violence Why public health must contribute to
   reduce violence
SO BRITISH MEDICAL JOURNAL
LA English
DT Letter
ID POLICE
EM sivarajasingam@cardiff.ac.uk
OI Shepherd, Jonathan/0000-0001-6466-2298
CR BRINK O, 2001, NORDISK TIDSSKRIFT K, V88, P230
   FAERGEMANN C, 2006, THESIS U SO DENMARK
   Florence C, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d3313
   SIVARAJASINGAM V, 2011, BMJ
   Warburton AL, 2006, EMERG MED J, V23, P12, DOI 10.1136/emj.2004.023028
NR 5
TC 4
Z9 4
U1 0
U2 0
PU B M J PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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J9 BRIT MED J
JI Br. Med. J.
PD JUL 19
PY 2011
VL 343
AR d4453
DI 10.1136/bmj.d4453
PG 2
WC Medicine, General & Internal
SC General & Internal Medicine
GA 797ZG
UT WOS:000293168500025
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DA 2019-08-06
ER

PT J
AU Dawson, A
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AF Dawson, Angus
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TI Could do Better: Research Data Sharing and Public Health
SO PUBLIC HEALTH ETHICS
LA English
DT Editorial Material
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CR Dawson A, 2010, BIOETHICS, V24, P218, DOI 10.1111/j.1467-8519.2010.01814.x
```

```
   Verweij M, 2009, PUBLIC HEALTH ETH-UK, V2, P1, DOI 10.1093/phe/php008
   Wellcome Trust, 2011, SHAR RES DAT IMPR PU
NR 3
TC 4
Z9 4
U1 1
U2 6
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1754-9973
J9 PUBLIC HEALTH ETH-UK
JI Public Health Ethics
PD APR
PY 2011
VL 4
IS 1
BP 1
EP 3
DI 10.1093/phe/phr011
PG 3
WC Ethics; Public, Environmental & Occupational Health; Medical Ethics
SC Social Sciences - Other Topics; Public, Environmental & Occupational
   Health; Medical Ethics
GA 891LP
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DA 2019-08-06
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PT J
AU Humphries, KH
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   Knudtson, ML
   Ghali, WA
AF Humphries, KH
   Carere, RG
   Izadnegahdar, M
   Galbraith, PD
   Knudtson, ML
   Ghali, WA
TI Cross-provincial use of cardiac services: The importance of data-sharing
   for clinical registries and outcomes research
SO CANADIAN JOURNAL OF CARDIOLOGY
LA English
DT Article
DE access to cardiac services; coronary angiography; coronary artery bypass
   surgery; percutaneous coronary intervention; population rates
ID CANADIANS USE; ACCESS
AB BACKGROUND: The structure of the Canadian health care system lends itself to
health services and health outcomes research. It is possible to track hospital
admissions and discharges, physician billings and prescriptions using
administrative databases. In addition, several provinces have developed
registries that provide detailed clinical and procedural information. Using the
unique personal health numbers assigned to all Canadian residents, linkage
between administrative databases and population-based clinical registries
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provides important information regarding the use of health services and health outcomes.

OBJECTIVE: To determine the extent of cross-border (British Columbia-Alberta border) use of cardiac services by British Columbia residents.

METHODS: Population rates of cardiac procedures were calculated using two prospective clinical registries (British Columbia Cardiac Registries and Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease [APPROACH]), as well as administrative databases (the British Columbia Ministry of Health's hospitalization and Medical Services Plan databases).

RESULTS: Analyses using only British Columbia data suggest low cardiac procedure rates for patients living in eastern British Columbia. By accessing APPROACH data, it was determined that more than 80% of British Columbia cardiac patients living along the British Columbia-Alberta border access procedural services in Alberta.

CONCLUSIONS: While residents of eastern British Columbia appear to have reduced access to cardiac services when data from British Columbia are analyzed in isolation, they are actually accessing care in Alberta. Analyses based solely on single province data sources will underestimate cardiac procedures rates.

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CR ANDERSON GM, 1989, MED CARE, V27, P288, DOI 10.1097/00005650-198903000-00007
Berger Earl, 2002, Hosp Q, V5, P40
Breen KJ, 2002, MED J AUSTRALIA, V177, P523
COHEN L, 1993, CAN MED ASSOC J, V148, P1206
Ghali WA, 2000, CAN J CARDIOL, V16, P1225
Johansen Helen, 2002, Health Rep, V13, P35
Katz SJ, 2002, HEALTH AFFAIR, V21, P19, DOI 10.1377/hlthaff.21.3.19
Katz SJ, 1998, HEALTH AFFAIR, V17, P225, DOI 10.1377/hlthaff.17.1.225
Kulynych J, 2002, NEW ENGL J MED, V347, P1133, DOI 10.1056/NEJMp020113
ROMANOW RJ, 2002, CPE32852002EIN NAT L
ROOS NP, 1985, AM J PUBLIC HEALTH, V75, P130, DOI 10.2105/AJPH.75.2.130
*US DEP HHS, 1988, INT CLASS DIS
Verity C, 2002, BRIT MED J, V324, P1210, DOI 10.1136/bmj.324.7347.1210

NR 13
TC 4
Z9 4
U1 0
U2 0
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PI OAKVILLE
PA 2902 S SHERIDAN WAY, OAKVILLE, ONTARIO L6J 7L6, CANADA
SN 0828-282X
J9 CAN J CARDIOL
JI Can. J. Cardiol.
PD MAR 1
PY 2005
VL 21
IS 3
BP 267
EP 272
PG 6
WC Cardiac & Cardiovascular Systems

```
SC Cardiovascular System & Cardiology
GA 905CX
UT WOS:000227546400003
PM 15776116
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ER

PT J
AU Ge, CP
   Susilo, W
   Fang, LM
   Wang, JD
   Shi, YQ
AF Ge, Chunpeng
   Susilo, Willy
   Fang, Liming
   Wang, Jiandong
   Shi, Yunqing
TI A CCA-secure key-policy attribute-based proxy re-encryption in the
   adaptive corruption model for dropbox data sharing system
SO DESIGNS CODES AND CRYPTOGRAPHY
LA English
DT Article
DE Proxy re-encryption; Attribute-based proxy re-encryption; Key-policy;
   Adaptive model
AB The notion of attribute-based proxy re-encryption extends the traditional
proxy re-encryption to the attribute-based setting. In an attribute-based proxy
re-encryption scheme, the proxy can convert a ciphertext under one access policy
to another ciphertext under a new access policy without revealing the underlying
plaintext. Attribute-based proxy re-encryption has been widely used in many
applications, such as personal health record and cloud data sharing systems. In
this work, we propose the notion of key-policy attribute-based proxy re-
encryption, which supports any monotonic access structures on users' keys.
Furthermore, our scheme is proved against chosen-ciphertext attack secure in the
adaptive model.
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FU National Natural Science Foundation of China [61702236, 61672270,
   61602216, 61272083, 61300236]; National Natural Science Foundation of
   Jiangsu [BK20130809]; National Science Foundation for Post-doctoral
   Scientists of China [2013M530254]; National Science Foundation for
   Post-doctoral Scientists of Jiangsu [1302137C]; China Postdoctoral
   Science special Foundation [2014T70518]; Open Fund of State Key
   Laboratory of Information Security, Institute of Information
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   Engineering, Chinese Academy of Sciences [2015-MSB-10]; Changzhou Sci
   Tech Program [CJ20179027]
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   National Science Foundation for Post-doctoral Scientists of China (No.
   2013M530254), the National Science Foundation for Post-doctoral
   Scientists of Jiangsu (No. 1302137C), and the China Postdoctoral Science
   special Foundation (No. 2014T70518), the Open Fund of State Key
   Laboratory of Information Security, Institute of Information
   Engineering, Chinese Academy of Sciences (No. 2015-MSB-10), the
   Changzhou Sci & Tech Program (Grant No. CJ20179027).
CR Ateniese G., 2005, NDSS, P29
   Beimel A, 1996, THESIS
   Blaze M, 1998, LECT NOTES COMPUT SC, V1403, P127
   Boneh D, 2005, LECT NOTES COMPUT SC, V3378, P325
   Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P223
   Canetti R., 1999, P PKC 1999 KAM JAP M, P53
   Canetti R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER
AND COMMUNICATIONS SECURITY, P185
   Cramer R., 2004, J COMPUT, V33, P167
   Fang LM, 2011, J SYST SOFTWARE, V84, P2293, DOI 10.1016/j.jss.2011.06.045
   Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
   Green M, 2007, LECT NOTES COMPUT SC, V4521, P288
   Jian Weng R. H.-K., 2009, ASIACCS 2009, P322
   Kaitai Liang, 2013, 2013 5th International Conference on Intelligent
Networking and Collaborative Systems, P552, DOI 10.1109/INCoS.2013.103
   Lewko A, 2010, LECT NOTES COMPUT SC, V6110, P62
   Liang K. T., 2014, P ISPEC 2014 FUJ CHI, P448
   Liang X., 2009, P 4 INT S INF COMP C, P276, DOI DOI 10.1145/1533057.1533094
   Libert B, 2008, LECT NOTES COMPUT SC, V4939, P360, DOI 10.1007/978-3-540-
78440-1_21
   Luo S, 2010, LECT NOTES COMPUT SC, V6476, P401, DOI 10.1007/978-3-642-17650-
0_28
   Sahai A, 2005, LECT NOTES COMPUT SC, V3494, P457
NR 19
TC 3
Z9 3
U1 2
U2 6
PU SPRINGER
PI DORDRECHT
PA VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS
SN 0925-1022
EI 1573-7586
J9 DESIGN CODE CRYPTOGR
JI Designs Codes Cryptogr.
PD NOV
PY 2018
VL 86
IS 11
BP 2587
EP 2603
DI 10.1007/s10623-018-0462-9
PG 17
WC Computer Science, Theory & Methods; Mathematics, Applied
SC Computer Science; Mathematics
GA GV8RK
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ER

PT J
AU Dolman, L
   Page, A
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AF Dolman, Lena
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   Freimuth, Robert R.
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   Fiume, Marc
   Haendel, Melissa
   Hansen, David P.
   Milosavljevic, Aleksandar
   Patel, Ronak Y.
   Pawliczek, Piotr
   Yates, Andrew D.
   Rehm, Heidi L.
TI ClinGen advancing genomic data-sharing standards as a GA4GH driver project
SO HUMAN MUTATION
LA English
DT Article
DE data sharing; genomic knowledge; phenotype ontology; standards; variant annotation; variant representation
AB The Clinical Genome Resource (ClinGen)'s work to develop a knowledge base to support the understanding of genes and variants for use in precision medicine and research depends on robust, broadly applicable, and adaptable technical standards for sharing data and information. To forward this goal, ClinGen has joined with the Global Alliance for Genomics and Health (GA4GH) to support the development of open, freely-available technical standards and regulatory frameworks for secure and responsible sharing of genomic and health-related data. In its capacity as one of the 15 inaugural GA4GH "Driver Projects," ClinGen is providing input on the key standards needs of the global genomics community, and has committed to participate on GA4GH Work Streams to support the development of: (1) a standard model for computer-readable variant representation; (2) a data model for linking variant data to annotations; (3) a specification to enable sharing of genomic variant knowledge and associated clinical interpretations; and (4) a set of best practices for use of phenotype and disease ontologies. ClinGen's participation as a GA4GH Driver Project will provide a robust environment to test drive emerging genomic knowledge sharing standards and prove

their utility among the community, while accelerating the construction of the ClinGen evidence base.

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FU NIH Office of the Director [5R24OD011883]; Canadian Institutes of Health Research [141210]; National Human Genome Research Institute [U41HG006834, U41HG009649, U41HG009650, UM1HG008900]; Wellcome [WT201535/Z/16/Z]; European Molecular Biology Laboratory
FX NIH Office of the Director, Grant/Award Number: 5R24OD011883; Canadian Institutes of Health Research, Grant/Award Number: 141210; National Human Genome Research Institute, Grant/Award Numbers: U41HG006834, U41HG009649, U41HG009650, UM1HG008900; Wellcome, Grant/Award Number: WT201535/Z/16/Z; European Molecular Biology Laboratory

CR Azzariti DR, 2018, CSH MOL CASE STUD, V4, DOI 10.1101/mcs.a002345
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Friedman J. M., 2018, GENETICS MED, DOI 10. 1038/s41436-018-0055-z
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Kirkpatrick BE, 2015, HUM MUTAT, V36, P974, DOI 10.1002/humu.22838
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Marx V, 2015, NATURE, V524, P503, DOI 10.1038/524503a
Mungall CJ, 2017, NUCLEIC ACIDS RES, V45, pD712, DOI 10.1093/nar/gkw1128
Rahimzadeh V, 2018, JAMA PEDIATR, V172, P476, DOI 10.1001/jamapediatrics.2017.5500
Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
Riggs E. R., 2018, GENETICS MED, DOI 10. 1038/s41436-018-0017-5

NR 12
TC 3
Z9 3
U1 0
U2 4
PU WILEY

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PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
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PG 4
WC Genetics & Heredity
SC Genetics & Heredity
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PM 30311379
DA 2019-08-06
ER

PT J
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AF Blasimme, Alessandro
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TI Data Sharing For Precision Medicine: Policy Lessons And Future
   Directions
SO HEALTH AFFAIRS
LA English
DT Article
ID BIG DATA; ENGAGEMENT; ACCESS
AB Data sharing is a precondition of precision medicine. Numerous organizations
have produced abundant guidance on data sharing. Despite such efforts, data are
not being shared to a degree that can trigger the expected data-driven
revolution in precision medicine. We set out to explore why. Here we report the
results of a comprehensive analysis of data-sharing guidelines issued over the
past two decades by multiple organizations. We found that the guidelines overlap
on a restricted set of policy themes. However, we observed substantial
fragmentation in the policy landscape across specific organizations and data
types. This may have contributed to the current stalemate in data sharing. To
move toward a more efficient data-sharing ecosystem for precision medicine,
policy makers should explore innovative ways to cope with central policy themes
such as privacy, consent, and data quality; focus guidance on interoperability,
attribution, and public engagement; and promote data-sharing policies that can
be adapted to multiple data types.
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CR Ackland R., 2013, WEB SOCIAL SCI CONCE
[Anonymous], 2009, NAT BIOTECHNOL, V27, P579, DOI 10.1038/nbt0709-579
[Anonymous], 2011, PREC MED BUILD KNOWL
Arzberger P, 2004, SCIENCE, V303, P1777, DOI 10.1126/science.1095958
Azaria A, 2016, P 2016 2 INT C OP BI
Bahcall O, 2015, NATURE, V526, P335, DOI 10.1038/526335a
Bastian M, 2009, INT AAAI C WEBL SOC, P361
Bauchner H, 2016, JAMA-J AM MED ASSOC, V315, P1237, DOI 10.1001/jama.2016.2420
Benchoufi M, 2017, TRIALS, V18, DOI 10.1186/s13063-017-2035-z
Blasimme A, 2017, AM J BIOETHICS, V17, P58, DOI 10.1080/15265161.2017.1328532
Blasimme A, 2016, PERSPECT BIOL MED, V59, P172, DOI 10.1353/pbm.2017.0002
Blasimme A, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0149-6
Borgatti SP, 2009, SCIENCE, V323, P892, DOI 10.1126/science.1165821
Chang A, 2016, BLOCKCHAIN HLTH IT A
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Dubovitskaya A, 2017, ARXIV170906528V1 COR
Elenko E, 2015, NAT BIOTECHNOL, V33, P456, DOI 10.1038/nbt.3222
European Data Protection Supervisor, 2018, ACC GROUND PROV GUID
Faden R.R., 1986, HIST THEORY INFORM C
Froelicher David, 2017, Proceedings on Privacy Enhancing Technologies, V2017, P232, DOI 10.1515/popets-2017-0047
Hunton and Williams LLP, 2011, ACC COMP STAK
Ienca M, 2018, SWISS MED WKLY, V148, DOI 10.4414/smw.2018.14688
Information Commissioner's Office, 2014, COND PRIV IMP ASS CO
Jain SH, 2015, NAT BIOTECHNOL, V33, P462, DOI 10.1038/nbt.3223
Katz Jay, 1973, Clin Res, V21, P785
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Khoury MJ, 2017, GENET MED
Koenig BA, 2014, HASTINGS CENT REP, V44, P33, DOI 10.1002/hast.329
Kohane IS, 2015, SCIENCE, V349, P37, DOI 10.1126/science.aab1328
Marx V, 2015, NATURE, V524, P503, DOI 10.1038/524503a
Meier-Abt P, 2018, SWISS MED WEEKLY
Nikolaenko V, 2013, P IEEE S SECUR PRIV, P334, DOI 10.1109/SP.2013.30
O'Doherty KC, 2011, SOC SCI MED, V73, P367, DOI 10.1016/j.socscimed.2011.05.046
Raisaro JL, IEEE ACM T COMPUTATI
Rogers R, 2013, DIGITAL METHODS, P1
Sage Bionetworks, 2018, BETT SCI TOG
Sansone SA, 2012, NAT GENET, V44, P121, DOI 10.1038/ng.1054
Scott J., 2011, SAGE HDB SOCIAL NETW
Sejnowski TJ, 2014, NAT NEUROSCI, V17, P1440, DOI 10.1038/nn.3839
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
Thorisson GA, 2009, NAT BIOTECHNOL, V27, P984, DOI 10.1038/nbt1109-984b
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Vayena E, 2018, J LAW MED ETHICS, V46, P119, DOI 10.1177/1073110518766026
Vayena E, 2018, B WORLD HEALTH ORGAN, V96, P66, DOI 10.2471/BLT.17.197426

```
   Vayena E, 2017, J BIOETHIC INQ, V14, P501, DOI 10.1007/s11673-017-9809-6
   Wallis JC, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067332
   Washington V, 2017, NEW ENGL J MED, V377, P904, DOI 10.1056/NEJMp1703370
   Winickoff DE, 2016, J RESPONSIBLE INNOV, V3, P169, DOI
10.1080/23299460.2016.1190443
NR 48
TC 3
Z9 3
U1 1
U2 1
PU PROJECT HOPE
PI BETHESDA
PA 7500 OLD GEORGETOWN RD, STE 600, BETHESDA, MD 20814-6133 USA
SN 0278-2715
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JI Health Aff.
PD MAY
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EP 709
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WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA HS4SG
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PM 29733719
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PT J
AU Murtagh, MJ
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Minion, Joel T.
Murphy, Tom
Prior, Gillian
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Burton, Paul R.
TI Better governance, better access: practising responsible data sharing in the METADAC governance infrastructure
SO HUMAN GENOMICS
LA English
DT Article
DE Data ethics; Data governance; Data access; Data Access Committee (DAC); Governance; Participant involvement; Ethnography; Qualitative research; Interdisciplinarity
ID COHORT PROFILE; ASSOCIATION; SCIENCE
AB Background: Genomic and biosocial research data about individuals is rapidly proliferating, bringing the potential for novel opportunities for data integration and use. The scale, pace and novelty of these applications raise a number of urgent sociotechnical, ethical and legal questions, including optimal methods of data storage, management and access. Although the open science movement advocates unfettered access to research data, many of the UK's longitudinal cohort studies operate systems of managed data access, in which access is governed by legal and ethical agreements between stewards of research datasets and researchers wishing to make use of them. Amongst other things, these agreements aim to respect the reasonable expectations of the research participants who provided data and samples, as expressed in the consent process. Arguably, responsible data management and governance of data and sample use are foundational to the consent process in longitudinal studies and are an important source of trustworthiness in the eyes of those who contribute data to genomic and biosocial research.

Methods: This paper presents an ethnographic case study exploring the foundational principles of a governance infrastructure for Managing Ethico-social, Technical and Administrative issues in Data ACcess (METADAC), which are operationalised through a committee known as the METADAC Access Committee. METADAC governs access to phenotype, genotype and 'omit' data and samples from five UK longitudinal studies.

Findings: Using the example of METADAC, we argue that three key structural features are foundational for practising responsible data sharing: independence and transparency; interdisciplinarity; and participant-centric decision-making. We observe that the international research community is proactively working towards optimising the use of research data, integrating/linking these data with routine data generated by health and social care services and other administrative data services to improve the analysis, interpretation and utility of these data. The governance of these new complex data assemblages will require a range of expertise from across a number of domains and disciplines, including that of study participants. Human-mediated decision-making bodies will be central to ensuring achievable, reasoned and responsible decisions about the use of these data; the METADAC model described in this paper provides an example of how this could be realised.

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FX The METADAC is funded jointly by the Medical Research Council (MRC), the Wellcome Trust and the Economic and Social Research Council (ESRC) - MR/N01104X/1 & MR/N01104X/2 - and is supported by the Wellcome Trust and MRC funded Fostering new Opportunities for Researchers via Wider Access to Research Data and Samples (58FORWARDS) study - 108439/Z/15/Z. The ethnographic study identified is similarly funded, though no funder played a role in the design of the study or in the collection, analysis and interpretation of the data.

CR Benzeval M, 2014, UNDERSTANDING SOC UK
Braidotti R., 2006, TRANSPOSITIONS NOMAD
Braidotti Rosi, 2009, NEW FORMATIONS, V68, P42, DOI DOI 10.3898/NEWF.68.03.2009
Braun V., 2006, QUALITATIVE RES PSYC, V3, P77, DOI DOI 10.1191/1478088706QP0630A
Buck N, 2012, LONGITUD LIFE COURSE, V3, P5
Burton PR, 2007, NATURE, V447, P661, DOI 10.1038/nature05911

Burton PR, 2017, POLICIES STRATEGIES
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Connelly R, 2014, INT J EPIDEMIOL, V43, P1719, DOI 10.1093/ije/dyu001
DAVIES B, 1990, J THEOR SOC BEHAV, V20, P43, DOI 10.1111/j.1468-5914.1990.tb00174.x
Dean RJ, 2017, POLICY POLIT, V45, P213, DOI 10.1332/030557316X14531466517034
Department_ of_ Education, SUMM LONG SURV
Dyke SOM, 2016, EUR J HUM GENET, V24, P1676, DOI 10.1038/ejhg.2016.115
Elliott J, 2006, INT J EPIDEMIOL, V35, P836, DOI 10.1093/ije/dyl174
Fitzgerald D, 2015, THEOR CULT SOC, V32, P3, DOI 10.1177/0263276414537319
Gaye A, 2014, INT J EPIDEMIOL, V43, P1929, DOI 10.1093/ije/dyu188
Geraghty KJ, 2016, PACE GATE CLIN TRIAL
GLASER BG, 1965, SOC PROBL, V12, P436, DOI 10.1525/sp.1965.12.4.03a00070
Gottweis H, 2011, NAT REV GENET, V12, P738, DOI 10.1038/nrg3083
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Harre R., 2003, SELF OTHERS POSITION
Harrison H, 2017, FORUM QUALITATIVE SO
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Ioannidis JPA, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001747
Jones KH, 2017, INT J MED INFORM, V97, P43, DOI 10.1016/j.ijmedinf.2016.09.010
Kim SYH, 2009, J EMPIR RES HUM RES, V4, P3, DOI 10.1525/jer.2009.4.4.3
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Lowrance W, 2006, ACCESS COLLECTIONS D
Masca N, 2011, INT J EPIDEMIOL, V40, P1629, DOI 10.1093/ije/dyr149
Medical_ Research_ Council, COH DIR
Minion JT, 2017, ETHICS CONUNDRUM REC
Munafo MR, 2017, NAT HUM BEHAV, V1, DOI 10.1038/s41562-016-0021
Murtagh M, 2016, EUROPEAN BIOBANK WEE
Murtagh M, 2012, NORSK EPIDEMIOL, V21, P203
Murtagh MJ, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-017-0167-z
Murtagh MJ, 2016, BIOPRESERV BIOBANK, V14, P231, DOI 10.1089/bio.2016.0002
NAFUS D, 2014, INT J COMMUNICATION, V8, P11, DOI DOI 10.1515/C0MM.2011.015
O'Doherty K, 2012, PUBLIC ENGAGEMENT EM
Organisation for Economic C-o, 2007, DEV OECD PRINC GUID
Pilat D, 2007, DATA SCI J, V6, P4
Power C, 2006, INT J EPIDEMIOL, V35, P34, DOI 10.1093/ije/dyi183
Prainsack B., 2017, PERSONALIZED MED EMP
Rial-Sebbag E, 2015, INT LIBR ETH LAW TEC, V14, P139, DOI 10.1007/978-94-017-9573-9_11
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Schwandt T. A., 1994, HDB QUALITATIVE RES, P118
Solberg B., 2015, J BIOREPOS SCI APPL, V3, P23
Stake R, 1995, ART CASE STUDY RES
Steptoe A, 2013, INT J EPIDEMIOL, V42, P1640, DOI 10.1093/ije/dys168
Stirling A, 2015, FUTURE DIRECTIONS SC, P133
Winickoff DE, 2008, BENEFIT SHARING POWE
NR 51
TC 3
Z9 3
U1 3
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PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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JI Hum. Genomics
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AU Seifert, A
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TI Willingness of Older Adults to Share Mobile Health Data with Researchers
SO GEROPSYCH-THE JOURNAL OF GERONTOPSYCHOLOGY AND GERIATRIC PSYCHIATRY
LA English
DT Article
DE mobile devices; wearables; data release; older Swiss adults; health data
ID PHYSICAL-ACTIVITY; QUANTIFIED SELF; SMARTPHONE APPLICATIONS; PERSONAL
   DATA; LIFE-STYLE; BIG-DATA; TECHNOLOGY; EDUCATION; PROMISE; APPS
AB This study explored the use of wearable devices to track self-recorded health
data and the willingness to share this data with researchers. Participants
aged >= 50 years (n = 1,013) were interviewed in a representative telephone
survey. Results indicated that 43.3% of all participants used one or more mobile
devices (activity tracker, smartwatch, smartphone, or tablet), and that 27.6%
used those devices for the purposes of recording health data. Additionally, 57.2%
of the participants who tracked their health data were willing to share it with
researchers. Income significantly contributed to predicting this willingness,
whereas other independent variables were not significant predictors. This study
indicates a relatively positive overall willingness to share self-recorded
mobile health data with the science community.
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CR Ajana B, 2017, DIGIT HEALTH, V3, DOI 10.1177/2055207616689509
   Appelboom G, 2014, ARCH PUBLIC HEALTH, V72, DOI 10.1186/2049-3258-72-28
```

Azmak O, 2015, BIG DATA, V3, P173, DOI 10.1089/big.2015.0012
Batsis John A, 2016, Gerontol Geriatr Med, V2, p2333721416678076, DOI 10.1177/2333721416678076
Bietz MJ, 2016, J AM MED INFORM ASSN, V23, pE42, DOI 10.1093/jamia/ocv118
Chen CN, 2012, J MED INTERNET RES, V14, P126, DOI 10.2196/jmir.2152
Chen J, 2016, TELEMED E-HEALTH, V22, P655, DOI 10.1089/tmj.2015.0159
Christen M, 2017, PHILOS STUD SER, V128, P193, DOI 10.1007/978-3-319-61043-6_10
Czaja SJ, 2006, PSYCHOL AGING, V21, P333, DOI 10.1037/0882-7974.21.2.333
Dallinga JM, 2015, BMC PUBLIC HEALTH, V15, DOI 10.1186/s12889-015-2165-8
Dobkin BH, 2013, CURR OPIN NEUROL, V26, P602, DOI 10.1097/WCO.0000000000000026
Dobkin BH, 2011, NEUROREHAB NEURAL RE, V25, P788, DOI 10.1177/1545968311425908
Ernsting C, 2017, J MED INTERNET RES, V19, DOI 10.2196/jmir.6838
Festinger L., 1962, THEORY COGNITIVE DIS
Fogg B. J., 2003, PERSUASIVE TECHNOLOG
Fox S, 2013, TRACKING FOR HLTH
Fuller D, 2017, SOC SCI MED, V191, P84, DOI 10.1016/j.socscimed.2017.08.043
Gerstorf D, 2014, RES HUM DEV, V11, P75, DOI 10.1080/15427609.2014.906725
Gilleard C, 2015, SOCIOL RES ONLINE, V20, DOI 10.5153/sro.3552
Gruenenfelder-Steiger AE, 2017, GEROPSYCH, V30, P119, DOI 10.1024/1662-9647/a000172
Hamaker E. L., 2012, HDB RES METHODS STUD, P43, DOI DOI 10.5860/CHOICE.50-1159
Higgins JP, 2016, AM J MED, V129, P11, DOI 10.1016/j.amjmed.2015.05.038
Hingle M, 2016, J NUTR EDUC BEHAV, V48, P213, DOI 10.1016/j.jneb.2015.12.009
Kamin Stefan T., 2013, Gerontechnology, V12, P16, DOI 10.4017/gt.2013.12.1.008.00
Lamonaca F, 2015, MEASUREMENT, V73, P82, DOI 10.1016/j.measurement.2015.04.017
Landi F, 2007, J CLIN EPIDEMIOL, V60, P518, DOI 10.1016/j.jclinepi.2006.09.010
Lindwall Magnus, 2012, J Aging Res, V2012, P493598, DOI 10.1155/2012/493598
Martin M., 2017, INNOVATION AGING S1, V1, P1313, DOI [10.1093/geroni/igx004.4812, DOI 10.1093/GERONI/IGX004.4812]
McMahon SK, 2016, JMIR MHEALTH UHEALTH, V4, P594, DOI 10.2196/mhealth.5120
Mercer K, 2016, JMIR MHEALTH UHEALTH, V4, P168, DOI 10.2196/mhealth.4225
Nissenbaum H, 2004, WASH LAW REV, V79, P119
O'Brien T, 2015, GERIATR NURS, V36, pS21, DOI 10.1016/j.gerinurse.2015.02.019
Peel NM, 2005, AM J PREV MED, V28, P298, DOI 10.1016/j.amepre.2004.12.002
Pevnick JM, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0165908
Prasad A, 2015, MHEALTH MULTIDISCIPLINARY VERTICALS, P545
Preusse KC, 2017, J APPL GERONTOL, V36, P127, DOI 10.1177/0733464815624151
Rocke C, 2009, PSYCHOL AGING, V24, P863, DOI 10.1037/a0016276
Rogers E. M., 2010, DIFFUSION INNOVATION
Schlomann Anna, 2017, Gerontechnology, V16, P115, DOI 10.4017/gt.2017.16.2.007.00
Schulz R, 2015, GERONTOLOGIST, V55, P724, DOI 10.1093/geront/gnu071
Seifert A., 2015, GERONTECHNOLOGY, V14, P57, DOI [10.4017/gt.2015.14.1.006.00, DOI 10.4017/GT.2015.14.1.006.00]
Seifert A, 2018, J APPL GERONTOL, V37, P99, DOI 10.1177/0733464816669805
Shull PB, 2014, GAIT POSTURE, V40, P11, DOI 10.1016/j.gaitpost.2014.03.189
Steinert A, 2018, UNIVERSAL ACCESS INF, V17, P411, DOI 10.1007/s10209-017-0539-7
Sula CA, 2016, B ASS INF SCI TECHNO, V42, P17, DOI DOI 10.1002/BUL2.2016.1720420207
Swan M, 2013, BIG DATA, V1, P85, DOI 10.1089/big.2012.0002

```
   Swan M, 2012, J SENS ACTUAR NETW, V1, P217, DOI 10.3390/jsan1030217
   Swiss Academy of Medical Sciences, 2017, MOD GEN CONS
   Taylor L, 2016, ENVIRON PLANN D, V34, P319, DOI 10.1177/0263775815608851
   Vandelanotte C, 2016, J NUTR EDUC BEHAV, V48, P219, DOI
10.1016/j.jneb.2015.12.006
   Vashist SK, 2014, DIAGNOSTICS, V4, P104, DOI 10.3390/diagnostics4030104
   World Health Organization, 2015, WORLD REP AG HLTH
NR 52
TC 3
Z9 3
U1 2
U2 15
PU HOGREFE & HUBER PUBLISHERS
PI GOTTINGEN
PA MERKELSTR 3, D-37085 GOTTINGEN, GERMANY
SN 1662-9647
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J9 GEROPSYCH
JI GeroPsych
PD MAR
PY 2018
VL 31
IS 1
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EP 49
DI 10.1024/1662-9647/a000181
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WC Psychology, Developmental
SC Psychology
GA FV1RL
UT WOS:000424342000004
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AF Prasser, Fabian
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   Spengler, Helmut
   Kuhn, Klaus A.
TI A Scalable and Pragmatic Method for the Safe Sharing of High-Quality
   Health Data
SO IEEE JOURNAL OF BIOMEDICAL AND HEALTH INFORMATICS
LA English
DT Article
ID GENOME-WIDE ASSOCIATION; PRIVACY PROTECTION; DE-IDENTIFICATION; PATIENT
   PRIVACY; BIOMEDICAL DATA; K-ANONYMITY; ANONYMIZATION; INFORMATION; CARE;
   SUPPRESSION
AB The sharing of sensitive personal health data is an important aspect of
biomedical research. Methods of data de-identification are often used in this
process to trade the granularity of data off against privacy risks. However,
traditional approaches, such as HIPAA safe harbor or k-anonymization, often fail
to provide data with sufficient quality. Alternatively, data can be de-
identified only to a degree which still allows us to use it as required, e.g.,
to carry out specific analyses. Controlled environments, which restrict the ways
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recipients can interact with the data, can then be used to cope with residual risks. The contributions of this article are twofold. First, we present a method for implementing controlled data sharing environments and analyze its privacy properties. Second, we present a de-identification method which is specifically suited for sanitizing health data which is to be shared in such environments. Traditional de-identification methods control the uniqueness of records in a dataset. The basic idea of our approach is to reduce the probability that a record in a dataset has characteristics which are unique within the underlying population. As the characteristics of the population are typically not known, we have implemented a pragmatic solution in which properties of the population are modeled with statistical methods. We have further developed an accompanying process for evaluating and validating the degree of protection provided. The results of an extensive experimental evaluation show that our approach enables the safe sharing of high-quality data and that it is highly scalable.

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CR Aggarwal C. C, 2005, P 31 INT C VER LARG, P901
[Anonymous], 2000, FED REGISTER, V65, P82
Athey Brian D, 2013, AMIA Jt Summits Transl Sci Proc, V2013, P6
Barth-Jones D. C., 2012, SSRN
Bayardo RJ, 2005, PROC INT CONF DATA, P217
Bos JW, 2014, J BIOMED INFORM, V50, P234, DOI 10.1016/j.jbi.2014.04.003
Chen G, 1998, J OFF STAT, V14, P79
Dankar FK, 2013, TRANS DATA PRIV, V6, P35
Dankar FK, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-66
De Waal A., 1999, NETHERLANDS OFFICIAL, V14, P17
Deng MN, 2011, REQUIR ENG, V16, P3, DOI 10.1007/s00766-010-0115-7
Denny JC, 2013, NAT BIOTECHNOL, V31, P1102, DOI 10.1038/nbt.2749
Duncan G. T., 2011, STAT CONFIDENTIALITY, P137
Duncan GT, 2011, STAT SOC BEHAV SC, P1, DOI 10.1007/978-1-4419-7802-8
Dwork C, 2006, LECT NOTES COMPUT SC, V3876, P265
Eder J, 2012, PUBLIC HEALTH GENOM, V15, P254, DOI 10.1159/000336663
El Emam K., 2015, SHARING CLIN TRIAL D, P1
El Emam K., 2014, ANONYMIZING HLTH DAT
El Emam K, 2008, J AM MED INFORM ASSN, V15, P627, DOI 10.1197/jamia.M2716
El Emam K, 2015, INT DATA PRIV LAW, V5, P73, DOI 10.1093/idpl/ipu033
El Emam K, 2009, J AM MED INFORM ASSN, V16, P670, DOI 10.1197/jamia.M3144
Emam K EI, 2013, GUIDE IDENTIFICATION
Hallinan D, 2012, COMPUT LAW SECUR REV, V28, P263, DOI 10.1016/j.clsr.2012.03.005
Heatherly RD, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0053875
Hoshino N., 2001, J OFF STAT, V17, P499
Iyengar VS, 2002, P 8 ACM SIGKDD INT C, P279, DOI DOI 10.1145/775047.775089
Kohlmayer F, 2015, J BIOMED INFORM, V58, P37, DOI 10.1016/j.jbi.2015.09.007
LeFevre K, 2006, P INT C DATA ENG, P25, DOI DOI 10.1109/ICDE.2006.101
Liu V, 2015, JAMA-J AM MED ASSOC, V313, P1471, DOI 10.1001/jama.2015.2252
Loukides G, 2013, IEEE J BIOMED HEALTH, V17, P60, DOI 10.1109/TITB.2012.2212281
Lu WJ, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/1472-6947-15-S5-S1
Machanavajjhala A., 2007, ACM T KNOWL DISCOV D, V1, P3, DOI DOI 10.1145/1217299.1217302
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
Merkel D., 2014, LINUX J, V2014, P2, DOI DOI 10.1097/01.NND.0000320699.47006.A3

Mickens R., 2015, MONOGRAPHS RES NOTES
Murphy SN, 2011, J AM MED INFORM ASSN, V18, pI103, DOI 10.1136/amiajnl-2011-000316
Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
N. R. Council, 2005, EXP ACC RES DAT REC
Narayanan A, 2008, P IEEE S SECUR PRIV, P111, DOI 10.1109/SP.2008.33
Nergiz M., 2006, P 22 INT C DAT ENG W, P96
Prasser F., 2015, MED DATA PRIVACY HDB, P111, DOI DOI 10.1007/978-3-319-23633-9_6
Prasser F, 2016, TRANS DATA PRIV, V9, P161
Prasser F, 2016, METHOD INFORM MED, V55, P347, DOI 10.3414/ME16-01-0012
Prasser F, 2016, BMC MED INFORM DECIS, V16, DOI 10.1186/s12911-016-0287-2
Prasser F, 2014, COMP MED SY, P66, DOI 10.1109/CBMS.2014.85
Richardson T, 2011, 6143 RFC
Rindfleisch TC, 1997, COMMUN ACM, V40, P92, DOI 10.1145/257874.257896
Ritchie F., 2015, IASSIST Q, V39, P5
Ritchie F, 2008, LABOUR GAZETTE, V2, P29
Samarati P., 1998, Proceedings of the Seventeenth ACM SIGACT-SIGMOD-SIGART Symposium on Principles of Database Systems. PODS 1998, DOI 10.1145/275487.275508
Schneeweiss S, 2014, NEW ENGL J MED, V370, P2161, DOI 10.1056/NEJMp1401111
Smith R, 2007, ICDAR 2007: NINTH INTERNATIONAL CONFERENCE ON DOCUMENT ANALYSIS AND RECOGNITION, VOLS I AND II, PROCEEDINGS, P629
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P571, DOI 10.1142/S021848850200165X
Sweeney L., 2001, THESIS
U. S. Department of Health and Human Services-Office for Civil Rights, 2013, HIPAA ADM SIMPL STAT
U. S. National Institutes of Health, 2014, NOTOD14124 US NAT I
Wan ZY, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0120592
Xia WY, 2015, J AM MED INFORM ASSN, V22, P1029, DOI 10.1093/jamia/ocv004
Yu F, 2014, BMC MED INFORM DECIS, V14, DOI 10.1186/1472-6947-14-S1-S3
Zayatz L. V., 1991, CENSUSSRDRR9108
NR 60
TC 3
Z9 3
U1 2
U2 9
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
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AU Vaduganathan, M
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TI Availability and Use of Shared Data From Cardiometabolic Clinical Trials
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DE clinical trial; information dissemination; outcome and process assessment (health care); research design
ID MEDICAL JOURNAL EDITORS; INTERNATIONAL COMMITTEE; SHARING DATA; ACCESS; REANALYSIS; PROPOSAL; COSTS; HEART
AB BACKGROUND: Sharing of patient-level clinical trial data has been widely endorsed. Little is known about how extensively these data have been used for cardiometabolic diseases. We sought to evaluate the availability and use of shared data from cardiometabolic clinical trials.

METHODS: We extracted data from ClinicalStudyDataRequest.com, a large, multisponsor data-sharing platform hosting individual patient-level data from completed studies sponsored by 13 pharmaceutical companies.

RESULTS: From January 2013 to May 2017, the platform had data from 3374 clinical trials, of which 537 (16%) evaluated cardiometabolic therapeutics (phase 1, 36%; phase 2, 17%; phase 2/3, 1%; phase 3, 42%; phase 4, 4%). They covered 74 therapies and 398925 patients. Diabetes mellitus (60%) and hypertension (15%) were the most common study topics. Median time from study completion to data availability was 79 months. As of May 2017, ClinicalStudyDataRequest.com had received 318 submitted proposals, of which 163 had signed data-sharing agreements. Thirty of these proposals were related to cardiometabolic therapies and requested data from 79 unique studies (15% of all trials, 29% of phase 3/4 trials). Most (96%) data requesters of cardiometabolic clinical trial data were from academic centers in North America and Western Europe, and half the proposals were unfunded. Most proposals were for secondary hypothesis-generating questions, with only 1 proposed reanalysis of the original study primary hypothesis. To date, 3 peer-reviewed articles have been published after a median of 19 months (9-32 months) from the data-sharing agreement

CONCLUSIONS: Despite availability of data from >500 cardiometabolic trials in a multisponsor data-sharing platform, only 15% of these trials and 29% of phase 3/4 trials have been accessed by investigators thus far, and a negligible minority of analyses have reached publication.

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CR Bierer BE, 2017, NEW ENGL J MED, V376, P1684, DOI 10.1056/NEJMsb1616595
   Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
   Bonini S, 2014, NEW ENGL J MED, V371, P2452, DOI 10.1056/NEJMp1409464
   Burns NS, 2017, NEW ENGL J MED, V376, P2205, DOI 10.1056/NEJMp1705323
   Butler J, 2015, AM HEART J, V170, P263, DOI 10.1016/j.ahj.2015.05.006
   Christakis DA, 2013, JAMA-J AM MED ASSOC, V310, P2499, DOI
10.1001/jama.2013.281337
   Coady SA, 2017, NEW ENGL J MED, V376, P1849, DOI 10.1056/NEJMsa1603542
   Devereaux PJ, 2016, NEW ENGL J MED, V375, P405, DOI 10.1056/NEJMp1605654
   Downing NS, 2014, JAMA-J AM MED ASSOC, V311, P368, DOI
10.1001/jama.2013.282034
   Ebrahim S, 2014, JAMA-J AM MED ASSOC, V312, P1024, DOI 10.1001/jama.2014.9646
   Goldacre B, 2017, BMJ-BRIT MED J, V358, DOI 10.1136/bmj.j3334
   Goodhill GJ, 2014, NATURE, V509, P33, DOI 10.1038/509033b
   Grossman RL, 2016, NEW ENGL J MED, V375, P1109, DOI 10.1056/NEJMp1607591
   Hilkens NA, 2017, NEUROLOGY, V88, P177, DOI 10.1212/WNL.0000000000003489
   ideaPoint Inc, CLINICALSTUDYDATAREQ
   Kent DM, 2016, INT J EPIDEMIOL, V45, P2075, DOI 10.1093/ije/dyw118
   Krumholz HM, 2016, NEW ENGL J MED, V375, P403, DOI 10.1056/NEJMp1607342
   Kush R, 2014, NEW ENGL J MED, V370, P2163, DOI 10.1056/NEJMp1401444
   Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
   Merson L, 2016, NEW ENGL J MED, V374, P2414, DOI 10.1056/NEJMp1605148
   Murugiah K, 2016, J AM HEART ASSOC, V5, DOI 10.1161/JAHA.116.003307
   Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374
   Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
   Packer M, 2001, NEW ENGL J MED, V344, P1651, DOI 10.1056/NEJM200105313442201
   Patel A, 2017, NEW ENGL J MED, V377, P298, DOI 10.1056/NEJMc1703337
   Patel MR, 2016, NEW ENGL J MED, V375, P407, DOI 10.1056/NEJMp1605260
   Pharmaceutical Research and Manufacturers of America European Federation of
Pharmaceutical Industries and Associations, 2013, EUR FED PHARM IND AS
   Pisani E, 2016, BMJ-BRIT MED J, V355, DOI 10.1136/bmj.i5295
   Rathi VK, 2014, TRIALS, V15, DOI 10.1186/1745-6215-15-384
   Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
   Ross JS, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2016-012769
   Strom BL, 2016, NEW ENGL J MED, V375, P1608, DOI 10.1056/NEJMp1610336
   Strom BL, 2014, NEW ENGL J MED, V371, P2052, DOI 10.1056/NEJMp1411794
   Taichman DB, 2017, NEW ENGL J MED, V376, P2277, DOI 10.1056/NEJMe1705439
   Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
   Taitsman JK, 2013, NEW ENGL J MED, V368, P977, DOI 10.1056/NEJMp1215258
   Walker SR, 2017, NEPHRON, V136, P85, DOI 10.1159/000454683
   Warren E, 2016, NEW ENGL J MED, V375, P401, DOI 10.1056/NEJMp1607282
   Wilhelm EE, 2014, JAMA-J AM MED ASSOC, V311, P1201, DOI 10.1001/jama.2014.850
   Zhu CS, 2017, PLOS MED, V14, DOI 10.1371/journal.pmed.1002304
NR 40
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TI Toward a Tiered Model to share clinical Trial Data and samples in
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SO FRONTIERS IN MEDICINE
LA English
DT Article
DE data sharing; precision medicine; oncology; clinical research;
   biobanking
ID OPEN-ACCESS; DRUG DEVELOPMENT; CANCER-RESEARCH; CHALLENGES; DISCOVERY;
   INSTITUTE; MEDICINE; INDUSTRY; ACADEMIA; PROJECT
AB The recent revolution in science and technology applied to medical research
has left in its wake a trial of biomedical data and human samples; however, its
opportunities remain largely unfulfilled due to a number of legal, ethical,
financial, strategic, and technical barriers. Precision oncology has been at the
vanguard to leverage this potential of "Big data" and samples into meaningful
solutions for patients, considering the need for new drug development approaches
in this area (due to high costs, late-stage failures, and the molecular
diversity of cancer). To harness the potential of the vast quantities of data
and samples currently fragmented across databases and biobanks, it is critical
to engage all stakeholders and share data and samples across research institutes.
Here, we identified two general types of sharing strategies. First, open access
models, characterized by the absence of any review panel or decision maker, and
second controlled access model where some form of control is exercised by either
the donor (i.e., patient), the data provider (i.e., initial organization), or an
independent party. Further, we theoretically describe and provide examples of
nine different strategies focused on greater sharing of patient data and
material. These models provide varying levels of control, access to various data
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and/or samples, and different types of relationship between the donor, data provider, and data requester. We propose a tiered model to share clinical data and samples that takes into account privacy issues and respects sponsors' legitimate interests. Its implementation would contribute to maximize the value of existing datasets, enabling unraveling the complexity of tumor biology, identify novel biomarkers, and re-direct treatment strategies better, ultimately to help patients with cancer.

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CR Aitken M., 2016, GLOB ONC TREND REP R
[Anonymous], 2017, 100 000 GEN PROJ PRO
[Anonymous], 2017, ENS GEN BROWS 90
Asadullah K, 2015, NAT REV DRUG DISCOV, V14, P805, DOI 10.1038/nrd4727
Beaulieu-Jones B. K., 2018, BIORXIV, DOI [10.1101/159756, DOI 10.1101/159756]
Bertagnolli MM, 2017, NEW ENGL J MED, V376, P1178, DOI 10.1056/NEJMsb1702054
Bierer BE, 2017, NEW ENGL J MED, V376, P1684, DOI 10.1056/NEJMsb1616595
Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
BIG AURORA, 2016, AIM UND MOL AB MET B
Budin-Ljosne I, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-016-0162-9
Cancer Research UK, 2016, STRAT MED PROGR
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Ciardiello F, 2008, NEW ENGL J MED, V358, P1160, DOI 10.1056/NEJMra0707704
Clinical Study Data Request Site, 2016, SPONS SPEC INF GSK
de Gramont A, 2010, J CLIN ONCOL, V28, P527, DOI 10.1200/JCO.2009.25.2544
De Roock W, 2010, LANCET ONCOL, V11, P753, DOI 10.1016/S1470-2045(10)70130-3
DeVita VT, 2014, NAT REV CLIN ONCOL, V11, P663, DOI 10.1038/nrclinonc.2014.153
Douillard JY, 2013, NEW ENGL J MED, V369, P1023, DOI 10.1056/NEJMoa1305275
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
European Agency for Safety and Health at Work, 2014, EU ACT PLAN CHILDH O, P1, DOI [10.1177/1742271X0301100302, DOI 10.1016/S0022-3913(12)00047-9]
European Commission DG Research, 2010, STRAT BIOM PERS MED
Exactis, 2017, PERS MY TREATM PMT I
FasterCures, 2015, CONS PED DEPTH LOOK
Ferri M, 2014, NEW ENGL J MED, V370, P484, DOI 10.1056/NEJMc1314515
Forda SR, 2013, NAT REV DRUG DISCOV, V12, P247, DOI 10.1038/nrd3981
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Green AK, 2015, ONCOLOGIST, V20, P464, DOI 10.1634/theoncologist.2014-0431
Hafen E, 2014, METHOD INFORM MED, V53, P82, DOI 10.3414/ME13-02-0051
Hewitt RE, 2011, CURR OPIN ONCOL, V23, P112, DOI 10.1097/CCO.0b013e32834161b8
Hinestrosa MC, 2007, NAT REV CANCER, V7, P309, DOI 10.1038/nrc2113
Hollingsworth SJ, 2015, PUBLIC HEALTH GENOM, V18, P338, DOI 10.1159/000441557
Hollingsworth SJ, 2015, DRUG DISCOV TODAY, V20, P1455, DOI 10.1016/j.drudis.2015.10.005
ICGC, 2017, SUBM RAW DAT EGA
Jonker DJ, 2007, NEW ENGL J MED, V357, P2040, DOI 10.1056/NEJMoa071834
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kaye J, 2012, NAT REV GENET, V13, P371, DOI 10.1038/nrg3218
Khalil DN, 2016, NAT REV CLIN ONCOL, V13, P273, DOI 10.1038/nrclinonc.2016.25

Khozin S, 2017, NAT REV DRUG DISCOV, V16, P306, DOI 10.1038/nrd.2017.26
Klauschen Frederick, 2014, Oncoscience, V1, P504
Krumholz HM, 2016, NEW ENGL J MED, V375, P403, DOI 10.1056/NEJMp1607342
Lacombe D, 2014, NAT REV CLIN ONCOL, V11, P492, DOI 10.1038/nrclinonc.2014.98
Lander ES, 2001, NATURE, V409, P860, DOI 10.1038/35057062
Lappalainen I, 2015, NAT GENET, V47, P692, DOI 10.1038/ng.3312
Lawler M, 2017, NEW ENGL J MED, V376, P2006, DOI 10.1056/NEJMp1612254
Lawler M, 2015, CANCER DISCOV, V5, P1133, DOI 10.1158/2159-8290.CD-15-0821
Lawrence MS, 2014, NATURE, V505, P495, DOI 10.1038/nature12912
Lu WJ, 2014, CLIN PHARMACOL THER, V95, P129, DOI 10.1038/clpt.2013.131
Lunshof Jeantine E, 2010, Dialogues Clin Neurosci, V12, P47
MacArthur J, 2017, NUCLEIC ACIDS RES, V45, pD896, DOI 10.1093/nar/gkw1133
Mailman MD, 2007, NAT GENET, V39, P1181
Malin B., 2013, DEIDENTIFICATION STR, V19
Masters GA, 2015, J CLIN ONCOL, V33, P786, DOI 10.1200/JCO.2014.59.9746
Melese T, 2009, NAT MED, V15, P502, DOI [10.1038/nm0509-500, 10.1038/nm0509-502]
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Merck, 2017, MERCK SET JOIN FORC
Mitchell Derick, 2015, Res Involv Engagem, V1, P4, DOI 10.1186/s40900-015-0001-z
Paul SM, 2010, NAT REV DRUG DISCOV, V9, P203, DOI 10.1038/nrd3078
Pencina MJ, 2016, AM HEART J, V172, P64, DOI 10.1016/j.ahj.2015.11.002
Peplow M, 2016, BMJ-BRIT MED J, V353, DOI 10.1136/bmj.i1757
PerMed2020, 2015, SRIA STRAT RES INN A
Pharmaceutical Research and Manufacturers of America European Federation of Pharmaceutical Industries and Associations, 2013, PRINC RESP CLIN TRIA
Pirnay JP, 2015, EMBO REP, V16, P557, DOI 10.15252/embr.201540070
Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
Said M, 2014, NAT REV DRUG DISCOV, V13, P789, DOI 10.1038/nrd4438
Sargent DJ, 2012, ONCOLOGIST, V17, P188, DOI 10.1634/theoncologist.2011-0332
Savage N, 2017, CELL, V168, P551, DOI 10.1016/j.cell.2017.01.003
Scannell JW, 2012, NAT REV DRUG DISCOV, V11, P191, DOI 10.1038/nrd3681
Spertus JA, 2012, CIRC-CARDIOVASC QUAL, V5, P143, DOI 10.1161/CIRCOUTCOMES.112.965814
Stevens H, 2016, NAT BIOTECHNOL, V34, P504, DOI 10.1038/nbt.3562
Stewart B. W., 2014, WORLD CANC REPORT 20
Stupp R., 2014, CANCERWORLD, P49
Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
Trusheim MR, 2007, NAT REV DRUG DISCOV, V6, P287, DOI 10.1038/nrd2251
Verlinden M, 2014, BIOPRESERV BIOBANK, V12, P415, DOI 10.1089/bio.2014.0034
Wilhelm EE, 2014, JAMA-J AM MED ASSOC, V311, P1201, DOI 10.1001/jama.2014.850
Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
Zardavas D, 2014, BRIT J CANCER, V111, P1881, DOI 10.1038/bjc.2014.341
Zatloukal K, 2012, BBMRI BUSINESS PLAN, P1
Zhu CQ, 2008, J CLIN ONCOL, V26, P4268, DOI 10.1200/JCO.2007.14.8924
NR 79
TC 3
Z9 3
U1 0
U2 0
PU FRONTIERS MEDIA SA
PI LAUSANNE
PA AVENUE DU TRIBUNAL FEDERAL 34, LAUSANNE, CH-1015, SWITZERLAND
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SC General & Internal Medicine
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PT J
AU Banerjee, S
   Hemphill, T
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AF Banerjee, Syagnik (Sy)
   Hemphill, Thomas
   Longstreet, Phil
TI Wearable devices and healthcare: Data sharing and privacy
SO INFORMATION SOCIETY
LA English
DT Article
DE HIPAA; informed consent; Internet of Things; privacy; regulatory policy;
   wearables
ID INDUSTRY SELF-REGULATION
AB Wearable devices introduce many new capabilities to the delivery of
healthcare. But wearables also pose grave privacy risks. Furthermore,
information overload gets in the way of informed consent by the patient. To
better protect American patients in an increasingly digital world, the U.S.
Congress passed the Health Insurance Portability and Accountability Act of 1996
(HIPAA). This article examines the adequacy of HIPAA vis-a-vis issues raised by
wearable technologies in the Internet of Things environment and identifies
policy gaps and factors that drive health data exposure. It presents a 2 x 2
Partnership-Identity Exposure Matrix, illustrates implications in four different
contexts, and provides recommendations for improving privacy protection.
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CR Addonizio G., 2015, 861 SET HALL LAW
   Alkon AH, 2011, FOOD HEALTH ENVIRON, P1
   Barcena M. B, 2014, SAFE IS YOUR QUANTIF
   Berry R., 2012, J INT COMMERCE EC, V4, P1
   Bertoni S., 2014, OSCAR HLTH USING MIS
   Biltekoff Charlotte, 2007, AM STUD, V48, P29
   Bipartisan Policy Center, 2012, WHAT IS DRIV US HLTH
   Blum B., 2015, ENHANCING CLIN PRACT
   Bohme R., 2010, P SIGCHI C HUM FACT
   Bradbury D., 2015, SAFE HARBOUR NAVIGAT
   Cate FH, 2013, INT DATA PRIV LAW, V3, P67, DOI 10.1093/idpl/ipt005
   Cate FH, 2010, CALIF LAW REV, V98, P1765
   Dohr A, 2010, Proceedings of the Seventh International Conference on
Information Technology: New Generations (ITNG 2010), P804, DOI
10.1109/ITNG.2010.104
```

Dolan B., 2014, IN DEPTH CONSUMER HL
Dolan B., 2014, PREDICTION HLTH WEAR
Evans D., 2011, INTERNET THINGS NEXT
Federal Trade Commission, 2014, DAT BROK CALL TRANSP
Firestone C. M., 2014, 29 ANN ASP I C COMM
Future of Privacy Forum, 2016, FPF MOB APPS STUD
GARVIN DA, 1983, CALIF MANAGE REV, V25, P37, DOI 10.2307/41165031
Gibbs Samuel, 2015, GUARDIAN
GUPTA AK, 1983, ACAD MANAGE REV, V8, P416, DOI 10.2307/257830
Guthman J., 2011, WEIGHING OBESITY FOO, V32
Healey Jason, 2015, HEALTHCARE INTERNET
HHS, 2012, GUID REG METH DE ID
Isidore C., 2015, APPLE AT T FIGHT SAL
Kelley M. B., 2013, CIA CHIEF TECH OFFIC
Langston N, 2010, TOXIC BODIES HORMONE
Lee K., 2015, WEARABLE HLTH TECHNO
Maddox T., 2014, SCARY TRUTH DATA SEC
Maddox Teena, 2015, DARK SIDE WEARABLES
Malik Mohd. Adnan, 2016, INTERNET THINGS IOT
Meyer D., 2016, HERE COMES POSTSAFE
Munro D., 2015, DATA BREACHES HEALTH
Nash L, 2006, INESCAPABLE ECOLOGIES: A HISTORY OF ENVIRONMENT, DISEASE, AND KNOWLEDGE, P1
Nelson G. S., 2015, PRACTICAL IMPLICATIO
Nissenbaum H, 2004, WASH LAW REV, V79, P119
Nissenbaum H., 2016, QUANTIFIED BIOSENSIN, P79
Olson P., 2014, WEARABLE TECH IS PLU
Privacy Rights Clearinghouse, 2013, PRIV RIGHTS CLEAR RE
Scholl M. A., 2008, INTRO RESOURCE GUIDE
Sherbit, 2015, INS CO PROF WEAR
Snyder M., 2015, POLICE WOMANS FITNES
Solove D., 2002, MINNESOTA LAW REV, V86
Staff FTC, 2015, TECHNICAL REPORT
Taylor H., 2016, INTERNET THINGS COUL
Terry K., 2014, MEDSCAPE MED NEWS
The Physicans Foundation, 2012, DRIV HEALTHC COSTS W
U. S. Government Publishing Office, 2013, FED REG, V78
US Department of Health and Human Services, 2003, SUMM HIPAA PRIV RUL
Walker KL, 2016, J PUBLIC POLICY MARK, V35, P144, DOI 10.1509/jppm.15.020
NR 51
TC 3
Z9 3
U1 9
U2 24
PU TAYLOR & FRANCIS INC
PI PHILADELPHIA
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PT J
AU Mazor, KM
   Richards, A
   Gallagher, M
   Arterburn, DE
   Raebel, MA
   Nowell, WB
   Curtis, JR
   Paolino, AR
   Toh, S
AF Mazor, Kathleen M.
   Richards, Allison
   Gallagher, Mia
   Arterburn, David E.
   Raebel, Marsha A.
   Nowell, W. Benjamin
   Curtis, Jeffrey R.
   Paolino, Andrea R.
   Toh, Sengwee
TI Stakeholders' views on data sharing in multicenter studies
SO JOURNAL OF COMPARATIVE EFFECTIVENESS RESEARCH
LA English
DT Article
DE comparative effectiveness research; data sharing; distributed research
   networks; electronic databases; multicenter studies; PCORnet;
   privacy-protecting methods
ID HEALTH DATA-NETWORKS; CENTERED OUTCOMES RESEARCH; MEDICAL-RECORDS;
   PRIMARY-CARE; INFORMATION; PRIVACY; REGRESSION; DATABASES; ATTITUDES;
   TAXONOMY
AB Aim: To understand stakeholders' views on data sharing in multicenter
comparative effectiveness research studies and the value of privacy-protecting
methods. Materials & methods: Semistructured interviews with five US stakeholder
groups. Results: We completed 11 interviews, involving patients (n = 15),
researchers (n = 10), Institutional Review Board and regulatory staff (n = 3),
multicenter research governance experts (n = 2) and healthcare system leaders (n
= 4). Perceptions of the benefits and value of research were the strongest
influences toward data sharing; cost and security risks were primary influences
against sharing. Privacy-protecting methods that share summary-level data were
acknowledged as being appealing, but there were concerns about increased cost
and potential loss of research validity. Conclusion: Stakeholders were open to
data sharing in multicenter studies that offer value and minimize security risks.
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CR Bell EA, 2014, AMIA ANN S P
Bradley EH, 2007, HEALTH SERV RES, V42, P1758, DOI 10.1111/j.1475-6773.2006.00684.x
Brown JS, 2010, MED CARE, V48, pS45, DOI 10.1097/MLR.0b013e3181d9919f
Concannon TW, 2012, J GEN INTERN MED, V27, P985, DOI 10.1007/s11606-012-2037-1
Curtis LH, 2014, HEALTH AFFAIR, V33, P1178, DOI 10.1377/hlthaff.2014.0121
Damschroder LJ, 2007, SOC SCI MED, V64, P223, DOI 10.1016/j.socscimed.2006.08.045
Daugherty SE, 2014, J AM MED INFORM ASSN, V21, P583, DOI 10.1136/amiajnl-2014-002758
Fireman B, 2009, AM J EPIDEMIOL, V170, P650, DOI 10.1093/aje/kwp173
Hill EM, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-72
Hsieh HF, 2005, QUAL HEALTH RES, V15, P1277, DOI 10.1177/1049732305276687
Karr AF, 2005, J COMPUT GRAPH STAT, V14, P263, DOI 10.1198/106186005X47714
Kass NE, 2003, J LAW MED ETHICS, V31, P429, DOI 10.1111/j.1748-720X.2003.tb00105.x
Luchenski SA, 2013, J MED INTERNET RES, V15, DOI 10.2196/jmir.2701
Paolino Andrea R, 2016, EGEMS (Wash DC), V4, P1216, DOI 10.13063/2327-9214.1216
Rassen JA, 2010, PHARMACOEPIDEM DR S, V19, P848, DOI 10.1002/pds.1867
Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
Ross Tyler R, 2014, EGEMS (Wash DC), V2, P1049, DOI 10.13063/2327-9214.1049
Stevenson F, 2013, FAM PRACT, V30, P227, DOI 10.1093/fampra/cms069
Stone MA, 2005, BRIT J GEN PRACT, V55, P783
Toh S, 2011, CLIN PHARMACOL THER, V90, P883, DOI 10.1038/clpt.2011.236
Toh S, 2014, MED CARE, V52, P664, DOI 10.1097/MLR.0000000000000147
Toh Sengwee, 2013, Pharmacoepidemiol Drug Saf, V22, P1171, DOI 10.1002/pds.3483
Toh S, 2013, MED CARE, V51, pS4, DOI 10.1097/MLR.0b013e31829b1bb1
Toh S, 2013, EPIDEMIOLOGY, V24, P349, DOI [10.1097/EDE.0b013e31828ac65e, 10.1097/EDE.0b013e3182a71390]
Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
Whiddett R, 2006, INT J MED INFORM, V75, P530, DOI 10.1016/j.ijmedinf.2005.08.009
Willison DJ, 2007, J AM MED INFORM ASSN, V14, P706, DOI 10.1197/jamia.M2457

```
   Wu Y, 2012, J AM MED INFORM ASSN, V19, P758, DOI 10.1136/amiajnl-2012-000862
NR 28
TC 3
Z9 3
U1 1
U2 7
PU FUTURE MEDICINE LTD
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PA UNITEC HOUSE, 3RD FLOOR, 2 ALBERT PLACE, FINCHLEY CENTRAL, LONDON, N3
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J9 J COMP EFFECT RES
JI J. Comp. Eff. Res.
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AU Arrighi, Y
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AF Arrighi, Y.
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TI The impact of economic conditions on the disablement process: A Markov
   transition approach using SHARE data
SO HEALTH POLICY
LA English
DT Article
DE Long Term Care; Frailty; Dependency; Markov modelling; Health Inequality
ID HOUSEHOLD PANEL SURVEY; ELDERLY-PEOPLE; SOCIOECONOMIC INEQUALITIES;
   HEALTH INEQUALITIES; LIFE-CYCLE; FRAILTY; CARE; DISABILITY; COUNTRIES;
   DETERMINANTS
AB A growing number of studies underline the relationship between socioeconomic
status and health at older ages. Following that literature, we explore the
impact of economic conditions on changes in functional health overtime. Frailty,
a state of physiological instability, has been identified in the public health
literature as a candidate for disability prevention but received little
attention from health economists. Using SHARE panel data, respondents aged 50
and over from ten European countries were categorised as robust, frail and
dependent. The determinants of health states' changes between two interviews
were analysed using multinomial Probit models accounting for potential sample
attrition. A particular focus was made on initial socioeconomic status, proxied
by three alternative measures. Concentration indices were computed for key
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transition probabilities. Across Europe, poorer and less educated elders were substantially more likely to experience health degradations and also less likely to experience health improvements. The economic gradient for the recovery from frailty was steeper than that of frailty onset, but remained lower than that of dependency onset. The existing social programs in favour of deprived and dependent elders could be widened to those diagnosed as frail to reduce the onset of dependency and economic inequalities in health at older ages. (C) 2017 Elsevier B.V. All rights reserved.

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FX The research leading to these results has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement no 115621 (SPRINTT project), resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies' in kind contribution.

CR Adena M, 2014, SOC SCI MED, V116, P202, DOI 10.1016/j.socscimed.2014.06.045
Ahnquist J, 2012, SOC SCI MED, V74, P930, DOI 10.1016/j.socscimed.2011.11.026
Baeten S, 2013, SOC SCI MED, V97, P66, DOI 10.1016/j.socscimed.2013.08.019
Bargain O, 2010, J ECON INEQUAL, V10, P375
Buckley NJ, 2004, J HEALTH ECON, V23, P1013, DOI 10.1016/j.jhealeco.2004.03.001
Cai LX, 2009, J SOCIOL, V45, P55, DOI 10.1177/1440783308099986
Christensen K, 2009, LANCET, V374, P1196, DOI 10.1016/S0140-6736(09)61460-4
Colombo F, 2011, OECD HLTH POLICY STU
Contoyannis P, 2004, J APPL ECONOMET, V19, P473, DOI 10.1002/jae.755
Cutler DM, 2011, OXFORD HDB HLTH EC, P124
d'Hombres B, 2010, HEALTH ECON, V19, P56, DOI 10.1002/hec.1445
Etman A, 2012, J EPIDEMIOL COMMUN H, V66, P1116, DOI 10.1136/jech-2011-200027
European Commission, 2015, 2015 AG REP EC BUDG
Fried LP, 2001, J GERONTOL A-BIOL, V56, pM146, DOI 10.1093/gerona/56.3.M146
Fried LP, 2004, J GERONTOL A-BIOL, V59, P255
Gill TM, 2006, ARCH INTERN MED, V166, P418, DOI 10.1001/.418
Giordano GN, 2010, SOC SCI MED, V70, P700, DOI 10.1016/j.socscimed.2009.10.044
Gjonca E, 2009, J EPIDEMIOL COMMUN H, V63, P928, DOI 10.1136/jech.2008.082776
Guthmuller S, 2014, J HUM RESOUR, V49, P167
Herd P, 2006, RES AGING, V28, P375, DOI 10.1177/0164027505285845
Hernandez-Quevedo C, 2008, J HEALTH ECON, V27, P1472, DOI 10.1016/j.jhealeco.2008.06.007
Hoeck S, 2012, EUR J PUBLIC HEALTH, V22, P671, DOI 10.1093/eurpub/ckr133
Huisman M, 2003, SOC SCI MED, V57, P861, DOI 10.1016/S0277-9536(02)00454-9
Ilinca S, 2015, HEALTH SERV RES, V50, P305, DOI 10.1111/1475-6773.12211
Jones AM, 2006, J R STAT SOC A STAT, V169, P543, DOI 10.1111/j.1467-985X.2006.00399.x
Kakwani N, 1997, J ECONOMETRICS, V77, P87, DOI 10.1016/S0304-4076(96)01807-6
Kakwani N. C., 1980, INCOME INEQUALITY PO
KAKWANI NC, 1977, ECON J, V87, P71, DOI 10.2307/2231833
Kalousova L, 2015, SOC SCI MED, V124, P275, DOI 10.1016/j.socscimed.2014.11.055
KATZ S, 1963, JAMA-J AM MED ASSOC, V185, P914, DOI 10.1001/jama.1963.03060120024016

Landrum M, 2009, HLTH OLDER AGES CAUS, P151
Lynn J, 2013, JAMA-J AM MED ASSOC, V310, P1935, DOI 10.1001/jama.2013.281923
McDonough P, 2010, SOC SCI MED, V70, P251, DOI 10.1016/j.socscimed.2009.10.001
Moffit R, 1999, ANN EC STAT, P129
NIJMAN T, 1992, J APPL ECONOM, V7, P243, DOI 10.1002/jae.3950070303
OECD, 2013, HLTH GLANC 2013 HLTH
Ramsay SE, 2008, ANN EPIDEMIOL, V18, P896, DOI 10.1016/j.annepidem.2008.09.006
Rautio N, 2005, SOC SCI MED, V60, P2405, DOI 10.1016/j.socscimed.2004.11.029
Riphahn RT, 2001, REV INCOME WEALTH, P379
Romero-Ortuno R, 2010, BMC GERIATR, V10, DOI 10.1186/1471-2318-10-57
Sachs J., 2006, END POVERTY EC POSSI
Santos-Eggimann B, 2009, J GERONTOL A-BIOL, V64, P675, DOI 10.1093/gerona/glp012
Sirven N, 2016, EUROPEAN J HLTH EC
Sirven N, 2012, SOC SCI MED, V75, P1288, DOI 10.1016/j.socscimed.2012.05.009
Stowasser T., 2012, INVESTIGATIONS EC AG, P267
Stowasser T, 2014, DISCOVERIES EC AGING, P187
Szanton SL, 2009, J EPIDEMIOLOGY COMMU
van Kippersluis H, 2010, SOC SCI MED, V70, P428, DOI 10.1016/j.socscimed.2009.10.020
van Kippersluis H, 2009, J HEALTH ECON, V28, P818, DOI 10.1016/j.jhealeco.2009.04.001
Van Ourti T, 2003, J HEALTH ECON, V22, P219, DOI 10.1016/S0167-6296(02)00100-5
Vermeulen J, 2011, BMC GERIATR, V11, DOI 10.1186/1471-2318-11-33
Wooldridge JM, 2010, ECONOMETRIC ANALYSIS OF CROSS SECTION AND PANEL DATA, 2ND EDITION, P1

NR 52
TC 3
Z9 3
U1 1
U2 8

PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000, IRELAND
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JI Health Policy
PD JUL
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SC Health Care Sciences & Services
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PT J
AU Schiffman, C
   Lin, C
   Shi, FN
   Chen, LN
   Sohn, L
   Huang, HY
AF Schiffman, Courtney
   Lin, Christina
   Shi, Funan
   Chen, Luonan
   Sohn, Lydia
   Huang, Haiyan
TI SIDEseq: A Cell Similarity Measure Defined by Shared Identified
   Differentially Expressed Genes for Single-Cell RNA sequencing Data
SO STATISTICS IN BIOSCIENCES
LA English
DT Article
DE single-cell RNA sequencing (scRNA seq); subpopulation identification;
   single-cell clustering; similarity measure; ovarian cancer; EMT inducers
   (Thrombin, TGFB-1)
ID CIRCULATING TUMOR-CELLS; EPITHELIAL-MESENCHYMAL TRANSITION; STEM-CELLS;
   CANCER-PATIENTS; SEQ; NORMALIZATION; TRANSCRIPTOMICS
AB One goal of single-cell RNA sequencing (scRNA seq) is to expose possible heterogeneity within cell populations due to meaningful, biological variation. Examining cell-to-cell heterogeneity, and further, identifying subpopulations of cells based on scRNA seq data has been of common interest in life science research. A key component to successfully identifying cell subpopulations (or clustering cells) is the (dis)similarity measure used to group the cells. In this paper, we introduce a novel measure, named SIDEseq, to assess cell-to-cell similarity using scRNA seq data. SIDEseq first identifies a list of putative differentially expressed (DE) genes for each pair of cells. SIDEseq then integrates the information from all the DE gene lists (corresponding to all pairs of cells) to build a similarity measure between two cells. SIDEseq can be implemented in any clustering algorithm that requires a (dis)similarity matrix. This new measure incorporates information from all cells when evaluating the similarity between any two cells, a characteristic not commonly found in existing (dis)similarity measures. This property is advantageous for two reasons: (a) borrowing information from cells of different subpopulations allows for the investigation of pairwise cell relationships from a global perspective and (b) information from other cells of the same subpopulation could help to ensure a robust relationship assessment. We applied SIDEseq to a newly generated human ovarian cancer scRNA seq dataset, a public human embryo scRNA seq dataset, and several simulated datasets. The clustering results suggest that the SIDEseq measure is capable of uncovering important relationships between cells, and outperforms or at least does as well as several popular (dis)similarity measures when used on these datasets.
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   Science Foundation of China [91529303, 61134013, 91439103].
CR Anders S, 2010, GENOME BIOL, V11, DOI 10.1186/gb-2010-11-10-r106
   Asiedu MK, 2014, ONCOGENE, V33, P1316, DOI 10.1038/onc.2013.57
   ATCC, 2010, TECH B
   Bullard JH, 2010, BMC BIOINFORMATICS, V11, DOI 10.1186/1471-2105-11-94
   Eberwine J, 2014, NAT METHODS, V11, P25, DOI 10.1038/nmeth.2769
   Eisenberg E, 2013, TRENDS GENET, V29, P569, DOI 10.1016/j.tig.2013.05.010
   Gorges TM, 2013, CANCER IMMUNOL IMMUN, V62, P931, DOI 10.1007/s00262-012-1387-1
   Gorges TM, 2012, BMC CANCER, V12, DOI 10.1186/1471-2407-12-178
   Gou WF, 2014, BMC CANCER, V14, DOI 10.1186/1471-2407-14-477
   Grun D, 2015, NATURE, V525, P251, DOI 10.1038/nature14966
   Grun D, 2014, NAT METHODS, V11, P637, DOI [10.1038/NMETH.2930, 10.1038/nmeth.2930]
   Hansen KD, 2012, BIOSTATISTICS, V13, P204, DOI 10.1093/biostatistics/kxr054
   Jiang H, 2012, MOL MED, V18, P1197, DOI 10.2119/molmed.2012.00075
   Jiang L, 2016, GENOME BIOL, V17, DOI 10.1186/s13059-016-1010-4
   Jiang P, 2016, BIOINFORMATICS, V32, P2514, DOI 10.1093/bioinformatics/btw176
   Kasimir-Bauer S, 2012, BREAST CANCER RES, V14, DOI 10.1186/bcr3099
   Levine JH, 2015, CELL, V162, P184, DOI 10.1016/j.cell.2015.05.047
   Lin HK, 2003, J BIOL CHEM, V278, P50902, DOI 10.1074/jbc.M300676200
   Mani SA, 2008, CELL, V133, P704, DOI 10.1016/j.cell.2008.03.027
   O'Driscoll L, 2006, J ENDOCRINOL, V191, P665, DOI 10.1677/joe.1.06894
   Ozkumur E, 2013, SCI TRANSL MED, V5, DOI 10.1126/scitranslmed.3005616
   Ramskold D, 2012, NAT BIOTECHNOL, V30, P777, DOI 10.1038/nbt.2282
   Risso D, 2014, NAT BIOTECHNOL, V32, P896, DOI 10.1038/nbt.2931
   Sandberg R, 2014, NAT METHODS, V11, P22, DOI 10.1038/nmeth.2764
   Stegle O, 2015, NAT REV GENET, V16, P133, DOI 10.1038/nrg3833
   Stegle O, 2012, NAT PROTOC, V7, P500, DOI 10.1038/nprot.2011.457
   Xu C, 2015, BIOINFORMATICS, V31, P1974, DOI 10.1093/bioinformatics/btv088
   Yan LY, 2013, NAT STRUCT MOL BIOL, V20, P1131, DOI 10.1038/nsmb.2660
   Zappia L, 2017, R PACKAGE VERSION 0
   Zeisel A, 2015, SCIENCE, V347, P1138, DOI 10.1126/science.aaa1934
   Zhong YC, 2013, J GYNECOL ONCOL, V24, P265, DOI 10.3802/jgo.2013.24.3.265
NR 31
TC 3
Z9 3
U1 1
U2 3
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 1867-1764
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J9 STAT BIOSCI
JI Stat. Biosci.

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PD JUN
PY 2017
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IS 1
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EP 216
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WC Mathematical & Computational Biology
SC Mathematical & Computational Biology
GA FA8LH
UT WOS:000405697000011
PM 30774736
OA Green Accepted
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ER

PT J
AU Thorogood, A
   St-Pierre, CD
   Knoppers, BM
AF Thorogood, Adrian
   St-Pierre, Constance Deschenes
   Knoppers, Bartha Maria
TI Substitute consent to data sharing: a way forward for international
   dementia research?
SO JOURNAL OF LAW AND THE BIOSCIENCES
LA English
DT Article
DE substitute consent; data sharing; research ethics; best interests;
   capacity
ID HEALTH; PRIVACY
AB A deluge of genetic and health-related data is being generated about patients
with dementia. International sharing of these data accelerates dementia research.
Seeking consent to data sharing is a challenge for dementia research where
patients have lost or risk losing legal capacity. The laws of most countries
enable substitute decision makers (SDMs) to consent on behalf of incapable
adults to research participation. We compare regulatory frameworks governing
capacity, research, and personal data protection across eight countries to
determine when SDMs can consent to data sharing. In most countries, an SDM can
consent to data sharing in the incapable adult's best interests. Best interests
typically include consideration of the individual's previously expressed wishes,
values and beliefs; well-being; and inclusion in decision making. Countries
differ in how these considerations are balanced. A clear previous consent or
refusal to share data typically binds the discretion of an SDM. Though generally
permissive, National patchworks of laws and guidelines cause confusion. Clarity
on the applicable law and processes to enhance ethical decision making are
needed to facilitate substitute consent. Researchers can encourage patients to
communicate their research preferences before a loss of capacity, and educate
SDMs about their ethical and legal duties. The research community must also
continue to promote the importance of data sharing in dementia.
C1 [Thorogood, Adrian; St-Pierre, Constance Deschenes; Knoppers, Bartha Maria]
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RP Thorogood, A (reprint author), McGill Univ, Ctr Genom & Policy, Montreal, PQ
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FU Can-SHARE project; Genome Quebec; Genome Canada; government of Canada;
   Ministere de l'Economie, Innovation et Exportation du Quebec; Canadian
   Institutes of Health Research [141210]
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CR ABA Commission on Law and Aging, 2015, HLTH CAR DEC MAK AUT
American Psychiatric Association'sTask Force on Research Ethics, 2006, PSYCHIAT SERV, V57, P553
Archibald Tom, 2008, HLTH L J SPEC ED, P145
Archibald Tom, 2008, HLTH L J SPEC ED, P156
Australian Law Reform Commission, 2003, ESS YOURS THEPR OFH
Bravo G, 2005, CAN J AGING, V24, P237, DOI 10.1353/cja.2005.0074
Campbell A, 2001, McGill Law J, V46, P473
Campbell Angela, 2001, MCGILL L J, P482
Cavoukian A., 2014, BIG DATA INNOVATION
Contreras JL, 2015, SCIENCE, V350, P1312, DOI 10.1126/science.aaa7485
Council for International Organizations of Medical Sciences (CIOMS), 2002, GUID 9, V9, P13
Deetjen Ulrike, 2015, OECD DIGITAL EC PAPE, V246
El Emam K, 2011, GENOME MED, V3, DOI 10.1186/gm239
Genomics England, 2016, PART INF SHEETS CONS
Hayden EC, 2013, NATURE, V497, P172, DOI 10.1038/497172a
Knoppers BM, 2012, AM J HUM GENET, V91, P577, DOI 10.1016/j.ajhg.2012.05.027
Lieberman JA, 2006, PSYCHIAT SERV, V57, P552
LOWRANCE WILLIAM W., 2002, LEARNING EXPERIENCE, P19
Narayan Arvind, 2014, NO SILVER B IDENTIFI
National Institutes of Health (NIH) Office of Extramural Research, 2009, RES INV DIV QUEST CA
NUFFIELD COUNCIL ON BIOETHICS, 2009, DEMENTIA ETHICAL ISS, P136
Oderkirk J, 2013, HEALTH POLICY, V112, P9, DOI 10.1016/j.healthpol.2013.06.006
OECD, 2015, ADDRESSING DEMENTIA, P13
Organisation for Economic Co-operation and Development, 1980, OECD GUID PROT PRIV
Organisation for Economic Co-operation and Development, 2013, GUID GOV PROT PRIV T
PATTINSON SHAUN D., 2014, MED LAW ETHICS, P408
Saks Elyn R, 2008, Yale J Health Policy Law Ethics, V8, P37
Shah S, 2011, AM J BIOETHICS, V11, P22, DOI 10.1080/15265161.2011.572511
Tashiro S, 2010, INT J JPN SOCIOL, V19, P4, DOI 10.1111/j.1475-6781.2010.01127.x
Thorogood Adrian, 2016, CAN J LAW TECH, V14, P173
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Wada K, 2011, AM J BIOETHICS, V11, P27, DOI 10.1080/15265161.2011.568584
WHO, 2016, DEM FACT SHEET
Winblad B, 2016, LANCET NEUROL, V15, P455, DOI 10.1016/S1474-4422(16)00062-4
Zawati, 2015, MCGILL J L HLTH, V79, P97

NR 35
TC 3
Z9 3
U1 0
U2 5

PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND

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SN 2053-9711
J9 J LAW BIOSCI
JI J. Law Biosci.
PD APR
PY 2017
VL 4
IS 1
BP 133
EP 158
DI 10.1093/jlb/lsw063
PG 26
WC Ethics; Law; Medical Ethics; Medicine, Legal
SC Social Sciences - Other Topics; Government & Law; Medical Ethics; Legal
   Medicine
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PT J
AU Littler, K
   Boon, WM
   Carson, G
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   Mathewson, S
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   Moorthy, VS
   O'Connor, D
   Roth, C
   Segovia, C
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   Carson, Gail
   Depoortere, Evelyn
   Mathewson, Sophie
   Mietchen, Daniel
   Moorthy, Vasee S.
   O'Connor, Denise
   Roth, Cathy
   Segovia, Carlos
TI Progress in promoting data sharing in public health emergencies
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Editorial Material
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OI Moorthy, Vasee/0000-0002-6535-2854; Mietchen, Daniel/0000-0001-9488-1870
FU World Health Organization [001]
NR 0
TC 3
Z9 3
U1 0
U2 2
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
EI 1564-0604
J9 B WORLD HEALTH ORGAN
JI Bull. World Health Organ.
PD APR
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA ET9MP
UT WOS:000400631900002
PM 28479616
OA Green Published, Bronze
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PT J
AU Debono, VB
   Mbuagbaw, L
   Thabane, L
AF Debono, Victoria Borg
   Mbuagbaw, Lawrence
   Thabane, Lehana
TI Sharing interim trial results by the Data Safety Monitoring Board with
   those responsible for the trial's conduct and progress: a narrative
   review
SO TRIALS
LA English
DT Review
DE Data Safety Monitoring Board; Data Monitoring Committee; Interim data
   sharing; Narrative review
ID RANDOMIZED CLINICAL-TRIALS; ADAPTIVE DESIGN; ETHICAL-ISSUES; COMMITTEES;
   CONFIDENTIALITY; INTEGRITY; CONTROVERSIES; INDEPENDENCE; STATISTICIAN;
   OPERATIONS
AB Background: Sharing interim data, results or result extrapolations is an
important issue that can affect trial integrity. The different ways in which
Data Safety Monitoring Boards (DSMBs) share interim results with non-DSMB
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members and the acceptability of such practices are poorly understood. Our objective was to undertake a narrative review specifically on what kind of interim results, if any, should be shared by the DSMB with non-DSMB members and why.

Methods: We conducted a narrative review using a systematic search strategy of several databases and major health research stakeholders. Literature was included if there was some discussion within the full text about sharing interim trial results with non-DSMB members.

Results: About 79.6% (129/162) of included citations were based on author's views, 16.7% (27/162) on research guidelines and 3.7% (6/162) on surveys. The largest group of citations, 73/162 (45%), expresses the opinion or argument against sharing interim results with exceptions. Trailing closely, 71/162 (43.8%) of the included citations support the opinion or argument that interim results should not be shared and should remain confidential with the DSMB. Half of the six surveys support sharing in some capacity, while the other three do not. Eleven circumstances were found that potentially warrant interim result sharing by the DSMB; they relate to (1) usual practices by DSMBs, (2) trial completion threatened, (3) patient safety, (4) regulatory approval and (5) other circumstances. Dominant risks for sharing under these conditions are associated with introducing trial bias.

Discussion/conclusion: There was no majority view in the literature. However, the largest group of citations included express the idea that interim results should remain confidential with the DSMB but also acknowledge circumstances when they could be shared with non-DSMB members. Limitations of this review are that (1) the included literature predominately provides personal perspectives, not evidence, and (2) surveys found globally focus on trial monitoring practices lacking detailed information on what specifically to share, with whom and why. More research is needed with the use of a detailed survey of the clinical trial community focused on DSMB sharing interim results, to better understand and guide DSMB interim result sharing practices.

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OI Mbuagbaw, Lawrence/0000-0001-5855-5461;

FU Canadian Institutes for Health Research (CIHR)
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CR Allardyce RA, 2011, ANZ J SURG, V81, P125, DOI 10.1111/j.1445-2197.2010.05433.x
Anand SS, 2011, CLIN TRIALS, V8, P716, DOI 10.1177/1740774511424421
[Anonymous], CONF INT RES CARD CV
[Anonymous], 2017, WHO WE AR
Antonijevic Z, 2013, THER INNOV REGUL SCI, V47, P495, DOI 10.1177/2168479013486996
Bloudoff-Indelicato M, 2015, NAT MED, V21, P200, DOI 10.1038/nm0315-200
Borer JS, 2008, JAMA-J AM MED ASSOC, V299, P1710, DOI 10.1001/jama.299.14.1710
Califf RM, 2001, AM HEART J, V141, P301, DOI 10.1067/mhj.2001.113152
Chalmers I, 2013, TRIALS, V14, DOI [10.1186/1745-6215-14-102, 10.1186/1468-6708-14-102]
Chow SC, 2012, J BIOPHARM STAT, V22, P853, DOI 10.1080/10543406.2012.676536
D'Agostino RB, 2004, STAT MED, V23, P1501, DOI 10.1002/sim.1873
Day S., 2015, CLIN INVESTIGATOR, V5, P615
Delgado-Herrera L, 2003, CONTROL CLIN TRIALS, V24, P51, DOI 10.1016/S0197-2456(02)00275-1

DeMets David, 2004, Clin Trials, V1, P162, DOI 10.1191/1740774504cn019xx
DeMets DL, 2011, CLIN TRIALS, V8, P722, DOI 10.1177/1740774511426581
DeMets DL, 2004, STAT MED, V23, P1513, DOI 10.1002/sim.1786
DeMets DL, 1995, CONTROL CLIN TRIALS, V16, P408, DOI 10.1016/S0197-2456(95)00073-9
DeMets DL, 2000, CONTROL CLIN TRIALS, V21, P54, DOI 10.1016/S0197-2456(99)00048-3
Dixon DO, 2011, CLIN TRIALS, V8, P727, DOI 10.1177/1740774511425181
Dixon DO, 2000, CONTROL CLIN TRIALS, V21, P1, DOI 10.1016/S0197-2456(99)00042-2
Eckstein L, 2015, ACCOUNT RES, V22, P81, DOI 10.1080/08989621.2014.919230
Ellenberg S. S., 2003, DATA MONITORING COMM
Ellenberg SS, 2001, STAT MED, V20, P2573, DOI 10.1002/sim.730
Fleming TR, 2008, CLIN TRIALS, V5, P157, DOI 10.1177/1740774508089459
Fleming TR, 2006, STAT MED, V25, P3305, DOI 10.1002/sim.2641
Fleming TR, 2015, CLIN TRIALS, V12, P5, DOI 10.1177/1740774514561243
Fleming TR, 2014, J BIOPHARM STAT, V24, P968, DOI 10.1080/10543406.2014.925719
Fleming TR, 2002, STAT MED, V21, P2843, DOI 10.1002/sim.1288
FREEMAN PR, 1993, STAT MED, V12, P1471
Friedman LM, 1998, FUNDAMENTALS CLIN TR
Gallo P, 2006, PHARM STAT, V5, P119, DOI 10.1002/pst.221
Gallo P, 2006, J BIOPHARM STAT, V16, P311, DOI 10.1080/10543400600614775
Gallo P, STAT BIOPHARM RES
Gallo P, 2006, DRUG INF J, V40, P445
Gallo P, 2006, J BIOPHARM STAT, V16, P275, DOI 10.1080/10543400600614742
GELLER NL, 1993, STAT MED, V12, P543, DOI 10.1002/sim.4780120520
GEORGE SL, 1993, STAT MED, V12, P435, DOI 10.1002/sim.4780120507
Glover JM, 2012, DRUG INF J, V46, P525, DOI 10.1177/0092861512452123
Golub H, 2006, STAT MED, V25, P3326, DOI 10.1002/sim.2627
Grant AM, 2005, HEALTH TECHNOL ASSES, V9, P1
GREEN S, 1993, STAT MED, V12, P451, DOI 10.1002/sim.4780120508
Hemmings R, 2004, DRUG SAFETY, V27, P1, DOI 10.2165/00002018-200427010-00001
Herson J, 2008, DRUG INF J, V42, P297, DOI 10.1177/009286150804200401
Herson J, 2009, CH CRC BIOSTAT SER, V30, P1
Hicks LK, 2007, INTENS CARE MED, V33, P1815, DOI 10.1007/s00134-007-0794-9
International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH), 1998, ICH HARM TRIP GUID S, P39
Korn EL, 2005, J CLIN ONCOL, V23, P5831, DOI 10.1200/JCO.2005.02.105
Lilford RJ, 2001, BMJ-BRIT MED J, V323, P441, DOI 10.1136/bmj.323.7310.441
London AJ, 2015, CLIN TRIALS, V12, P12, DOI 10.1177/1740774514561047
Migrino RQ, 2003, CONTROL CLIN TRIALS, V24, P501, DOI 10.1016/S0197-2456(03)00091-6
Miller FG, 2008, J MED ETHICS, V34, P198, DOI 10.1136/jme.2006.019109
Nissen SE, 2015, CLIN TRIALS, V12, P15, DOI 10.1177/1740774514561661
Parks M, 2013, MEMORANDUM DISCLOSUR
Peppercorn J, 2008, LANCET, V371, P527, DOI 10.1016/S0140-6736(08)60239-1
POCOCK SJ, 1993, STAT MED, V12, P1459, DOI 10.1002/sim.4780121512
ROCKHOLD FW, 1993, STAT MED, V12, P471, DOI 10.1002/sim.4780120512
Rouse DJ, 2003, OBSTET GYNECOL SURV, V58, P329
Sartor O, 2015, UROL ONCOL-SEMIN ORI, V33, P143, DOI 10.1016/j.urolonc.2014.12.013
Shah SK, 2011, JAIDS-J ACQ IMM DEF, V58, P433, DOI 10.1097/QAI.0b013e318236eca3
Siegel JP, 2004, STAT MED, V23, P1527, DOI 10.1002/sim.1789
Silverman Henry, 2007, Proc Am Thorac Soc, V4, P180, DOI 10.1513/pats.200701-010GC
Slutsky AS, 2004, NEW ENGL J MED, V350, P1143, DOI 10.1056/NEJMsb033476

```
   Smith MA, 1997, J CLIN ONCOL, V15, P2736, DOI 10.1200/JCO.1997.15.7.2736
   Stephens RJ, 2014, LUNG CANCER, V85, P116, DOI 10.1016/j.lungcan.2014.05.012
   Tereskerz PM, 2011, ACCOUNT RES, V18, P1, DOI 10.1080/08989621.2011.542680
   US Food and Drug Administration, 2014, TRANSCR HEAR PART 15
   US Food and Drug Administration, 2001, FDA GUID CLIN TRIAL, P237
   US Food and Drug Administration, 2014, PRES PART 15 PUBL HE
   US Food and Drug Administration, 2006, EST OP CLIN TRIAL DA, P38
   Vail A, 2001, STAT MED, V20, P3777, DOI 10.1002/sim.1171
   WILLIAMS GW, 1993, STAT MED, V12, P481, DOI 10.1002/sim.4780120513
   Wittes J, 2007, CLIN TRIALS, V4, P218, DOI 10.1177/1740774507079439
   Wong G, 2013, BMC MED, V11, DOI 10.1186/1741-7015-11-20
   YUSUF, 1993, STAT MED, V12, P527
   YUSUF S, 1993, STAT MED, V12, P553
NR 75
TC 3
Z9 3
U1 0
U2 4
PU BIOMED CENTRAL LTD
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PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
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J9 TRIALS
JI Trials
PD MAR 9
PY 2017
VL 18
AR 120
DI 10.1186/s13063-017-1858-y
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WC Medicine, Research & Experimental
SC Research & Experimental Medicine
GA EO9HJ
UT WOS:000396999500007
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PT J
AU Savage, N
AF Savage, Neil
TI Getting Data Sharing Right to Help Fulfill the Promise of Cancer
   Genomics
SO CELL
LA English
DT Editorial Material
AB Limited access to the profusion of sequence information derived from cancer
patients worldwide stymies basic research and clinical decisions. Efforts are
underway to streamline and safeguard data use.
NR 0
TC 3
Z9 3
U1 1
U2 7
PU CELL PRESS
PI CAMBRIDGE
PA 50 HAMPSHIRE ST, FLOOR 5, CAMBRIDGE, MA 02139 USA
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SN 0092-8674
EI 1097-4172
J9 CELL
JI Cell
PD FEB 9
PY 2017
VL 168
IS 4
BP 551
EP 554
DI 10.1016/j.cell.2017.01.003
PG 4
WC Biochemistry & Molecular Biology; Cell Biology
SC Biochemistry & Molecular Biology; Cell Biology
GA EN8VJ
UT WOS:000396277600003
PM 28187273
DA 2019-08-06
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PT J
AU Beier, M
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   Siewert, R
   Witt, M
   Wu, J
   Krefting, D
AF Beier, Maximilian
   Jansen, Christoph
   Mayer, Geert
   Penzel, Thomas
   Rodenbeck, Andrea
   Siewert, Rene
   Witt, Michael
   Wu, Jie
   Krefting, Dagmar
TI Multicenter data sharing for collaboration in sleep medicine
SO FUTURE GENERATION COMPUTER SYSTEMS-THE INTERNATIONAL JOURNAL OF ESCIENCE
LA English
DT Article
DE Biosignal; Polysomnography; EDF; XNAT; OpenStack; Docker
ID PLATFORM
AB Sleep is a fundamental biological process crucial for survival and health of
(not only) humans. But many circumstances like physiological and mental
disorders, environment and lifestyle may affect healthy sleep. To date, 88
different sleep disorders are internationally recognized. They cover a broad
field of medical areas. Analysis of human sleep is typically based on
multidimensional biosignal recordings, so called polysomnographies (PSG).
Therefore research often includes digital signal processing. Clinical sleep
research is an inherent multidisciplinary field. Inter-institutional and
interdisciplinary collaborations are required to address the complexity of sleep
regulation and disturbance. But to date, collaborative sleep research is poorly
supported by IT systems. In particular, the management and processing of PSGs is
challenging. A large variety of PSG devices, data formats, measurement
procedures and quality variations impedes consistent biosignal data processing.
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In this manuscript we introduce a virtual research platform supporting inter-institutional data sharing and processing. The infrastructure is based on XNAT a free and open source neuroimaging research platform, a loosely coupled service oriented architecture and scalable virtualization in the back end. The system is capable of local pseudonymization of biosignal data, mapping to a standardized set of parameters and automatic quality assessment. Terms and quality measures are derived from the "Manual for the Scoring of Sleep and Associated Events" of the American Academy of Sleep Medicine (AASM), the de facto standard for diagnostic biosignal analysis in sleep medicine. (C) 2016 Elsevier B.V. All rights reserved.

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FX The authors would like to thank Sebastian Canisius for defining the electronic forms and Ludger Grote for sharing experiences and recommendation from the ESADA project. The authors would also like to thank Marion Bitterlich and Cathleen Dorr for managing the PSG uploader with a miserable Internet connection. The presented work is supported by the German Federal Ministry of Education and Research (Somnonetz-01EZ1132, BB-IT-Boost), the German Federal Ministry of Economic Affairs and Energy (Macchiato: KF2254902JL3, berCF: KF3470401BZ4) and the Berlin Institute for Applied Research (QM ROCT): IFAFQMROCT.

CR Azarbarzin A, 2015, SLEEP, V38, P1313, DOI 10.5665/sleep.4916
Bartsch R, 2007, PHYS REV LETT, V98, DOI 10.1103/PhysRevLett.98.054102
Bashan A, 2012, NAT COMMUN, V3, DOI 10.1038/ncomms1705
COLEMAN RM, 1982, JAMA-J AM MED ASSOC, V247, P997, DOI 10.1001/jama.247.7.997
da Silva R. F., 2015, SELF MANAGING OPERAT, P187
Field Laurence, 2013, REALISING THE FULL P
Fraser M., VIRTUAL RESEARCH ENV
Guilleminault C, 2001, BRAIN, V124, P1482, DOI 10.1093/brain/124.8.1482
Hedner J, 2011, EUR RESPIR J, V38, P635, DOI 10.1183/09031936.00046710
Iber C., 2007, TECH REP
Kemp B, 2003, CLIN NEUROPHYSIOL, V114, P1755, DOI 10.1016/S1388-2457(03)00123-8
Kemp B., CLIN NEUROPHYSIOL, P82
Kendzerska T, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001599
Krefting D., 2010, FUTURE GENER COMPUT
Krefting D, 2009, FUTURE GENER COMP SY, V25, P326, DOI 10.1016/j.future.2008.05.005
Luca G, 2013, J SLEEP RES, V22, P482, DOI 10.1111/jsr.12044
Mahowald MW, 2005, NATURE, V437, P1279, DOI 10.1038/nature04287
Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
Meiners Torsten, 2014, PRINCIPLES OF DATA M
Neinstein A., 2015, J AM MED INF ASS
Olabarriaga S., 2006, 2 IEEE INT C E SCI G, P53
Owens J, 2014, PEDIATRICS, V134, pE921, DOI 10.1542/peds.2014-1696
Penzel T, 2007, CHAOS, V17, DOI 10.1063/1.2711282
Quan SF, 2011, SLEEP, V34, P303, DOI 10.1093/sleep/34.3.303

```
   Rappelsberger P, 2001, KLIN NEUROPHYSIOL, V32, P76, DOI 10.1055/s-2001-16206
   Redolfi A., 2009, FUTURE NEUROL, V4
   Richardson Leonard, RESTFUL WEB SERVICES
   Roebuck A, 2014, PHYSIOL MEAS, V35, pR1, DOI 10.1088/0967-3334/35/1/R1
   Roth T, 2007, J CLIN SLEEP MED, V3, P7, DOI DOI 10.1080/08098130802697269
   Schwartz Y, 2012, FRONT NEUROINFORM, V6, DOI 10.3389/fninf.2012.00012
   Shahand S., 2014, CONCURR COMPUT PRACT
   Shanahan L, 2014, J AM ACAD CHILD PSY, V53, P550, DOI
10.1016/j.jaac.2013.12.029
   Wessel N, 2013, IEEE ENG MED BIO, P6567, DOI 10.1109/EMBC.2013.6611060
   Wilkins-Diehr N, 2007, CONCURR COMP-PRACT E, V19, P743, DOI 10.1002/cpe.1098
   Wu J, 2014, IEEE ACM INT SYMP, P764, DOI 10.1109/CCGrid.2014.103
   Xiao Q, 2014, AM J EPIDEMIOL, V180, P997, DOI 10.1093/aje/kwu222
   2009, J CLIN SLEEP MED JCS, V5, P263
NR 37
TC 3
Z9 3
U1 0
U2 18
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0167-739X
EI 1872-7115
J9 FUTURE GENER COMP SY
JI Futur. Gener. Comp. Syst.
PD FEB
PY 2017
VL 67
BP 466
EP 480
DI 10.1016/j.future.2016.03.025
PG 15
WC Computer Science, Theory & Methods
SC Computer Science
GA EE4ES
UT WOS:000389555700039
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ER

PT B
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Nazir, S
TI A Secure Data Sharing Using Identity-Based Encryption Scheme for
e-Healthcare System
SO 2017 3RD INTERNATIONAL CONFERENCE ON SCIENCE IN INFORMATION TECHNOLOGY
(ICSITECH)
LA English
DT Proceedings Paper
CT 3rd International Conference on Science in Information Technology
(ICSITech)
CY OCT 25-26, 2017
CL Univ Pendidikan Indonesia, Bandung, INDONESIA
SP Univ Pendidikan Indonesia, Dept Comp Sci Educ, RISTEKDIKTI, UNIV PUTRA MALAYSIA, Univ Teknologi Malaysia, UTM Big Data Ctr, Univ Ahmad Dahlan, Univ Mulawarman, UPN Veteran Yogyakarta, Univ Muhammadiyah Surakarta, Univ Malaysia Sabah, Univ Budi Luhur, IEEE Indonesia Sect, Minist Res Technol & Higher Educ
HO Univ Pendidikan Indonesia
DE e-Healthcare; data sharing; IBE; confidentiality; data integrity
AB Data sharing information regarding health status in the e-healthcare systems becomes one of private and very sensitive information that should be kept from exposure by illegal activities. However, since the information are exchanged across public networks (i.e., Internet and wireless networks), the information become vulnerable. Due to the participating users in the network can not be trusted, a secure data sharing process in the e-healthcare system would be mandatory. In this paper, we propose a secure data sharing in the e-healthcare system using Identity-Based Encryption (IBE) with signature to provide: (1) data sharing can be accessed by only authorized users based on unique public identity (ID) and kept its integrity from alteration during transmission simultaneously, and (2) data sharing are encrypted and authenticated such that the data can only be exchanged by authorized users. Meanwhile, experimental results are able to show the practicality of proposed system.
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FX The authors would like to thank to the anonymous reviewers for their
best suggestions. A part of this paper is supported by Ministry of
Research, Technology, and Higher Education of Indonesia, Penelitian
Produk Terapan Scheme, 2017.
CR Appenzeller G., 2009, REQUEST COMMENT 5408
Boneh D, 2004, J CRYPTOL, V17, P297, DOI 10.1007/s00145-004-0314-9
Boneh D., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P213
Boyen X., 2007, REQUEST COMMENT 5091
Costigan N., 2004, THESIS
Kihidis A., 2010, 14 C INF PCI
Martin L., 2009, REQUEST COMMENT 5409
Rodrigues J., 2013, J MED INTERNET RES, V15
Stalling W., 2011, NETWORK SECURITY ESS
Sun JY, 2011, INT CON DISTR COMP S, P373, DOI 10.1109/ICDCS.2011.83
Yuliana M, 2016, PROCEEDINGS OF 2016 2ND INTERNATIONAL CONFERENCE ON SCIENCE IN INFORMATION TECHNOLOGY (ICSITECH) - INFORMATION SCIENCE FOR GREEN SOCIETY AND ENVIRONMENT, P232, DOI 10.1109/ICSITech.2016.7852639
NR 11
TC 3

```
Z9 3
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-5090-5866-2
PY 2017
BP 429
EP 434
PG 6
WC Computer Science, Information Systems
SC Computer Science
GA BJ8FL
UT WOS:000428147600076
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ER

PT S
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BE Blobel, B
   Goossen, W
TI Smartphones to Access to Patient Data in Hospital Settings:
   Authentication Solutions for Shared Devices
SO PHEALTH 2017
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 14th International Conference on Wearable Micro and Nano Technologies
   for Personalized Health (pHealth)
CY MAY 14-16, 2017
CL Eindhoven, NETHERLANDS
SP Hlth Level 7 Int, Dutch Med Informat Assoc VMBI, European Federat Med
Informat
DE mHealth; RFID; Cybersecurity; Electronic Health Records
ID SECURITY
AB Although mobile devices become more and more common in clinicians' hands,
transforming them into an institutional tool to access electronic health record
information at the patient's bedside still raises many questions. One of these
questions is the provenance of mobile devices when these are deployed at an
institutional level. Some advocate the use of personal devices, known as BYOD,
for its lower cost, others favor the use of institutional devices which allow a
standardization of the development, deployment and support processes. The
financial disadvantage of institutional devices could be reduced by sharing
devices between several care-providers. The problem with this solution is the
authentication management. Indeed, smartphones are defined for individual use
and do not efficiently manage multiple identities on a single device. In this
article we present the outcome of a Delphi study aiming at identifying an
authentication strategy that combines security and acceptable usability in order
to share a pool of devices in a medical ward.
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OI Ehrler, Frederic/0000-0001-9734-3242; Lovis,
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CR Al Ayubi SU, 2016, JMIR MHEALTH UHEALTH, V4, P446, DOI 10.2196/mhealth.4424
   Booth P, P ANN INT C IEEE ENG, P117
   Fernandez-Aleman JL, 2015, INT J MED INFORM, V84, P454, DOI
10.1016/j.ijmedinf.2015.01.010
   Gehringer EF, P IEEE 2002 INT S TE, P369
   Kainda R, 2010, FIFTH INTERNATIONAL CONFERENCE ON AVAILABILITY, RELIABILITY,
AND SECURITY: ARES 2010, PROCEEDINGS, P275, DOI 10.1109/ARES.2010.77
   Luethi M, P 42 ANN HAW INT C S, P1
   Luxton DD, 2012, TELEMED E-HEALTH, V18, P284, DOI 10.1089/tmj.2011.0180
   Martinez-Perez B, 2014, J MED SYST, V38, DOI 10.1007/s10916-013-0004-y
   Minami M, P 2011 IEEE CONS COM, P523
   Oulasvirta A, 2012, PERS UBIQUIT COMPUT, V16, P105, DOI 10.1007/s00779-011-
0412-2
   Schaub F, 2012, MUM 12 P 11 INT C MO
   Ventola C Lee, 2014, P T, V39, P356
NR 12
TC 3
Z9 3
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
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J9 STUD HEALTH TECHNOL
PY 2017
VL 237
BP 73
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PG 6
WC Medical Informatics
SC Medical Informatics
GA BJ6MB
UT WOS:000426824800008
PM 28479546
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PT J
AU Popovic, JR
AF Popovic, Jennifer R.
TI Distributed data networks: a blueprint for Big Data sharing and
   healthcare analytics
SO ANNALS OF THE NEW YORK ACADEMY OF SCIENCES
LA English
DT Article
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DE distributed data network; common data model; machine learning algorithm; healthcare analytics; Big Data

AB This paper defines the attributes of distributed data networks and outlines the data and analytic infrastructure needed to build and maintain a successful network. We use examples from one successful implementation of a large-scale, multisite, healthcare-related distributed data network, the U.S. Food and Drug Administration-sponsored Sentinel Initiative. Analytic infrastructure-development concepts are discussed from the perspective of promoting six pillars of analytic infrastructure: consistency, reusability, flexibility, scalability, transparency, and reproducibility. This paper also introduces one use case for machine learning algorithm development to fully utilize and advance the portfolio of population health analytics, particularly those using multisite administrative data sources.

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RI PAN, ZEQIANG/X-6341-2018

CR Andrade SE, 2011, PHARMACOEPIDEM DR S, V20, P1168, DOI 10.1002/pds.2217
[Anonymous], 2016, DISTRIBUTED DATABASE
[Anonymous], 2009, P 2009 SAS GLOB FOR
[Anonymous], 2016, SENTINEL DISTRIBUTED
[Anonymous], 2016, ROUTINE QUERYING TOO
Bates D.W., 2013, HLTH AFF, V33, P1123
Behrman RE, 2011, NEW ENGL J MED, V364, P498, DOI 10.1056/NEJMp1014427
Benchimol EI, 2011, J CLIN EPIDEMIOL, V64, P821, DOI 10.1016/j.jclinepi.2010.10.006
Brown J, 2009, DEFINING EVALUATING
Brown J.S., 2013, LEARNING HLTH SYSTEM
Curtis LH, 2014, HEALTH AFFAIR, V33, P1178, DOI 10.1377/hlthaff.2014.0121
Duke University Margolis Center for Health Policy, 2016, 8 ANN SENT IN PUBL W
Hasan S, 2011, J AM MED INFORM ASSN, V18, P449, DOI 10.1136/amiajnl-2011-000106
Herman RA, 2012, PHARMACOEPIDEM DR S, V21, P203, DOI 10.1002/pds.2315
Mehzar M., 2016, WOODCOCK DRUG SAFETY
Mini-Sentinel Operations Center, 2010, MIN COMM DAT MOD GUI
Patel UD, 2013, VALIDATION ACUTE KID
Popovic J.R., 2015, P 2015 PHARM IND SAS
Psaty BM, 2014, NEW ENGL J MED, V370, P2165, DOI 10.1056/NEJMp1401664
Routine Querying System, 2016, ROUT QUER SYST
Sherman T., 2013, P 2013 PHARMASUG C C
Toh S, 2014, MED CARE, V52, P664, DOI 10.1097/MLR.0000000000000147
Toh Sengwee, 2013, Pharmacoepidemiol Drug Saf, V22, P1171, DOI 10.1002/pds.3483
Waljee AK, 2014, CLIN TRANSL GASTROEN, V5, DOI 10.1038/ctg.2013.19
Walsh Kathleen E, 2013, Pharmacoepidemiol Drug Saf, V22, P1205, DOI 10.1002/pds.3505

NR 25
TC 3
Z9 3
U1 2
U2 13
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0077-8923
EI 1749-6632

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J9 ANN NY ACAD SCI
JI Ann. N.Y. Acad. Sci.
PD JAN
PY 2017
VL 1387
IS 1
SI SI
BP 105
EP 111
DI 10.1111/nyas.13287
PG 7
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA ER4VR
UT WOS:000398800200011
PM 27862002
DA 2019-08-06
ER

PT J
AU Park, RW
AF Park, Rae Woong
TI Sharing Clinical Big Data While Protecting Confidentiality and Security:
   Observational Health Data Sciences and Informatics
SO HEALTHCARE INFORMATICS RESEARCH
LA English
DT Editorial Material
ID NETWORK
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RI Singh, Arun Kumar/M-8977-2013
OI Singh, Arun Kumar/0000-0002-9974-4696
CR Go AS, 2008, CIRC-CARDIOVASC QUAL, V1, P138, DOI
10.1161/CIRCOUTCOMES.108.801654
   Hripcsak G, 2016, P NATL ACAD SCI USA, V113, P7329, DOI
10.1073/pnas.1510502113
   Mayer-Schonberger V, 2016, EUR HEART J, V37, P996, DOI
10.1093/eurheartj/ehv648
   Murdoch TB, 2013, JAMA-J AM MED ASSOC, V309, P1351, DOI 10.1001/jama.2013.393
   Platt R, 2009, NEW ENGL J MED, V361, P645, DOI 10.1056/NEJMp0905338
NR 5
TC 3
Z9 4
U1 0
U2 4
PU KOREAN SOC MEDICAL INFORMATICS
PI SEOUL
PA 1618 KYUNGHEEGUNG ACHIM BLDG 3, 72 NAESOO-DONG CHONGRO-KU, SEOUL,
   110-872, SOUTH KOREA
SN 2093-3681
EI 2093-369X
J9 HEALTHC INFORM RES
JI Healthc. Inform. Res.
PD JAN
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PY 2017
VL 23
IS 1
BP 1
EP 3
DI 10.4258/hir.2017.23.1.1
PG 3
WC Medical Informatics
SC Medical Informatics
GA EO0ZE
UT WOS:000396426400001
PM 28261525
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PT J
AU Liu, XP
   Li, XB
   Motiwalla, L
   Li, WJ
   Zheng, H
   Franklin, PD
AF Liu, Xiaoping
   Li, Xiao-Bai
   Motiwalla, Luvai
   Li, Wenjun
   Zheng, Hua
   Franklin, Patricia D.
TI Preserving Patient Privacy When Sharing Same-Disease Data
SO ACM JOURNAL OF DATA AND INFORMATION QUALITY
LA English
DT Article
DE Data sharing; disclosure risk; HIPAA
ID DISCLOSURE
AB Medical and health data are often collected for studying a specific disease.
For such same-disease microdata, a privacy disclosure occurs as long as an
individual is known to be in the microdata. Individuals in same-disease
microdata are thus subject to higher disclosure risk than those in microdata
with different diseases. This important problem has been overlooked in data-
privacy research and practice, and no prior study has addressed this problem. In
this study, we analyze the disclosure risk for the individuals in same-disease
microdata and propose a new metric that is appropriate for measuring disclosure
risk in this situation. An efficient algorithm is designed and implemented for
anonymizing same-disease data to minimize the disclosure risk while keeping data
utility as good as possible. An experimental study was conducted on real patient
and population data. Experimental results show that traditional reidentification
risk measures underestimate the actual disclosure risk for the individuals in
same-disease microdata and demonstrate that the proposed approach is very
effective in reducing the actual risk for same-disease data. This study suggests
that privacy protection policy and practice for sharing medical and health data
should consider not only the individuals' identifying attributes but also the
health and disease information contained in the data. It is recommended that
data-sharing entities employ a statistical approach, instead of the HIPAA's Safe
Harbor policy, when sharing same-disease microdata.
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FU National Library of Medicine (NLM); National Institute of Arthritis and
Musculoskeletal and Skin Diseases (NIAMS) of the National Institutes of
Health (NIH) [R01LM010942, R01AR054479]
FX This research was supported by the National Library of Medicine (NLM)
and National Institute of Arthritis and Musculoskeletal and Skin
Diseases (NIAMS) of the National Institutes of Health (NIH) under Grant
Numbers R01LM010942 and R01AR054479. The content is solely the
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official views of NLM, NIAMS, or NIH.
CR ADAM NR, 1989, COMPUT SURV, V21, P515
[Anonymous], 2000, FED REGISTER, V65, P82
Basole RC, 2015, ACM J DATA INF QUAL, V6, DOI 10.1145/2755489
Breiman L., 1984, CLASSIFICATION REGRE
Centers for Disease Control and Prevention (CDC), 1992, NAT PROGR CANC REG
Christen Peter, 2014, ACM Journal of Data and Information Quality, V5, DOI 10.1145/2629604
DALENIUS T, 1982, J STAT PLAN INFER, V6, P73, DOI 10.1016/0378-3758(82)90058-1
de Montjoye YA, 2013, SCI REP-UK, V3, DOI 10.1038/srep01376
DUNCAN G, 1989, J BUS ECON STAT, V7, P207, DOI 10.2307/1391438
Garfinkel R, 2007, INFORM SYST RES, V18, P23, DOI 10.1287/isre.1070.0112
Golle P, 2006, P 5 ACM WORKSH PRIV, DOI [10.1145/1179601.1179615, DOI 10.1145/1179601.1179615]
LeFevre K, 2006, P INT C DATA ENG, P25, DOI DOI 10.1109/ICDE.2006.101
Li N, 2007, INT CONF NANO MICRO, P692
Li X.B., 2009, J DATA INFORM QUALIT, V1, P3
Li XB, 2014, MIS QUART, V38, P679, DOI 10.25300/MISQ/2014/38.3.03
Li XB, 2013, MANAGE SCI, V59, P796, DOI 10.1287/mnsc.1120.1584
Li XB, 2011, INFORM SYST RES, V22, P774, DOI 10.1287/isre.1100.0289
Li XB, 2009, OPER RES, V57, P1496, DOI 10.1287/opre.1090.0702
LIEW CK, 1985, ACM T DATABASE SYST, V10, P395, DOI 10.1145/3979.4017
Machanavajjhala A., 2006, P INT C DAT ENG, V2006, P24, DOI DOI 10.1109/ICDE.2006.1
Madnick S.E., 2009, J DATA INFORM QUALIT, V1, P1, DOI DOI 10.1145/1515693.1516680
National Institutes of Health, 2003, NIH DAT SHAR POL IMP
National Science Foundation (NSF), 2011, DISS SHAR RES RES
Pipino L.L., 2002, COMMUN ACM, V45, P211, DOI DOI 10.1145/505248.506010
Rabeneck L, 2001, J CLIN EPIDEMIOL, V54, P1195, DOI 10.1016/S0895-4356(01)00397-3
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Sweeney L., 2000, LIDAPWP4 CARN MELL U
van Dam RM, 2006, DIABETES CARE, V29, P398, DOI 10.2337/diacare.29.02.06.dc05-1512
2002, FED REG, V67, P53181
NR 29
TC 3
Z9 3

```
U1 0
U2 0
PU ASSOC COMPUTING MACHINERY
PI NEW YORK
PA 2 PENN PLAZA, STE 701, NEW YORK, NY 10121-0701 USA
SN 1936-1955
J9 ACM J DATA INF QUAL
JI ACM J. Data Inf. Qual.
PD OCT
PY 2016
VL 7
IS 4
AR UNSP 17
DI 10.1145/2956554
PG 14
WC Computer Science, Information Systems
SC Computer Science
GA FF9JX
UT WOS:000409333700003
OA Green Accepted
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ER

PT J
AU Huda, S
   Fahmi, N
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   Al Rasyid, MUH
AF Huda, Samsul
   Fahmi, Nurul
   Sudarsono, Amang
   Al Rasyid, M. Udin Harun
TI SECURE DATA SENSOR SHARING ON UBIQUITOUS ENVIRONMENTAL HEALTH MONITORING
   APPLICATION
SO JURNAL TEKNOLOGI
LA English
DT Article
DE Secure data sensor; environmental health data center; access policy
AB In Internet of Things (IoT) era, The limitation storage on Wireless Sensor
Network (WSN) can be solved by synchronized data sensors from the gateway node
to the data center server. Data in the data center can be remotely accessed by
the user at any time and anywhere from end user devices such as PCs, laptop PCs,
and smart phones., and data should be accessed securely. The Only legitimated
user can access the data sensor from an environmental health data center. CP-ABE
(Ciphertext-Policy Attribute-Based Encryption) is becoming a robust
cryptographic scheme solution to this issue. To enable a secure data sensor
sharing and access on an environmental health data center, we propose a secure
system model using CP-ABE which ensures confidentiality, integrity, and user
privacy features. Experimental results prove that the implementation of CP-ABE
does not overload the system.
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FU Ministry of Research, Technology, and Higher Education of Indonesia,
   Insentif Riset SINAS Scheme [147/M/Kp/IV/2015]
FX This research was made possible through the help and support in part by
   Ministry of Research, Technology, and Higher Education of Indonesia,
   Insentif Riset SINAS Scheme, under Grant No. 147/M/Kp/IV/2015.
CR Al Rasyid MUH, 2015, SENSOR MATER, V27, P727
   Benthencourt J., 2015, CPABE TOOLKIT ADV CR
   Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
   Fabian B, 2015, INFORM SYST, V48, P132, DOI 10.1016/j.is.2014.05.004
   Fu Jingyi, 2014, [The Journal of China Universities of Posts and
Telecommunications, ‰∏≠ÂõΩÈÇÆÁîµÈ´òÊ†°Â≠¶Êä•], V21, P45
   Huda S, 2015, 2015 International Electronics Symposium (IES), P134, DOI
10.1109/ELECSYM.2015.7380829
   Liu JH, 2012, INT J SMART SENS INT, V5, P191
   Othman MF, 2012, PROCEDIA ENGINEER, V41, P1204, DOI
10.1016/j.proeng.2012.07.302
   Rong CM, 2012, CLOUD COMPUTING, P113
   Shucheng Y, 2010, P IEEE INFOCOM, P1, DOI DOI 10.1109/INFCOM.2010.5462174
   Sudarsono A, 2014, 2014 SECOND INTERNATIONAL SYMPOSIUM ON COMPUTING AND
NETWORKING (CANDAR), P536, DOI 10.1109/CANDAR.2014.34
   Topal M., 2015, LIBGCRYPT STANDALONE
   Tsai K.-L., 2014, J INTERNET SERV INF, V4, P47
NR 13
TC 3
Z9 3
U1 0
U2 0
PU PENERBIT UTM PRESS
PI JOHOR
PA PENERBIT UTM PRESS, SKUDAI, JOHOR, 81310, MALAYSIA
SN 0127-9696
EI 2180-3722
J9 J TEKNOL
JI J. Teknol.
PY 2016
VL 78
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WC Engineering, Multidisciplinary
SC Engineering
GA EG7FN
UT WOS:000391211800009
DA 2019-08-06
ER

PT J
AU Menditto, E
   De Gea, AB
   Cahir, C
   Marengoni, A
   Riegler, S
   Fico, G
   Costa, E
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AF Menditto, Enrica
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   Pecorelli, Sergio
   Pani, Luca
   Prados-Torres, Alexandra
TI Scaling up health knowledge at European level requires sharing
   integrated data: an approach for collection of database specification
SO CLINICOECONOMICS AND OUTCOMES RESEARCH
LA English
DT Article
DE health care databases; adherence; electronic health records; outcome
   research
ID CARE DATABASES; PHARMACOEPIDEMIOLOGY; PERSISTENCE; PREVALENCE;
   MEDICINES; OUTCOMES; COHORT; DRUG
AB Computerized health care databases have been widely described as an excellent
opportunity for research. The availability of "big data" has brought about a
wave of innovation in projects when conducting health services research. Most of
the available secondary data sources are restricted to the geographical scope of
a given country and present heterogeneous structure and content. Under the
umbrella of the European Innovation Partnership on Active and Healthy Ageing,
collaborative work conducted by the partners of the group on "adherence to
prescription and medical plans" identified the use of observational and large-
population databases to monitor medication-taking behavior in the elderly. This
article describes the methodology used to gather the information from available
databases among the Adherence Action Group partners with the aim of improving
data sharing on a European level. A total of six databases belonging to three
different European countries (Spain, Republic of Ireland, and Italy) were
included in the analysis. Preliminary results suggest that there are some
similarities. However, these results should be applied in different contexts and
European countries, supporting the idea that large European studies should be
designed in order to get the most of already available databases. Keywords:
health care databases, adherence, electronic health records, outcome research
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   Alessandro/0000-0002-9941-7003; Pani, Luca/0000-0001-9273-2839
CR Abbing-Karahagopian V, 2014, CURR CLIN PHARMACOL, V9, P130, DOI
10.2174/1574884708666131111211802
   Ayanian JZ, 1999, EUR HEART J, V20, P1689, DOI 10.1053/euhj.1999.1823
   Blake KV, BEHALF ENCEPP WORKIN
   Calderon-Larranaga A, 2015, EUR J INTERN MED, V26, P203, DOI
10.1016/j.ejim.2015.02.011
   Calderon-Larranaga A, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0084967
   Casula M, 2014, AM J MANAG CARE, V20, pE138
   Harpe SE, 2009, PHARMACOTHERAPY, V29, P138, DOI 10.1592/phco.29.2.138
   Hennessy S, 2006, BASIC CLIN PHARMACOL, V98, P311, DOI 10.1111/j.1742-
7843.2006.pto_368.x
   Iolascon G, 2013, AGING CLIN EXP RES, V25, pS137, DOI 10.1007/s40520-013-
0127-5
   Jutte DP, 2011, ANNU REV PUBL HEALTH, V32, P91, DOI 10.1146/annurev-
publhealth-031210-100700
   Jutte DP, ADM RECORD LINKAGE T
   Malter Frederic, 2013, FIELDWORK MONITORING
   Martin-Sanchez F, 2014, Yearb Med Inform, V9, P14, DOI 10.15265/IY-2014-0020
   Michelsen K, 2015, PROMOTING BETTER INT
   Moriarty F, 2015, EUR J CLIN PHARMACOL, V71, P473, DOI 10.1007/s00228-015-
1815-1
   Oliveira JL, 2013, PHARMACOEPIDEM DR S, V22, P459, DOI 10.1002/pds.3375
   Onder G, 2014, J GERONTOL A-BIOL, V69, P430, DOI 10.1093/gerona/glt118
   Riera-Guardia N, 2013, RTI PRESS PUBLICATIO, VRR-0019-1308
   Salisbury C, 2011, BRIT J GEN PRACT, V61, DOI 10.3399/bjgp11X548929
   Schneeweiss S, 2005, J CLIN EPIDEMIOL, V58, P323, DOI
10.1016/j.jclinepi.2004.10.012
   Trifiro G, 2014, J INTERN MED, V275, P551, DOI 10.1111/joim.12159
   Trifiro G, 2011, STUD HEALTH TECHNOL, V166, P25, DOI 10.3233/978-1-60750-740-
6-25
   Vayena E, 2015, PLOS COMPUT BIOL, V11, DOI 10.1371/journal.pcbi.1003904
   Wettermark B, 2013, EUR J CLIN PHARMACOL, V69, pS43, DOI 10.1007/s00228-013-
1496-6
NR 24
TC 3
Z9 3
U1 0
U2 3
PU DOVE MEDICAL PRESS LTD
PI ALBANY
PA PO BOX 300-008, ALBANY, AUCKLAND 0752, NEW ZEALAND
SN 1178-6981
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JI CLINICOECONOMICS OUTCOMES RES.
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EP 265
DI 10.2147/CEOR.S97548
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WC Health Care Sciences & Services
SC Health Care Sciences & Services
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PT J
AU Kendall, CE
   Younger, J
   Manuel, DG
   Hogg, W
   Glazier, RH
   Taljaard, M
AF Kendall, Claire E.
   Younger, Jaime
   Manuel, Douglas G.
   Hogg, William
   Glazier, Richard H.
   Taljaard, Monica
TI Health administrative data can be used to define a shared care typology
   for people with HIV
SO JOURNAL OF CLINICAL EPIDEMIOLOGY
LA English
DT Article
DE Human immunodeficiency virus; Primary health care; Chronic disease;
   Comorbidity; Health services delivery; Shared care; HIV/AIDS; Integrated
   care
ID INFECTIOUS-DISEASES SOCIETY; ANTIRETROVIRAL THERAPY; MEDICINE
   ASSOCIATION; PHYSICIAN; POPULATION; ONTARIO; AIDS; AGE; COMORBIDITY;
   SPECIALTY
AB Objectives: Building on an existing theoretical shared primary
care/specialist care framework to (1) develop a unique typology of care for
people living with human immunodeficiency virus (HIV) in Ontario, (2) assess
sensitivity of the typology by varying typology definitions, and (3) describe
characteristics of typology categories.
   Study Design and Setting: Retrospective population-based observational study
from April 1, 2009, to March 31, 2012. A total of 13,480 eligible patients with
HIV and receiving publicly funded health care in Ontario. We derived a typology
of care by linking patients to usual family physicians and to HIV specialists
with five possible patterns of care. Patient and physician characteristics and
outpatient visits for HIV-related and non-HIV-related care were used to assess
the robustness and characteristics of the typology.
   Results: Five possible patterns of care were described as low engagement
(8.6%), exclusively primary care (52.7%), family physician-dominated
comanagement (10.0%), specialist-dominated comanagement (30.5%), and exclusively
specialist care (5.2%). Sensitivity analyses demonstrated robustness of typology
assignments. Visit patterns varied in ways that conform to typology assignments.
   Conclusion: We anticipate this typology can be used to assess the impact of
care patterns on the quality of primary care for people living with HIV. (C)
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FU Ontario Ministry of Health and Long Term Care (MOHLTC); Institute for Clinical Evaluative Sciences (ICES) - MOHLTC; Canadian Institutes for Health Research (CIHR) Fellowship in the Area of Health Services/Population Health HIV/AIDS Research
FX This research was funded in part by the Ontario Ministry of Health and Long Term Care (MOHLTC). This study was supported by the Institute for Clinical Evaluative Sciences (ICES), which is funded by an annual grant from the MOHLTC. The opinions, results, and conclusions reported in this article are those of the authors and are independent from the funding sources. No endorsement by ICES or the Ontario MOHLTC is intended or should be inferred. C.E.K. holds a Canadian Institutes for Health Research (CIHR) Fellowship in the Area of Health Services/Population Health HIV/AIDS Research. R.H.G. is supported as a Clinician Scientist in the Department of Family and Community Medicine at the University of Toronto and at St. Michael's Hospital.
CR Aberg JA, 2014, CLIN INFECT DIS, V58, pE1, DOI 10.1093/cid/cit665
Antoniou T, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021748
Barnett ML, 2011, HEALTH SERV RES, V46, P1592, DOI 10.1111/j.1475-6773.2011.01262.x
Cahill S, 2010, GROWING OLDER EPIDEM, P56
Chen AH, 2009, ARCH INTERN MED, V169, P1024, DOI 10.1001/archinternmed.2009.140
Dombrowski JC, 2012, AIDS, V26, P77, DOI 10.1097/QAD.0b013e32834dcee9
Duffus WA, 2003, CLIN INFECT DIS, V36, P1577, DOI 10.1086/375070
Forrest CB, 2009, ARCH INTERN MED, V169, P1062, DOI 10.1001/archinternmed.2009.114
Fultz SL, 2005, CLIN INFECT DIS, V41, P738, DOI 10.1086/432621
Gallant JE, 2011, CLIN INFECT DIS, V53, P1043, DOI 10.1093/cid/cir689
Gershon AS, 2009, CAN RESPIR J, V16, P183, DOI 10.1155/2009/963098
Glazier RH, 2012, COMP PRIMARY CARE MO
Goulet JL, 2007, CLIN INFECT DIS, V45, P1593, DOI 10.1086/523577
Guaraldi G, 2011, CLIN INFECT DIS, V53, P1120, DOI 10.1093/cid/cir627
Haggerty J, 2007, ANN FAM MED, V5, P336, DOI 10.1370/afm.682
Handford CD, 2006, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD004348
Handford CD, 2012, AIDS CARE, V24, P267, DOI 10.1080/09540121.2011.608419
Hasse B, 2011, CLIN INFECT DIS, V53, P1130, DOI 10.1093/cid/cir626
Huntley AL, 2012, ANN FAM MED, V10, P134, DOI 10.1370/afm.1363
Hutchison B, 2013, HEALTH AFFAIR, V32, P695, DOI 10.1377/hlthaff.2012.1087
Hux JE, 2002, DIABETES CARE, V25, P512, DOI 10.2337/diacare.25.3.512
Iron Karey, 2011, Healthc Q, V14, P23
JAAKKIMAINEN L, 2006, PRIMARY CARE ONTARIO
Justice Amy C, 2010, Curr HIV/AIDS Rep, V7, P69, DOI 10.1007/s11904-010-0041-9

Katz A., 2013, UNDERSTANDING HLTH S
Kendall CE, 2006, CAN FAM PHYSICIAN, V52, P1449
Kendall CE, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-161
Kitahata MM, 2009, NEW ENGL J MED, V360, P1815, DOI 10.1056/NEJMoa0807252
Kitahata MM, 2003, J GEN INTERN MED, V18, P95, DOI 10.1046/j.1525-1497.2003.11049.x
Knottnerus JA, 2002, J CLIN EPIDEMIOL, V55, P1201, DOI 10.1016/S0895-4356(02)00528-0
Kralj B, 2000, ONTARIO MED REV, V67, P33
Krentz HB, 2011, HEALTH POLICY, V103, P124, DOI 10.1016/j.healthpol.2011.08.003
Lafata JE, 2001, MED CARE, V39, P491
Landon BE, 2003, J GEN INTERN MED, V18, P233, DOI 10.1046/j.1525-1497.2003.20705.x
Leece P, 2010, CAN FAM PHYSICIAN, V56, pE425
Maldonado V, 2012, STATE HIV PRIMARY CA
Muggah E, 2012, BMC HEALTH SERV RES, V12, DOI 10.1186/1472-6963-12-452
Page J, 2003, HIV Med, V4, P276, DOI 10.1046/j.1468-1293.2003.00157.x
Public Health Agency of Canada, 2010, HIV AIDS EP UPD NAT, P1
Rackal JM, 2011, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD003938.pub2
Rebeiro P, 2013, JAIDS-J ACQ IMM DEF, V62, P356, DOI 10.1097/QAI.0b013e31827f578a
Reinhold JP, 2005, AM J GASTROENTEROL, V100, P1805, DOI 10.1111/j.1572-0241.2005.50038.x
Remis RS, 2012, HIV AIDS ONTARIO PRE
Rodriguez HP, 2007, MED CARE, V45, P189, DOI 10.1097/01.mlr.0000250252.14148.7e
Sackoff JE, 2006, ANN INTERN MED, V145, P397, DOI 10.7326/0003-4819-145-6-200609190-00003
Sheth AN, 2006, AIDS PATIENT CARE ST, V20, P318, DOI 10.1089/apc.2006.20.318
Starfield B, 2005, MILBANK Q, V83, P457, DOI 10.1111/j.1468-0009.2005.00409.x
Steele LS, 2004, MED CARE, V42, P960, DOI 10.1097/00005650-200410000-00004
Stukel Therese A, 2013, Open Med, V7, pe40
Tu Karen, 2007, Open Med, V1, pe18
Tu LV, 1999, CAN MED ASSOC J, V161, P1257
Wilson IB, 2005, ANN INTERN MED, V143, P729, DOI 10.7326/0003-4819-143-10-200511150-00010
NR 52
TC 3
Z9 3
U1 0
U2 3
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0895-4356
EI 1878-5921
J9 J CLIN EPIDEMIOL
JI J. Clin. Epidemiol.
PD NOV
PY 2015
VL 68
IS 11
BP 1301
EP 1311
DI 10.1016/j.jclinepi.2015.02.008
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WC Health Care Sciences & Services; Public, Environmental & Occupational

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   Health
SC Health Care Sciences & Services; Public, Environmental & Occupational
   Health
GA CV9NC
UT WOS:000364612900007
PM 25835491
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PT J
AU Green, LA
   Klinkman, M
AF Green, Larry A.
   Klinkman, Michael
TI The Foundational and Urgent Importance of a Shared Primary Care Data
   Model
SO ANNALS OF FAMILY MEDICINE
LA English
DT Editorial Material
DE primary health care; community health services; health information
   technology; outcome and process assessment (health care); electronic
   health records; medical informatics; classification; population health;
   health data standards
ID MEDICAL-CARE; HEALTH; MULTIMORBIDITY; PROJECT; ECOLOGY; SUPPORT; SYSTEM
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CR Alper J., 2013, ROUNDTABLE VALUE SCI
   American Board of Medical Specialties, BETT PAT CAR IS BUIL
   [Anonymous], 2015, CONN HLTH CAR NAT SH
   Bodenheimer T, 2014, ANN FAM MED, V12, P166, DOI 10.1370/afm.1616
   Clinical and Translational Science Awards consortium, 2011, CTSA COMM ENG KEY
FU, V2nd
   Comm. Integr. Primary Care and Public Health Inst. Med., 2012, PRIM CAR PUBL
HLTH E
   Committee on Core Metrics for Better Health at Lower Cost, 2015, VIT SIGNS
COR METR H
   Committee on crossing the quality chasm, 2005, AD MENT HLTH ADD DIS
   Committee on Quality of Health Care in America and the Institute of Medicine,
2001, CROSS QUAL CHASM NEW
   Data for health advisory committee, 2015, DAT HLTH LEARN WHAT
   DeMaio S, 2015, SIMPLIFYING MOC FAMI
   Donaldson MS, 1996, PRIMARY CARE AM HLTH
   European Committee for Standardization (CEN). Health informatics, 2013, 251
CENTC
   Friedman D, 2002, 2002 NCHS DAT US C J
   Green LA, 2001, NEW ENGL J MED, V344, P2021, DOI 10.1056/NEJM200106283442611
   Grossman C, 2012, ROUNDTABLE VALUE SCI
   Haughey T., 2011, CONCEPTUAL DATA MODE
   Kanaan SB, 2011, COMMUNITY LEARNING S
   Klinkman MS., 2007, C HARM PRIM CAR CLIN, P55
   Kounalakis Dimitris K, 2003, J Med Syst, V27, P239, DOI
10.1023/A:1022571211109
   Krist AH, 2014, J AM MED INFORM ASSN, V21, P764, DOI 10.1136/amiajnl-2013-
002229
   Laux G, 2008, BMC HEALTH SERV RES, V8, DOI 10.1186/1472-6963-8-14
```

```
   Lesko S, 2012, ANN FAM MED, V10, P250, DOI 10.1370/afm.1350
   *NAT COMM COMM HLT, 1966, HLTH COMM AFF
   O'Malley AS, 2015, J AM MED INFORM ASSN, V22, P426, DOI 10.1093/jamia/ocu029
   OConnell ME, 2009, PREVENTING MENTAL, EMOTIONAL, AND BEHAVIORAL DISORDERS
AMONG YOUNG PEOPLE: PROGRESS AND POSSIBILITIES, P1
   Olsen LA, 2007, LEARNING HEALTHCARE
   Phillips Jr RL, 2007, C HARM PRIM CAR CLIN
   Phillips RL, 2014, ANN FAM MED, V12, pS1, DOI 10.1370/afm.1699
   Phillips RL, 2010, HEALTH AFFAIR, V29, P806, DOI 10.1377/hlthaff.2010.0020
   Rizza A, 2012, BMC FAM PRACT, V13, DOI 10.1186/1471-2296-13-113
   Shi L, 2012, SCI CAIRO, V2012, DOI DOI 10.6064/2012/432892
   Soler Jean K, 2012, Inform Prim Care, V20, P25
   Stange KC, 2009, ANN FAM MED, V7, P387
   Stange KC, 2009, ANN FAM MED, V7, P484, DOI 10.1370/afm.1032
   Stange KC, 2009, ANN FAM MED, V7, P387, DOI 10.1370/afm.990
   Stange KC, 2009, ANN FAM MED, V7, P293, DOI 10.1370/afm.1023
   Stange KC, 2009, ANN FAM MED, V7, P100, DOI 10.1370/afm.971
   Stange KC, 2009, ANN FAM MED, V7, P198, DOI 10.1370/afm.1003
   Starfield B, 2005, MILBANK Q, V83, P457, DOI 10.1111/j.1468-0009.2005.00409.x
   Stevens Rosemary, 1998, AM MED PUBLIC INTERE
   The Office of the National Coordinator for Health Information Technology,
2014, CONN HLTH CAR NAT 10
   Wachter RM, NY TIMES
   WHITE KL, 1961, NEW ENGL J MED, V265, P885, DOI 10.1056/NEJM196111022651805
   Wonca International Classification Committee, 2014, 2014 ANN M DOC
   Woolf SH, 2015, US HLTH INT PERSPECT
   Young RA, 2012, ANN FAM MED, V10, P156, DOI 10.1370/afm.1348
NR 47
TC 3
Z9 3
U1 1
U2 10
PU ANNALS FAMILY MEDICINE
PI LEAWOOD
PA 11400 TOMAHAWK CREEK PARKWAY, LEAWOOD, KS 66211-2672 USA
SN 1544-1709
EI 1544-1717
J9 ANN FAM MED
JI Ann. Fam. Med.
PD JUL-AUG
PY 2015
VL 13
IS 4
BP 303
EP 311
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WC Primary Health Care; Medicine, General & Internal
SC General & Internal Medicine
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PT J
AU Longstaff, H
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Khramova, V
Portales-Casamar, E
Illes, J

AF Longstaff, Holly
Khramova, Vera
Portales-Casamar, Elodie
Illes, Judy

TI Sharing with More Caring: Coordinating and Improving the Ethical Governance of Data and Biomaterials Obtained from Children

SO PLOS ONE

LA English

DT Article

ID INCIDENTAL FINDINGS; GENOMIC RESEARCH; LEGAL; PARTICIPANTS; BIOBANKS; ERA; DNA

AB Introduction

Research on complex health conditions such as neurodevelopmental disorders increasingly relies on large-scale research and clinical studies that would benefit from data sharing initiatives. Organizations that share data stand to maximize the efficiency of invested research dollars, expedite research findings, minimize the burden on the patient community, and increase citation rates of publications associated with the data.

Objective

This study examined ethics and governance information on websites of databases involving neurodevelopmental disorders to determine the availability of information on key factors crucial for comprehension of, and trust and participation in such initiatives.

Methods

We identified relevant databases identified using online keyword searches. Two researchers reviewed each of the websites and identified thematic content using principles from grounded theory. The content for each organization was interrogated using the gap analysis method.

Results

Sixteen websites from data sharing organizations met our inclusion criteria. Information about types of data and tissues stored, data access requirements and procedures, and protections for confidentiality were significantly addressed by data sharing organizations. However, special considerations for minors (absent from 63%), controls to check if data and tissues are being submitted (absent from 81%), disaster recovery plans (absent from 81%), and discussions of incidental findings (absent from 88%) emerged as major gaps in thematic website content. When present, content pertaining to special considerations for youth, along with other ethics guidelines and requirements, were scattered throughout the websites or available only from associated documents accessed through live links.

Conclusion

The complexities of sharing data acquired from children and adolescents will only increase with advances in genomic and neuro science. Our findings suggest that there is a need to improve the consistency, depth and accessibility of governance and policies on which these collaborations can lean specifically for vulnerable young populations.

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CR [Anonymous], 2014, PRES COMM STUD BIOET
[Anonymous], 2014, PAN RES ETH
Becker Cinda, 2006, Mod Healthc, V36, P6
Bryman Alan, 1994, ANAL QUALITATIVE DAT
Cambon-Thomsen A, 2007, EUR RESPIR J, V30, P373, DOI 10.1183/09031936.00165006
Charmaz K, 2014, CONSTRUCTING GROUNDE, P109
Folstein SE, 2001, NAT REV GENET, V2, P943, DOI 10.1038/35103559
Foster MW, 2007, NAT REV GENET, V8, P633, DOI 10.1038/nrg2124
Gledhill J., 2011, HABERMAS RAWLS DISPU, P181
Green RC, 2013, GENET MED, V15, P565, DOI 10.1038/gim.2013.73
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Haynes CL, 2007, J MED ETHICS, V33, P302, DOI 10.1136/jme.2006.016907
Hogan DB, 2013, CAN J NEUROL SCI, V40, pS5, DOI 10.1017/S0317167100017108
Institute of Medicine (IOM), 2014, DIS FRAM CLIN TRAIL
Jiang XQ, 2013, MED CARE, V51, pS58, DOI 10.1097/MLR.0b013e31829b1d10
Kodituwakku PW, 2009, DEV DISABIL RES REV, V15, P218, DOI 10.1002/ddrr.73
Kopelman LM, 2006, MT SINAI J MED, V73, P596
Kosseim P, 2014, 4 INT SEM UBES UNPUB
Longstaff H, 2013, CELL STEM CELL, V12, P517, DOI 10.1016/j.stem.2013.04.016
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
O'Brien SJ, 2009, ANNU REV GENOM HUM G, V10, P193, DOI 10.1146/annurev-genom-082908-150133
Olesen V., 1994, ANAL QUALITATIVE DAT
Peakman T, 2010, GENOME MED, V2, DOI 10.1186/gm193
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Sherwin S, 2001, CBAC COMMISSIONED PA
Sherwin S., 1992, NO LONGER PATIENT FE
Shevell MI, 2003, PEDIATR NEUROL, V28, P352, DOI 10.1016/S0887-8994(03)00006-7
SMITH GD, 1994, BRIT MED J, V308, P1519, DOI 10.1136/bmj.308.6943.1519
Strauss A, 1990, BASICS QUALITATIVE R
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
Van Hecke A, 2008, J EVAL CLIN PRACT, V14, P812, DOI 10.1111/j.1365-2753.2007.00846.x
Waitzkin H., 1991, POLITICS MED ENCOUNT
Wilfond BS, 2008, J LAW MED ETHICS, V36, P332, DOI 10.1111/j.1748-720X.2008.00277.x
Wolf SM, 2012, GENET MED, V14, P361, DOI 10.1038/gim.2012.23
NR 36
TC 3
Z9 3
U1 0
U2 13
PU PUBLIC LIBRARY SCIENCE
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PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
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JI PLoS One

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SC Science & Technology - Other Topics
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PT J
AU Calhoun, VD
AF Calhoun, Vince D.
TI A spectrum of sharing: maximization of information content for brain
   imaging data
SO GIGASCIENCE
LA English
DT Review
DE Data sharing; Privacy; Classification; Multivariate; Neuroinformatics;
   Deep learning; Independent component analysis
ID ELECTRONIC DATA CAPTURE; COMMON DATA ELEMENTS; HEALTH RECORDS;
   FUNCTIONAL CONNECTIVITY; DE-IDENTIFICATION; FMRI DATA; NETWORKS; MRI
AB Efforts to expand sharing of neuroimaging data have been growing
exponentially in recent years. There are several different types of data sharing
which can be considered to fall along a spectrum, ranging from simpler and less
informative to more complex and more informative. In this paper we consider this
spectrum for three domains: data capture, data density, and data analysis. Here
the focus is on the right end of the spectrum, that is, how to maximize the
information content while addressing the challenges. A summary of associated
challenges of and possible solutions is presented in this review and includes: 1)
a discussion of tools to monitor quality of data as it is collected and
encourage adoption of data mapping standards; 2) sharing of time-series data
( not just summary maps or regions); and 3) the use of analytic approaches which
maximize sharing potential as much as possible. Examples of existing solutions
for each of these points, which we developed in our lab, are also discussed
including the use of a comprehensive beginning-to-end neuroinformatics platform
and the use of flexible analytic approaches, such as independent component
analysis and multivariate classification approaches, such as deep learning.
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CR Allen E, 2011, FRONTIERS SYSTEMS NE, V5, P12
   Buccigrossi Robert, 2008, AMIA Annu Symp Proc, P1000
   Calhoun VD, 2014, NEURON, V84, P262, DOI 10.1016/j.neuron.2014.10.015
```

Calhoun VD, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0073309
Calhoun VD, 2013, PSYCHOMETRIKA, V78, P243, DOI 10.1007/s11336-012-9291-3
Calhoun Vince D, 2012, IEEE Rev Biomed Eng, V5, P60, DOI 10.1109/RBME.2012.2211076
Calhoun VD, 2009, IEEE T INF TECHNOL B, V13, P711, DOI 10.1109/TITB.2008.923773
Cassa CA, 2008, INT J HEALTH GEOGR, V7, DOI 10.1186/1476-072X-7-45
Chaudhuri K, 2011, J MACH LEARN RES, V12, P1069
Craddock RC, 2013, NAT METHODS, V10, P524, DOI [10.1038/NMETH.2482, 10.1038/nmeth.2482]
Da Mota B, 2014, FRONT NEUROINFORM, V8, DOI 10.3389/fninf.2014.00031
Damaraju E, 2014, NEUROIMAGE-CLIN, V5, P298, DOI 10.1016/j.nicl.2014.07.003
Dillon DG, 2014, J CLIN EPIDEMIOL, V67, P1358, DOI 10.1016/j.jclinepi.2014.06.012
Dinov I, 2010, PLOS ONE, V5, DOI 10.1371/journal.pone.0013070
El Emam K, 2011, GENOME MED, V3, DOI 10.1186/gm239
Erhardt EB, 2011, BRAIN CONNECT, V1, P105, DOI 10.1089/brain.2011.0022
Fraccaro P, 2013, INFORM HEALTH SOC CA, V38, P313, DOI 10.3109/17538157.2013.812648
Ghitza UE, 2013, ADDICTION, V108, P3, DOI 10.1111/j.1360-0443.2012.03876.x
Grove MJ, 2013, STUD HEALTH TECHNOL, V192, P1186, DOI 10.3233/978-1-61499-289-9-1186
Hall D, 2012, NEUROINFORMATICS, V10, P331, DOI 10.1007/s12021-012-9151-4
Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
Hjelm D, NEUROIMAGE IN PRESS
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Jack CR, 2008, J MAGN RESON IMAGING, V27, P685, DOI 10.1002/jmri.21049
Jafri MJ, 2008, NEUROIMAGE, V39, P1666, DOI 10.1016/j.neuroimage.2007.11.001
King C, 2014, GLOBAL HEALTH ACTION, V7, DOI 10.3402/gha.v7.25878
King M, FRONT NEURO IN PRESS
Laird AR, 2009, J NEUROSCI, V29, P14496, DOI 10.1523/JNEUROSCI.4004-09.2009
Loring DW, 2011, EPILEPSIA, V52, P1186, DOI 10.1111/j.1528-1167.2011.03018.x
Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
Marcus Daniel S, 2011, Front Neuroinform, V5, P4, DOI 10.3389/fninf.2011.00004
McGarvey PB, 2012, J AM MED INFORM ASSN, V19, pE125, DOI 10.1136/amiajnl-2011-000546
Mennes M, 2013, NEUROIMAGE, V82, P683, DOI 10.1016/j.neuroimage.2012.10.064
Milham MP, 2012, NEURON, V73, P214, DOI 10.1016/j.neuron.2011.11.004
Mitchel JT, 2011, DRUG INF J, V45, P421, DOI 10.1177/009286151104500404
Moeller S, 2010, MAGN RESON MED, V63, P1144, DOI 10.1002/mrm.22361
Murtagh MJ, 2012, PUBLIC HEALTH GENOM, V15, P243, DOI 10.1159/000336673
Neamatullah I, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-32
Obeid Jihad S, 2013, AMIA Jt Summits Transl Sci Proc, V2013, P189
Obeid JS, 2013, J BIOMED INFORM, V46, P259, DOI 10.1016/j.jbi.2012.10.006
Plis SM, FRONTIERS B IN PRESS
Poldrack RA, 2013, FRONT NEUROINFORM, V7, DOI 10.3389/fninf.2013.00012
Poline JB, 2012, FRONT NEUROINFORM, V6, DOI 10.3389/fninf.2012.00009
Potkin SG, 2009, SCHIZOPHRENIA BULL, V35, P19, DOI 10.1093/schbul/sbn162
Potluru V, 2014, NEURAL INFORM PROCES
Sarwate AD, FRONTIERS N IN PRESS
Scott A., 2011, FRONT NEUROINFORM, V5, P1, DOI [10.3389/fninf.2011.00033, DOI 10.3389/FNINF.2011.00033]
Sui J, 2012, J NEUROSCI METH, V204, P68, DOI 10.1016/j.jneumeth.2011.10.031
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI 10.1142/S0218488502001648
Thompson PM, 2014, BRAIN IMAGING BEHAV, V8, P153, DOI 10.1007/s11682-013-9269-5

```
   Turner JA, 2012, NEUROINFORMATICS, V10, P57, DOI 10.1007/s12021-011-9126-x
   Ugurbil K, 2013, NEUROIMAGE, V80, P80, DOI 10.1016/j.neuroimage.2013.05.012
   Van Dijk KRA, 2010, J NEUROPHYSIOL, V103, P297, DOI 10.1152/jn.00783.2009
   Van Essen DC, 2013, NEUROIMAGE, V80, P62, DOI
10.1016/j.neuroimage.2013.05.041
   Van Horn JD, 2002, NAT REV NEUROSCI, V3, P314, DOI 10.1038/nrn788
   Van Horn JD, 2001, PHILOS T R SOC B, V356, P1323, DOI 10.1098/rstb.2001.0916
   Van Horn JD, 2009, CURR OPIN NEUROL, V22, P370, DOI
[10.1097/WCO.0b013e32832dg2de, 10.1097/WCO.0b013e32832d92de]
   Warner J, 2013, CAN J NEUROL SCI, V40, pS62, DOI 10.1017/S0317167100017212
   Wood D, FRONT NEURO IN PRESS
   Zuo XN, SCI DATA IN PRESS
NR 60
TC 3
Z9 3
U1 0
U2 13
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
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JI GigaScience
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   Takizawa, M
   Xhafa, F
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   Park, JH
TI Secure and Efficient Mobile Personal Health Data Sharing in Resource
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SO 2015 IEEE 29TH INTERNATIONAL CONFERENCE ON ADVANCED INFORMATION
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LA English
DT Proceedings Paper
CT IEEE 29th International Conference on Advanced Information Networking
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CL Gwangju, SOUTH KOREA
SP IEEE Tech Comm Distributed Proc TCDP, FTRA, Gwangju Convention & Visitors Bureau, KIPS

AB Personal health record (PHR) systems are widely used in the developed world, but little has been done to explore the utility of these PHR systems in the developing world. A key reason for this is that many developing world areas suffer from technological impediments resulting from poor infrastructure, low literacy, intermittent power connectivity, and unstable bandwidth connectivity. In technological resource constrained environments such as these, deploying standard PHR systems is challenging. Therefore PHR systems need to be redesigned for usability and reliability in resource constrained scenarios. Additionally, the inherent privacy and security sensitivity of healthcare data makes re-designing the PHR systems to take into account the security and privacy requirements, a necessity. The goal is to opt for security mechanisms that offer the same levels of security as is the case in the standard PHR systems that are used in the developed world, but that are also lightweight in terms of performance and storage overhead. In this paper, based on the observation that mobile phone use is widely proliferated in developing countries, we propose an access control framework supported by identity-based encryption for a secure Mobile-PHR system. Results from our prototype evaluation (laboratory and field studies) indicate that the proposed IBE scheme effectively secures PHRs beyond the healthcare provider's security domain and is efficient performance-wise.

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CR Abdalla M, 2005, LECT NOTES COMPUT SC, V3376, P191
Adida Ben, 2010, AMIA Annu Symp Proc, V2010, P6
Anokwa Y., 2008, DEPLOYING MED RECORD
Anokwa Y., 2012, P 5 INT C INF COMM T, P13, DOI DOI 10.1145/2160673.2160676
Avancha S, 2012, ACM COMPUT SURV, V45, DOI 10.1145/2379776.2379779
Blake L.F., 1999, ELLIPTIC CURVES CRYP, V265
Boneh D., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P213
Braa J., 2003, WITFOR 2003 WHITE BO
Cocks C., 2001, LNCS, V2260, P360, DOI DOI 10.1007/3-540-45325-3_32
Dmitrienko A., 2013, BIOMEDICAL ENG SYSTE, P365, DOI DOI 10.1007/978-3-642-29752-6_27
Dmitrienko A, 2011, HEALTHINF 2011: PROCEEDINGS OF THE INTERNATIONAL CONFERENCE ON HEALTH INFORMATICS, P87
Ekler P, 2008, CONSUM COMM NETWORK, P1154, DOI 10.1109/ccnc08.2007.259
Harrison JP, 2006, NURS ECON, V24, P283
Hoxmeier J.A., 2000, P ASS INF SYST AM C, P140
International Telecommunication Union, 2013, FACTS FIG
Kaliski B., 2000, PKCS 5 PASSWORD BASE
Kwankam SY, 2004, B WORLD HEALTH ORGAN, V82, P800
Luk Rowena, 2009, Proceedings of the 2009 International Conference on Information and Communication Technologies and Development (ICTD 2009), P118, DOI 10.1109/ICTD.2009.5426714
Nielsen J, 1999, COMMUN ACM, V42, P65, DOI 10.1145/291469.291470
Rashid AT, 2009, ELECTR J INF SYS DEV, V36
RIVEST RL, 1978, COMMUN ACM, V21, P120, DOI 10.1145/359340.359342
Robison J., 2012, 2012 IEEE 14th International Conference on e-Health Networking, Applications and Services (Healthcom 2012), P184, DOI 10.1109/HealthCom.2012.6379393

Shamir A., 1984, LNCS, P47, DOI [DOI 10.1007/3-540-39568-7, 10.1007/3-540-39568-7_5]
Sood S.P., 2008, HAW INT C SYST SCI P, P248
*WHO, 2005, KNOWL MAN STRAT
Zheng Y, 2011, THESIS
NR 26
TC 3
Z9 3
U1 0
U2 1
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-4799-1775-4
PY 2015
BP 411
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DI 10.1109/WAINA.2015.113
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Batista, P
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TI Managing and Sharing Health Data through Information Accountability Protocols
SO 2015 17TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATION & SERVICES (HEALTHCOM)
LA English
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CT 17th International Conference on E-health Networking, Application & Services (HealthCom)
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CL Boston, MA
DE Access Control; electronic health records; EHR; eHealth; privacy; security
ID CARE
AB Concerns over the security and privacy of patient information are one of the biggest hindrances to sharing health information and the wide adoption of eHealth systems. At present, there are competing requirements between healthcare consumers' (i.e. patients) requirements and healthcare professionals' (HCP) requirements. While consumers want control over their information, healthcare professionals want access to as much information as required in order to make well informed decisions and provide quality care. In order to balance these

requirements, the use of an Information Accountability Framework devised for
eHealth systems has been proposed. In this paper, we take a step closer to the
adoption of the Information Accountability protocols and demonstrate their
functionality through an implementation in FluxMED, a customisable EHR system.
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CR Aldeco-Perez R., 2008, INT AC RES C VIS COM
   Appari Ajit, 2010, International Journal of Internet and Enterprise
Management, V6, P279, DOI 10.1504/IJIEM.2010.035624
   Asabi S., 2013, COMPUSOFT, V2, P65
   Boyd J., 2003, ACCOUNTABILITY, V69
   Department of Health, 2014, PERS CONTR EL HLTH R
   Faria-Campos AC, 2014, LECT N BIOINFORMAT, V8826, P33, DOI 10.1007/978-3-319-12418-6_5
   Feigenbaum J., 2011, P 3 INT C WEB SCI
   Feigenbaum J, 2011, PROCEEDINGS OF THE 2011 NEW SECURITY PARADIGMS WORKSHOP
(NSPW'11), P45
   Gajanayake R, 2011, IEEE INTERNET COMPUT, V15, P31, DOI 10.1109/MIC.2011.51
   Grunwell D., 2015, 8 AUSTR WORKSH HLTH, P33
   Grunwell D., 2013, E HLTH TECHNICAL COM, V2, P3
   Grunwell D, 2014, IEEE ICC, P4258, DOI 10.1109/ICC.2014.6883989
   Lana-Peixoto MA, 2011, ARQ NEURO-PSIQUIAT, V69, P687, DOI 10.1590/S0004-282X2011000500021
   Privacy Rights Clearinghouse, CHRON DAT BREACH
   Sahama T., 2013, 15 INT C E IN PRESS
   Sim KS, 2014, SPRINGERPLUS, V3, DOI 10.1186/2193-1801-3-268
   Tierney WM, 2015, J GEN INTERN MED, V30, pS31, DOI 10.1007/s11606-014-3053-0
   Weitzner DJ, 2008, COMMUN ACM, V51, P82, DOI 10.1145/1349026.1349043
NR 18
TC 3
Z9 3
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
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PT J
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   Sacchi, L

Rubrichi, S
Mazzanti, A
Quaglini, S
AF Parimbelli, E.
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Rubrichi, S.
Mazzanti, A.
Quaglini, S.
TI UceWeb: a Web-based Collaborative Tool for Collecting and Sharing
Quality of Life Data
SO METHODS OF INFORMATION IN MEDICINE
LA English
DT Article
DE Utility elicitation; quality of life; web-application; collaborative
platform; repository
ID UTILITY ELICITATION; HEALTH; QALYS
AB Objectives: This work aims at building a platform where quality-of-life data, namely utility coefficients, can be elicited not only for immediate use, but also systematically stored together with patient profiles to build a public repository to be further exploited in studies on specific target populations (e.g. cost/utility analyses).

Methods: We capitalized on utility theory and previous experience to define a set of desirable features such a tool should show to facilitate sound elicitation of quality of life. A set of visualization tools and algorithms has been developed to this purpose. To make it easily accessible for potential users, the software has been designed as a web application. A pilot validation study has been performed on 20 atrial fibrillation patients.

Results: A collaborative platform, UceWeb, has been developed and tested. It implements the standard gamble, time trade-off and rating-scale utility elicitation methods. It allows doctors and patients to choose the mode of interaction to maximize patients' comfort in answering difficult questions. Every utility elicitation may contribute to the growth of the repository.

Conclusion: UceWeb can become a unique source of data allowing researchers both to perform more reliable comparisons among healthcare interventions and build statistical models to gain deeper insight into quality of life data.

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CR Ancker JS, 2006, J AM MED INFORM ASSN, V13, P608, DOI 10.1197/jamia.M2115
Ancker JS, 2011, MED DECIS MAKING, V31, P143, DOI 10.1177/0272989X10369006
Bayoumi A, 2004, ANN M SOC MED DEC MA
Blumenschein K, 1998, HEALTH POLICY, V45, P187, DOI 10.1016/S0168-8510(98)00041-4
Cormen T. H., 2001, INTRO ALGORITHMS
FRYBACK DG, 1993, MED DECIS MAKING, V13, P89, DOI 10.1177/0272989X9301300202
GAFNI A, 1994, HEALTH SERV RES, V29, P207
Garber AM, 2005, P AM MED INF ASS ANN

```
   Gerzeli S, 2012, CLIN DRUG INVEST, V32, P253, DOI 10.2165/11598940-000000000-
00000
   Gold MR, 2002, ANNU REV PUBL HEALTH, V23, P115, DOI
10.1146/annurev.publhealth.23.100901.140513
   Iida N, 2000, METHOD INFORM MED, V39, P213
   Kind P, 2009, VALUE HEALTH, V12, pS27, DOI 10.1111/j.1524-4733.2009.00519.x
   Lenert LA, 2002, MED DECIS MAKING, V22, P464, DOI 10.1177/0272989X02238296
   Li I, CHI 12 HUM FACT
   Maly M, 2006, METHOD INFORM MED, V45, P211
   Morimoto Takeshi, 2002, J Epidemiol, V12, P160
   Prosser LA, 2012, PHARMACOECONOMICS, V30, P83, DOI 10.2165/11597720-
000000000-00000
   Reed Johnson F, 2009, VALUE HLTH S1, V12, pS27
   Ryan Mandy, 2003, Expert Rev Pharmacoecon Outcomes Res, V3, P717, DOI
10.1586/14737167.3.6.717
   Ryder Hilary F, 2009, Semin Spine Surg, V21, P216
   Sacchi L, 2013, P 14 C ART INT MED M
   Spertus J, 2011, CIRC-ARRHYTHMIA ELEC, V4, P15, DOI 10.1161/CIRCEP.110.958033
   Sumner W, 1991, P 15 ANN S COMP APPL, P710
   Torrance GW, 2001, MED DECIS MAKING, V21, P329, DOI 10.1177/02729890122062622
   Von Neumann J., 1947, THEORY GAMES EC BEHA
   2000, FED REG, V65, P82462
NR 26
TC 3
Z9 3
U1 1
U2 4
PU SCHATTAUER GMBH-VERLAG MEDIZIN NATURWISSENSCHAFTEN
PI STUTTGART
PA HOLDERLINSTRASSE 3, D-70174 STUTTGART, GERMANY
SN 0026-1270
J9 METHOD INFORM MED
JI Methods Inf. Med.
PY 2015
VL 54
IS 2
BP 156
EP 163
DI 10.3414/ME14-01-0021
PG 8
WC Computer Science, Information Systems; Health Care Sciences & Services;
   Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA CE4MF
UT WOS:000351804000007
PM 25362865
DA 2019-08-06
ER

PT J
AU Weigmann, K
AF Weigmann, Katrin
TI Health research 2.0 : The use in research of personal fitness or health
   data shared on social network raises both scientific and ethical
   concerns
SO EMBO REPORTS
LA English
DT Editorial Material
```

```
AB Social networking on the Internet empowers patients to discuss their
illnesses and access a bonanza of health information. However, research using
the personal data shared on these networks raises important ethical and
statistical questions.image
CR Do CB, 2011, PLOS GENET, V7
   Fornai F, 2008, P NATL ACAD SCI USA, V105, P2052, DOI 10.1073/pnas.0708022105
   Gibson G, 2010, PLOS GENET, V6
   Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
   Hayden EC, 2012, NATURE, V486, P312, DOI 10.1038/486312a
   Hood L, 2011, NAT REV CLIN ONCOL, V8, P184, DOI 10.1038/nrclinonc.2010.227
   Howard HC, 2010, EMBO REP, V11, P579, DOI 10.1038/embor.2010.105
   Janssens ACJW, 2012, PLOS MED, V9
   Prainsack B, 2011, ACCOUNT RES, V18, P132, DOI 10.1080/08989621.2011.575032
   Sterckx S, 2012, GENET MED, V15, P382
   Swan M, 2012, J MED INTERNET RES, V14, DOI 10.2196/jmir.1988
   Wicks P, 2011, NAT BIOTECHNOL, V29, P411, DOI 10.1038/nbt.1837
NR 12
TC 3
Z9 3
U1 0
U2 6
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1469-221X
EI 1469-3178
J9 EMBO REP
JI EMBO Rep.
PD MAR
PY 2014
VL 15
IS 3
BP 223
EP 226
DI 10.1002/embr.201438510
PG 4
WC Biochemistry & Molecular Biology; Cell Biology
SC Biochemistry & Molecular Biology; Cell Biology
GA AC3BO
UT WOS:000332390200010
PM 24517912
OA Green Published, Bronze
DA 2019-08-06
ER

PT J
AU Greene, J
AF Greene, Jan
TI Behavioral Health Data in the Electronic Health Record Privacy Concerns
   Slow Sharing
SO ANNALS OF EMERGENCY MEDICINE
LA English
DT Editorial Material
ID INFORMATION EXCHANGE
CR Bailey JE, 2013, ANN EMERG MED, V62, P16, DOI
10.1016/j.annemergmed.2013.01.006
   Halamka JD, 2013, ANN EMERG MED, V62, P25, DOI
10.1016/j.annemergmed.2013.05.009
```

```
   Kozubal DE, 2013, INT J MED INFORM, V82, P260, DOI
10.1016/j.ijmedinf.2012.11.007
   Robert Wood Johnson Foundation, 2013, HLTH INF TECHN UN ST
NR 4
TC 3
Z9 3
U1 0
U2 10
PU MOSBY-ELSEVIER
PI NEW YORK
PA 360 PARK AVENUE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0196-0644
EI 1097-6760
J9 ANN EMERG MED
JI Ann. Emerg. Med.
PD OCT
PY 2013
VL 62
IS 4
BP 19A
EP 21A
DI 10.1016/j.annemergmed.2013.08.003
PG 3
WC Emergency Medicine
SC Emergency Medicine
GA 229ZZ
UT WOS:000325307700001
PM 24180009
DA 2019-08-06
ER

PT J
AU Fikse, WF
   Malm, S
   Lewis, TW
AF Fikse, W. F.
   Malm, S.
   Lewis, T. W.
TI Opportunities for international collaboration in dog breeding from the
   sharing of pedigree and health data
SO VETERINARY JOURNAL
LA English
DT Article
DE Canine; Hip dysplasia; Scoring scheme; Genetic correlation; Breeding
   values
ID ELBOW DYSPLASIA; GENETIC TRENDS; HIP
AB Pooling of pedigree and phenotype data from different countries may improve
the accuracy of derived indicators of both genetic diversity and genetic merit
of traits of interest. This study demonstrates significant migration of
individuals of four pedigree dog breeds between Sweden and the United Kingdom.
Correlations of estimates of genetic merit (estimated breeding values, EBVs) for
the Federation Cynologique Internationale and the British Veterinary Association
and Kennel Club evaluations of hip dysplasia (HD) were strong and favourable,
indicating that both scoring schemes capture substantially the same genetic
trait. Therefore pooled use of phenotypic data on hip dysplasia would be
expected to improve the accuracy of EBV for HD in both countries due to
increased sample data. (C) 2013 Published by Elsevier Ltd.
C1 [Fikse, W. F.] SLU, Dept Anim Breeding & Genet, Uppsala, Sweden.
```

[Malm, S.] Swedish Kennel Club, Spanga, Sweden.
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FU Kennel Club Charitable Trust
FX The authors are grateful to all those involved in the gathering of hip
score data and to the Swedish and UK Kennel Clubs for providing pedigree
data. TWL gratefully acknowledges funding from the Kennel Club
Charitable Trust.
CR BLANCHARD PJ, 1983, J DAIRY SCI, V66, P1947, DOI 10.3168/jds.S0022-0302(83)82033-5
Efron B., 1993, INTRO BOOTSTRAP
Hedhammar AA, 2011, VET J, V189, P189, DOI 10.1016/j.tvjl.2011.06.018
Jamrozik J, 2000, LIVEST PROD SCI, V66, P85, DOI 10.1016/S0301-6226(00)00158-5
Lewis T. W., 2010, PLOS ONE, V5
Malm S, 2008, J ANIM BREED GENET, V125, P403, DOI 10.1111/j.1439-0388.2008.00725.x
Wilson BJ, 2012, MAMM GENOME, V23, P195, DOI 10.1007/s00335-011-9366-y
Woolliams JA, 2011, VET J, V189, P169, DOI 10.1016/j.tvjl.2011.06.015
NR 8
TC 3
Z9 3
U1 0
U2 22
PU ELSEVIER SCI LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, OXON, ENGLAND
SN 1090-0233
EI 1532-2971
J9 VET J
JI Vet. J.
PD SEP
PY 2013
VL 197
IS 3
BP 873
EP 875
DI 10.1016/j.tvjl.2013.04.025
PG 3
WC Veterinary Sciences
SC Veterinary Sciences
GA 248BB
UT WOS:000326667600060
PM 23932651
DA 2019-08-06
ER

PT J
AU Vest, JR
Issel, LM
AF Vest, Joshua R.
Issel, L. Michele
TI Data Sharing Between Local Health and State Health Departments:
Developing and Describing a Typology of Data Gaps
SO JOURNAL OF PUBLIC HEALTH MANAGEMENT AND PRACTICE

LA English
DT Article
DE computer communication networks; information systems; public health informatics; public health practice; organization and administration
ID PUBLIC-HEALTH; INFORMATION-SYSTEM; NETWORKS

AB Context: Local health departments (LHDs) and state health agencies (SHAs) require quantitative data to fulfill their obligation to ensure public health. However, data collection and sharing are not straightforward processes in the US public health system. Responsibilities are divided among many actors, jurisdictions overlap, events that can occur elsewhere, and not every public health agency possesses information systems capable of sharing data. Collectively, these characteristics define a system that likely has gaps in data sharing among public health entities. Objective: A data-sharing gap is the inability to transmit, in near real time, data among public health agencies within a state for a specific public health activity. This article presents theoretically and empirically based typology of data-sharing gaps between LHDs and SHAs and describes the extent of data-sharing types for 6 activities. Design, Setting and Main Outcome: Drawing on concepts from network theory, public health responsibilities, and technological capacity, we conceptualize a 9-category data-sharing typology that characterizes the flow of data between SHAs and LHDs. Using existing organizational surveys, we created a sample of LHD-SHA exchange dyads, which we use to describe the distribution of sharing and gaps for immunizations, vital records, reportable conditions, laboratory, well water, and electronic health records. State-level maps describe the prevalence of data-sharing gaps nationwide. Results: For vital records, reportable conditions, and well-water assessments, gaps in data sharing were the norm. For the other 3 public health activities, a lower portion of the dyads experienced gaps, but gaps were still very common. Most troubling was the relatively infrequent occurrence of truly bidirectional information sharing. Conclusions: The data-sharing typology provides a useful basis for the formulations of policies to improve public health information systems and to guide future research.

C1 [Vest, Joshua R.] Weill Cornell Med Coll, Dept Publ Hlth, Ctr Healthcare Informat & Policy, New York, NY 10065 USA.
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OI Issel, Louellen/0000-0002-4328-1805; Vest, Joshua/0000-0002-7226-9688

CR [Anonymous], 2011, 2010 NAT PROF LOC HL
Association of State and Territorial Health Officials, 2010, DAT AN
Association of State and Territorial Health Officials, 2010, ASTHO PROF STAT PUBL, V1
Beitsch LM, 2006, J PUBLIC HEALTH MAN, V12, P232
Brand W., 2011, Morbidity and Mortality Weekly Report, V60, P10
deLeon P, 2009, POLICY STUD J, V37, P59, DOI 10.1111/j.1541-0072.2008.00295.x
Fitzgerald E, 2009, PUBLIC HEALTH REP, V124, P825, DOI 10.1177/003335490912400610
Grandien C, 2012, CORP COMMUN, V17, P209, DOI 10.1108/13563281211220247
Groom Holly, 2010, J Public Health Manag Pract, V16, pE1, DOI 10.1097/PHH.0b013e3181b0b8bc
Lammers JC, 2006, COMMUN THEOR, V16, P356, DOI 10.1111/j.1468-2885.2006.00274.x
Lumpkin JR, 2002, HEALTH AFFAIR, V21, P45, DOI 10.1377/hlthaff.21.6.45
Mahon BE, 2008, BMC PUBLIC HEALTH, V8, DOI 10.1186/1471-2458-8-160
Mays GP, 2010, MILBANK Q, V88, P81, DOI 10.1111/j.1468-0009.2010.00590.x
Merrill J, 2010, J PUBLIC HEALTH MAN, V16, P564, DOI 10.1097/PHH.0b013e3181e31cee

```
   National Association of City & County Health Officials, 2010, AD HEP B VIR
HBV VAC
   National Association of County and City Health Officials, 2008, NAT PROF LOC
HLTH DE
   National Association of County & City Health Officials, 2009, 2008 NAT PROF
LOC HL
   Papadouka V, 2011, J PUBLIC HEALTH MAN, V17, P565, DOI
10.1097/PHH.0b013e3182214746
   Salinsky E, 2006, HEALTH AFFAIR, V25, P1017, DOI 10.1377/hlthaff.25.4.1017
   Teutsch S.M., 2010, PRINCIPLES PRACTICE, P18
   Turning Point National Excellence Collaborative for Information Technology,
2005, FIN REP COLL
   Vest JR, 2012, J PUBLIC HEALTH MAN, V18, P160, DOI
10.1097/PHH.0b013e318226c9ef
   Walker J, 2005, HEALTH AFFAIR, V24, pw10
   Wholey DR, 2009, HEALTH SERV RES, V44, P1842, DOI 10.1111/j.1475-
6773.2009.01011.x
   Yasnoff W A, 2001, J Public Health Manag Pract, V7, P1
NR 25
TC 3
Z9 3
U1 0
U2 16
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA 530 WALNUT ST, PHILADELPHIA, PA 19106-3621 USA
SN 1078-4659
J9 J PUBLIC HEALTH MAN
JI J. Public Health Manag. Pract.
PD JUL-AUG
PY 2013
VL 19
IS 4
BP 357
EP 365
DI 10.1097/PHH.0b013e31826d8045
PG 9
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 154FQ
UT WOS:000319657800015
PM 23719391
DA 2019-08-06
ER

PT S
AU He, S
   Ganzinger, M
   Knaup, P
AF He, Shan
   Ganzinger, Matthias
   Knaup, Petra
BE Mantas, J
   Andersen, SK
   Mazzoleni, MC
   Blobel, B
   Quaglini, S
   Moen, A
```

TI The Intellectual Property Management for Data Sharing in a German Liver Cancer Research Network
SO QUALITY OF LIFE THROUGH QUALITY OF INFORMATION
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 24th Medical Informatics in Europe Conference (MIE)
CY AUG 26-29, 2012
CL Pisa, ITALY
SP European Federat Med Informat, Italian Med Informat Assoc, Italian E Hlth Community
DE Intellectual property; biomedical research network; data sharing
AB Sharing data in biomedical research networks has great potential benefits including efficient use of resources, avoiding duplicate experiments and promoting collaboration. However, concerns from data producers about difficulties of getting proper acknowledgement for their contributions are becoming obstacles for efficient and network wide data sharing in reality. Effective and convenient ways of intellectual property management and acknowledging contributions to the data producers are required. This paper analyzed the system requirements for intellectual property management in a German liver cancer research network and proposed solutions for facilitating acknowledgement of data contributors using informatics tools instead of pure policy level strategies.
C1 [He, Shan; Ganzinger, Matthias; Knaup, Petra] Heidelberg Univ, Dpt Med Informat, D-69120 Heidelberg, Germany.
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CR [Anonymous], 2011, D LIB MAGAZINE, P17
de Carvalho ECA, 2010, PLOS ONE, V5, DOI 10.1371/journal.pone.0009314
Fienberg S. E., 1985, SHARING RES DATA
Ganzinger M, 2011, STUD HEALTH TECHNOL, V169, P867, DOI 10.3233/978-1-60750-806-9-867
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Paskin N, 2010, DIGITAL OBJECT IDENT
Thorisson GA, 2009, NAT BIOTECHNOL, V27, P984, DOI 10.1038/nbt1109-984b
Wdcc ML, SCIENCE
NR 8
TC 3
Z9 3
U1 1
U2 12
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
EI 1879-8365
BN 978-1-61499-101-4
J9 STUD HEALTH TECHNOL
PY 2012
VL 180
BP 891
EP 895
DI 10.3233/978-1-61499-101-4-891
PG 5
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BA3ZL

```
UT WOS:000335219500173
PM 22874321
DA 2019-08-06
ER

PT J
AU Lopez, AD
AF Lopez, Alan D.
TI Sharing data for public health: where is the vision?
SO BULLETIN OF THE WORLD HEALTH ORGANIZATION
LA English
DT Editorial Material
C1 Univ Queensland, Sch Populat Hlth, Herston, Qld 4006, Australia.
RP Lopez, AD (reprint author), Univ Queensland, Sch Populat Hlth, Herston Rd,
Herston, Qld 4006, Australia.
EM a.lopez@sph.uq.edu.au
RI Lopez, Alan/F-1487-2010
OI Lopez, Alan/0000-0001-5818-6512
CR Horton R, 2007, LANCET, V370, P1526, DOI 10.1016/S0140-6736(07)61418-4
   Murray CJL, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000262
   Murray CJL, 1997, B WORLD HEALTH ORGAN, V75, P377
   Obermeyer Z, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000260
   Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
   Rajaratnam JK, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000253
   Setel PW, 2007, LANCET, V370, P1569, DOI 10.1016/S0140-6736(07)61307-5
NR 7
TC 3
Z9 3
U1 0
U2 0
PU WORLD HEALTH ORGANIZATION
PI GENEVA 27
PA MARKETING AND DISSEMINATION, CH-1211 GENEVA 27, SWITZERLAND
SN 0042-9686
J9 B WORLD HEALTH ORGAN
JI Bull. World Health Organ.
PD JUN
PY 2010
VL 88
IS 6
BP 467
EP 467
DI 10.2471/BLT.10.078956
PG 1
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA 610PR
UT WOS:000278746400016
PM 20539863
OA Green Published, Bronze
DA 2019-08-06
ER

PT B
AU Su, Y
   Yin, L
   Al-Hakim, L
AF Su, Ying
```

```
   Yin, Ling
   Al-Hakim, Latif
BE Tan, H
TI Cloud Computing Platform for National Scientific Data Sharing of
   Population and Health
SO 2010 SECOND ETP/IITA WORLD CONGRESS IN APPLIED COMPUTING, COMPUTER
   SCIENCE, AND COMPUTER ENGINEERING
LA English
DT Proceedings Paper
CT 2nd ETP/IITA World Congress in Applied Computing, Computer Science, and
   Computer Engineering
CY APR 17-18, 2010
CL Shenzhen, PEOPLES R CHINA
SP Intelligent Informat Technol Applicat Res Assoc, Engn Technol Press
DE Cloud Computing; Information sharing; Scientific Data; Data integration
   Description Framework
AB This paper presents a novel information sharing framework based on SQL Server
Data Services (SSDS) for service registry and repository that facilitates data
integration. A SSDS is a service-oriented architecture composed with reusable
services to support searching, querying, deleting, and storing data. SSDS can be
easily changed or maintained by reusing different services. Thus, it can be used
to share information in the cloud. The Information Sharing System (ISS)
component of the SSDS employs domain ontology to share data sources. The domain
ontology utilizes mathematical equivalence relations to map data sources into
appropriate domain ontology. Our implementation is based on a real application,
the National Scientific Data Sharing of Population and Health (NSDSPH).
C1 [Su, Ying; Al-Hakim, Latif] Inst Sci & Tech Informat China, Informat Qual Lab,
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RI Su, Ying/D-4158-2009
OI Su, Ying/0000-0002-9915-1698
CR BAUER DW, 2008, SIM C 2008 WSC 2008, P1029
   CHANG HH, 2009, E BUS ENG 2009 ICEBE, P608
   Rings T, 2009, J GRID COMPUT, V7, P375, DOI 10.1007/s10723-009-9132-5
   SU Y, 2009, J SOFTWARE, V4, P915
NR 4
TC 3
Z9 3
U1 0
U2 0
PU ETP-ENGINEERING TECHNOLOGY PRESS
PI HONG KONG
PA ROOM 2202, PING CHUN HOUSE PING TIN ESTATE, LAM TIN, KOWLOON, HONG KONG,
   00000, PEOPLES R CHINA
BN 978-988-18242-2-6
PY 2010
BP 51
EP 54
DI 10.1109/ICCCENG.2010.5560359
PG 4
WC Computer Science, Interdisciplinary Applications
SC Computer Science
GA BPO96
UT WOS:000279572200014
DA 2019-08-06
ER
```

PT S
AU Liu, X
   Peyton, L
   Kuziemsky, C
AF Liu, Xia
   Peyton, Liam
   Kuziemsky, Craig
BE Babin, G
   Kropf, P
   Weiss, M
TI A Requirement Engineering Framework for Electronic Data Sharing of Health Care Data Between Organizations
SO E-TECHNOLOGIES-INNOVATION IN AN OPEN WORLD
SE Lecture Notes in Business Information Processing
LA English
DT Proceedings Paper
CT 4th International MCETECH Conference on e-Technologies
CY MAY 04-06, 2009
CL Ottawa, CAPE VERDE
SP Talent First Net, Univ Ottawa, Telfer Sch Business, Carleton Univ, Univ Quebec, HEC Montreal, Univ Neuchatel
DE Requirements Engineering; User Requirements Notation; health care; data sharing; privacy; quality of care
ID NOTATION

AB Health care is increasingly provided to citizens by a network of collaboration that includes multiple providers and locations. Typically, that collaboration is on an ad-hoe basis via phone calls, faxes, and paper based documentation. Internet and wireless technologies provide an opportunity to improve this Situation via electronic data sharing. These new technologies make possible new ways of working and collaboration but it can be difficult for health care organizations to understand how to use the new technologies while still ensuring that their policies and objectives are being met. It is also important to have a systematic approach to validate that e-health processes deliver the performance improvements that are expected. Using a case study of a palliative care patient receiving home care from a team of collaborating health organizations, we introduce a framework based on requirements engineering. Key concerns and objectives are identified and modeled (privacy, security, quality of care, and timeliness of service). And, then, proposed business processes which use new technologies are modeled in terms of these concerns and objectives to assess their impact and ensure that electronic data sharing is well regulated.

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CR Alvarez G, 2006, J CRIT CARE, V21, P236, DOI 10.1016/j.jcrc.2006.02.004
   Amyot D, 2003, COMPUT NETW, V42, P285, DOI 10.1016/S1389-1286(03)00244-5
   Ash JS, 2004, J AM MED INFORM ASSN, V11, P104, DOI 10.1197/jamia.M1471
   CUMMINGS I, 1998, OXFORD TXB PALLIATIV, P19
   Darimont R., 2006, INT WORKSH REG MOD T
   European Union, 2002, DIR PRIV EL COMM
   Ghanavati S, 2007, LECT NOTES COMPUT SC, V4495, P218
   HE Q, 2006, IWIA 2006, P79
   *ITU T, 2002, Z1500203 ITUT
   Kealey J., 2006, 2006 IEEE CAN C EL C, P2432
   KUZIEMSKY C, 2004, INFORM TECHNOLOGY PA
   KUZIEMSKY C, 2008, PALLIATIVE HEALTHCAR
   Liu L, 2004, INFORM SYST, V29, P187, DOI 10.1016/S0306-4379(03)00052-8
   MUSSBACHER G, 2007, 10 WORKSH REQ ENG WE, P56
   *PIPEDA GOV CAN, 2005, HLTH INF CUST PROV O

Roy JF, 2006, LECT NOTES COMPUT SC, V4320, P198
Stead WW, 2005, J AM MED INFORM ASSN, V12, P113, DOI 10.1197/jamia.M1685
Weiss M, 2005, INT J E-BUS RES, V1, P63, DOI 10.4018/jebr.2005070104
NR 18
TC 3
Z9 3
U1 0
U2 7
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 1865-1348
BN 978-3-642-01186-3
J9 LECT NOTES BUS INF
PY 2009
VL 26
BP 279
EP 289
PG 11
WC Computer Science, Information Systems; Computer Science, Software
Engineering; Information Science & Library Science; Social Issues
SC Computer Science; Information Science & Library Science; Social Issues
GA BJS12
UT WOS:000267059700024
DA 2019-08-06
ER

PT J
AU Barhamgi, M
Renslimane, D
Ouksel, AM
AF Barhamgi, Mahmoud
Renslimane, Djamal
Ouksel, Aris M.
TI PWSMS: A peer-to-peer web service management system for data sharing in
collaborative environments
SO COMPUTER SYSTEMS SCIENCE AND ENGINEERING
LA English
DT Article
DE data integration; collaborative systems
ID SEMANTIC WEB; VIEWS
AB in today's collaborative environments such as bioinformatics and healthcare,
access to an increasing number of data sources has been made in the form of
Data-Providing Web Services. Current approaches to composing Web services are
not suitable for this special class of Web services as they do not take into
consideration the semantic relationship that holds between input and output sets
of a Web service. In this paper, we present our Peer-to-Peer Web Service
Management System (PWSMS) for data exchange through Data-Providing Web Services.
A novel approach is proposed for automatically composing data-providing services
by making usage of the mature work that has been done in the conventional data
integration and mediation systems. Specifically, we model data-providing
services as RDF parameterized views over mediated ontologies. We devise an
algorithm for composing services based on conventional query rewriting
techniques. Similarly to the conventional services composition, users may want
to run the generated composite service over several values of the same input
parameters. To deal with this issue, we treat parameterized queries where values
for input parameters are specified as ranges or not given at all. We also
propose an efficient probabilistic algorithm for detecting the minimum set of

services satisfying constraints (over inputs/outputs) specified in the query. Finally, we present algorithms for optimizing the generated composition. These algorithms have been implemented in our PWSMS system.

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CR Aberer K, 2002, SIGMOD REC, V31, P48
Barhamgi M, 2007, LECT NOTES COMPUT SC, V4495, P531
BERGAMASCHI S, 2004, AP2PC, P120
Bergamaschi Sonia, 2003, AGENTS PEER TO PEER, P113
Chawathe Sudarshan, 1994, IPSJ, P7
CHEN H, 2006, P 22 INT C DAT ENG I
CRUZ I, 2004, AP2PC, P108
DIMITROV DA, 2006, INT SEM WEB C, P764
DOGAC A, 2006, INFORM SYSTEMS J
Dustdar S., 2005, International Journal of Web and Grid Services, V1, P1, DOI 10.1504/IJWGS.2005.007545
Halevy AY, 2001, VLDB J, V10, P270, DOI 10.1007/s007780100054
Halevy AY, 2004, IEEE T KNOWL DATA EN, V16, P787, DOI 10.1109/TKDE.2004.1318562
Halevy AY, 2000, SIGMOD RECORD, V29, P40
HULL D, 2006, P 21 NAT C ART INT 1
Lenzerini M., 2002, PODS, P233, DOI DOI 10.1145/543613.543644
Levy A. Y., 1995, Proceedings of the Fourteenth ACM SIGACT-SIGMOD-SIGART Symposium on Principles of Database Systems. PODS 1995, P95, DOI 10.1145/212433.220198
LOSER A, 2003, CAISE, P258
Maamar Z, 2005, IEEE INTERNET COMPUT, V9, P79, DOI 10.1109/MIC.2005.91
Manolescu I., 2001, VLDB, P241
Medjahed B, 2003, VLDB J, V12, P333, DOI 10.1007/s00778-003-0101-5
Medjahed B, 2005, IEEE T KNOWL DATA EN, V17, P954, DOI 10.1109/TKDE.2005.101
Milanovic N, 2004, IEEE INTERNET COMPUT, V8, P51, DOI 10.1109/MIC.2004.58
Ooi BC, 2003, SIGMOD RECORD, V32, P59
Ouksel AM, 2006, LECT NOTES COMPUT SC, V4290, P121
Papazoglou MP, 2003, FOURTH INTERNATIONAL CONFERENCE ON WEB INFORMATION SYSTEMS ENGINEERING, PROCEEDINGS, P3
PAPAZOGLOU MP, 2003, CAISE, P485
Rao J., 2004, SEMANTIC WEB SERVICE, P43, DOI DOI 10.1007/978-3-540-30581-1_5
RIZVI S, 2004, SIGMOD C, P551
RODRIGUEZGIANOL.P, 2005, VLDB, P1291
Sirin E, 2004, IEEE INTELL SYST, V19, P42, DOI 10.1109/MIS.2004.27
Spyropoulou E, 2006, LECT NOTES COMPUT SC, V4152, P55
SRIVASTAVA B, 2003, ICAPS 2003
Srivastava D., 1993, Annals of Mathematics and Artificial Intelligence, V8, P315, DOI 10.1007/BF01530796
Steinbrunn M., 1997, VLDB Journal, V6, P191, DOI 10.1007/s007780050040
WU D, 2003, INT SEM WEB C, P195
YANG J, 2003, COOPIS DOA ODBASE, P244

NR 36
TC 3
Z9 4
U1 0

```
U2 1
PU C R L PUBLISHING LTD
PI LEICESTER
PA 5 WEIR RD, KIBWORTH BEAUCHAMP, LEICESTER LE8 0LQ, ENGLAND
SN 0267-6192
J9 COMPUT SYST SCI ENG
JI Comput. Syst. Sci. Eng.
PD MAR
PY 2008
VL 23
IS 2
BP 89
EP 106
PG 18
WC Computer Science, Hardware & Architecture; Computer Science, Theory &
   Methods
SC Computer Science
GA 311CM
UT WOS:000256577700004
DA 2019-08-06
ER

PT S
AU Hu, PJH
   Zeng, D
   Chen, HC
   Larson, CA
   Tseng, CJ
AF Hu, Paul Jen-Hwa
   Zeng, Daniel
   Chen, Hsinchun
   Larson, Catherine A.
   Tseng, Chunju
BE Zeng, D
TI A Web-based system for infectious disease data integration and sharing:
   Evaluating outcome, task performance efficiency, user information
   satisfaction, and usability
SO INTELLIGENCE AND SECURITY INFORMATICS: BIOSURVEILLANCE, PROCEEDINGS
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
CT 2nd NSF Biosurveillance Workshop
CY MAY 22, 2007
CL New Brunswick, NJ
SP NSF
DE infectious disease informatics; public health information systems;
   cross-jurisdictional information sharing; outbreak detection; system
   evaluation
AB To better support the surveillance of infectious disease and epidemic
outbreaks by public health professionals, we design and implement BioPortal, an
advanced Web-based system for cross-jurisdictional information sharing and
integration. In this paper, we report two empirical studies that evaluate the
outcomes, task performance efficiency, user information satisfaction, and
usability associated with BioPortal. Overall, our results suggest that the use
of BioPortal can improve users' surveillance performance as measured by analysis
accuracy and efficiency (i.e., the amount of time required to complete an
analysis task). Our subjects were highly satisfied with the information support
of BioPortal and considered it reasonably usable. Our evaluation findings show
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the effectiveness and value of BioPortal and, at the same time, shed light on
several areas where its design can further improve.
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CR DAVIS FD, 1989, MIS QUART, V13, P319, DOI 10.2307/249008
   DeLone WH, 1992, INFORM SYST RES, V3, P60, DOI 10.1287/isre.3.1.60
   Diehl V. A., 1988, P SIGCHI C HUM FACT, V88, P213, DOI DOI
10.1145/57167.57203
   ERICSSON CD, 2000, CLIN INFECT DIS, V31, P776
   HU PJ, 2005, LECT NOTES COMPUTER, V3495
   IVES B, 1983, COMMUN ACM, V26, P785, DOI 10.1145/358413.358430
   Li YG, 2004, AM J EPIDEMIOL, V160, P719, DOI 10.1093/aje/kwh273
   Pinner RW, 2003, EMERG INFECT DIS, V9, P781
   Siegrist DW, 1999, EMERG INFECT DIS, V5, P505, DOI 10.3201/eid0504.990407
   Thacker SB, 2001, AM J EPIDEMIOL, V154, P985, DOI 10.1093/aje/154.11.985
   Yasnoff WA, 2001, J AM MED INFORM ASSN, V8, P535, DOI
10.1136/jamia.2001.0080535
   Zeng D, 2004, LECT NOTES COMPUT SC, V3073, P28
NR 12
TC 3
Z9 3
U1 0
U2 1
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 0302-9743
EI 1611-3349
BN 978-3-540-72607-4
J9 LECT NOTES COMPUT SC
PY 2007
VL 4506
BP 134
EP +
PG 4
WC Computer Science, Artificial Intelligence; Computer Science, Information
   Systems; Computer Science, Interdisciplinary Applications; Computer
   Science, Theory & Methods
SC Computer Science
GA BGG61
UT WOS:000246687800013
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ER

PT S
AU Hicken, VN
   Thornton, SN
   Rocha, RA
AF Hicken, VN
   Thornton, SN
   Rocha, RA
BE Fieschi, M
```

Coiera, E
Li, YCJ
TI Integration challenges of clinical information systems developed without a shared data dictionary
SO MEDINFO 2004: PROCEEDINGS OF THE 11TH WORLD CONGRESS ON MEDICAL INFORMATICS, PT 1 AND 2
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 11th World Congress on Medical Informatics
CY SEP 07-11, 2004
CL Amer Med Informat Assoc, San Francisco, CA
SP Int Med Informat Assoc
HO Amer Med Informat Assoc
DE systems integration; longitudinal computerized medical records systems; information management; terminologies; data quality; common data elements; data model reconciliation; EHR systems standardization; ontology development
ID CARE

AB Legacy systems have proven to be long-term integration challenges for Intermountain Health Care (IHC) despite commitment and attention to share clinical information across settings and among clinicians. This study measures the extent of the disparity of data elements across three independent data systems in current use. A sample of relevant data elements was selected across systems covering prenatal, labor and delivery, and newborn intensive care units (NICU). The findings revealed only 17% of these sample data elements had compatible structure across all three systems. The implications from differences in granularity, missing data, and duplicate data entry, include diminished data quality, greater risk for medical error, increased costs of integration and inefficient use of clinician time. Retrospective guidelines for managing conceptual context and granularity are given to assist in designing an integrated longitudinal patient electronic medical record.

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CR *3M HIS, 2002, MAK SENS DAT US MED
*AAP ACOG, 2002, GUID PER CAR
Clayton PD, 2003, METHOD INFORM MED, V42, P1
de Keizer NF, 2000, METHOD INFORM MED, V39, P16
DICK RE, 1991, COMPUTER BASED PATIE
HEARD S, 2003, HL7
Institute of Medicine, 2001, CROSS QUAL CHASM NEW
Institute of Medicine Committee on Data Standards for Patient Safety, 2003, KEY CAP EL HLTH REC
KOGAN MD, 2003, COMMUNICATION 0711
Maloni J A, 1996, J Obstet Gynecol Neonatal Nurs, V25, P17, DOI 10.1111/j.1552-6909.1996.tb02508.x
Rosenal T W, 1995, Proc Annu Symp Comput Appl Med Care, P2
SHORTELL SM, 1994, MED CARE, V32, P508, DOI 10.1097/00005650-199405000-00009
SIMPSON KR, 2001, PERINATAL NURSING
Stead WW, 2000, J AM MED INFORM ASSN, V7, P146, DOI 10.1136/jamia.2000.0070146
TWEDE M, 1985, CONT OBGYN, V24, P13
WILLIAMS S, 2003, COMMUNICATION 0702
2004, HLTH LEVEL 7, V1

NR 17
TC 3

```
Z9 3
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
EI 1879-8365
BN 1-58603-444-8
J9 STUD HEALTH TECHNOL
PY 2004
VL 107
BP 1053
EP 1057
PG 5
WC Computer Science, Information Systems; Medical Informatics
SC Computer Science; Medical Informatics
GA BBO53
UT WOS:000226723300212
PM 15360973
DA 2019-08-06
ER

PT J
AU Love, DE
   Paita, LMC
   Custer, WS
AF Love, DE
   Paita, LMC
   Custer, WS
TI Data sharing and dissemination strategies for fostering competition in
   health care
SO HEALTH SERVICES RESEARCH
LA English
DT Article; Proceedings Paper
CT Conference on Data Needs for Studies of Competition in Market Ares
CY JUN 21-22, 1999
CL WASHINGTON, D.C.
DE health care market; health information; data sharing; data
   dissemination; health care purchasers; health care providers
ID SYSTEM
AB Objectives. To introduce the concept of common models for data sharing and
dissemination, highlight the current operational, technical, and political
issues surrounding existing data sharing and dissemination initiatives in a
health care market, and suggest an ideal model for future data initiatives.
   Data Sources/Study Setting h literature review and case studies of existing
data sharing and dissemination initiatives that promote the collection and use
of comparative information on provider cost and quality.
   Principal Findings. Three broad types of common models for data sharing and
dissemination have evolved over the past decade or so: (1) provider-initiated
initiatives developed through collaboration among providers of health care; (2)
purchaser-initiated activities driven by a coalition of purchasers; and (3)
indirect collaboration-data-sharing initiatives between providers and purchasers
with a significant facilitating or regulating role by a third group of
stakeholders. The success of a data-sharing and dissemination strategy is
determined by how the complex operational, technical, and political issues are
addressed. General principles by which a health data initiative might abide
include the following: standardized databases as the physical foundation,
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indicators that reflect the changing market; linkages between and across data sets for comprehensive and complete data; economic value; policy relevance; use of evolving technologies to collect, integrate, and disseminate data; and stakeholder support.

Conclusions. Regulatory solutions alone will not overcome the complex political and technical challenges to data sharing and dissemination. The "ideal" model or process nurturing a market for health care information will incorporate compromise and negotiation to address the issues of data ownership and proprietary concerns, therefore securing the necessary political and financial support of the private sector.

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Georgia State Univ, Atlanta, GA 30303 USA.
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CR Aday L. A., 1998, EVALUATING HEALTHCAR
*AHRQ, 2000, HEALTHC COST UT PROJ
*CAMC, 1997, HARN COMP PAT COMM S
*DHHS, 1998, HLTH INS PORT ACC AC
Durham ML, 1998, HEALTH AFFAIR, V17, P111, DOI 10.1377/hlthaff.17.1.111
Eisenberg JM, 1998, HEALTH AFFAIR, V17, P98, DOI 10.1377/hlthaff.17.1.98
*F G INC, 1999, 1999 COMP PERF DAT S
*F G INC, 1997, 1997 COMP PERF DAT S
*F G INC, 1998, 1998 COMP PERF DAT S
Frech H. E. T., 1996, COMPETITION MONOPOLY
Gold M, 1998, IMPROVING USE DATA H
*JOINT COMM ACCR H, 1999, PERF MEAS HLTH CAR O
MILLENSON ML, 1997, DEMANDING MED EXCELL, P222
Miller RH, 1996, HEALTH AFFAIR, V15, P107, DOI 10.1377/hlthaff.15.2.107
*NAHDO, 1998, INV STAT
*NAHDO, 18 ANN M
*NCQA, 1997, HEDIS 3 0, V1
*NQF, 2000, MISS GOALS NAT QUAL
*PBGH, 2000, OV CALINX CAL INF EX
*PENNS HLTH CAR CO, 1998, PENN GUID COR ART BY
*PENNS HLTH CAR CO, 1999, NEW DIR PHC4 1998 AN
*UHIN, 2000, UHIN

NR 22
TC 3
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U2 1
PU HEALTH ADMINISTRATION PRESS
PI CHICAGO
PA C/O FOUNDATION AMER COLL HEALTHCARE EXECUTIVES ONE N FRANKLIN ST, STE 1700, CHICAGO, IL 60606-3491 USA
SN 0017-9124
J9 HEALTH SERV RES
JI Health Serv. Res.
PD APR
PY 2001
VL 36
IS 1
BP 277
EP 290
PN 2
PG 14
WC Health Care Sciences & Services; Health Policy & Services

SC Health Care Sciences & Services
GA 420UR
UT WOS:000168024100006
PM 11327177
DA 2019-08-06
ER

PT J
AU Swuste, P
   Hale, A
   Zimmerman, G
AF Swuste, P
   Hale, A
   Zimmerman, G
TI Sharing workplace solutions by solution data banks
SO SAFETY SCIENCE
LA English
DT Article; Proceedings Paper
CT 10th Anniversary Conference of the Safety-Science-Group of the Delft-University-of-Technology
CY DEC, 1994
CL DELFT UNIV TECHNOL, DELFT, NETHERLANDS
SP Delft Univ Technol, Safety Sci Grp
HO DELFT UNIV TECHNOL
AB The need to exchange information on solutions and control measures to reduce occupational hazards has become an important issue amongst occupational safety and health professionals. During the first conference of the IOHA this issue was discussed during the successful workshop ''Sharing knowledge on preventive measures''. An expert working group of the European Commission has recently drawn up a report advising the development of a European initiative in this area, and in september 1994 a WHO working group was formed on this topic. Data banks on solutions are one of the possible ways to supply this information. This article summarizes the conclusions of the review of existing data banks and specifies the objectives and structure of a proposed bank. Based upon a consideration of the available classification systems for information on solutions, it specifies how data on solutions could be stored, and provides intelligent assistance to users in locating solutions close to the source or in gaining access to information on comparable processes which are intrinsically less hazardous. The proposed data bank has a navigation system with two principle entry points, corresponding to two basic types of solution: firstly based on the production process, subdivided into the production principle and function as an access point to substitute methods of production; secondly the hazard and its emission and transmission process as an access point for more conventional hygiene control measures. A third access directly to control measures can be used by expert users. (C) 1997 Elsevier Science Ltd.
RP Swuste, P (reprint author), DELFT UNIV TECHNOL, SAFETY SCI GRP, KANAALWEG 2B, NL-2628 EB DELFT, NETHERLANDS.
CR ABEYTUNGA PK, 1990, S WORKPL SOL SHAR EX
   BADGER WL, 1936, ELEMENTS CHEM ENG
   BARNETT RL, 1986, J SAFETY RES, V17, P49, DOI 10.1016/0022-4375(86)90093-9
   BEAUMONT P, 1990, J HLTH SAFETY, V4, P15
   Blackadder D. A., 1971, HDB UNIT OPERATIONS
   BOLZ HA, 1958, MAT HANDLING HDB
   BURINGH E, 1992, STAUB REINHALT LUFT, V52, P347
   *CEN, 1992, EN2621 CEN
   EEKELS J, 1987, ONTWERPMETHODOLOGIE
   ELSE DE, 1986, J OCCUP HEALTH, V2, P340
   GEANKOPLIS G, 1978, TRANSPORT PROCESSES

```
   Ghosh A., 1986, MANUFACTURING SCI
   HAEL A, 1994, DGVF2 DELFT U TECHN
   HALE A, 1978, THESIS U ASTON BIRMI
   HALL B, 1990, J OCCUPATIONAL HLTH, V6, P35
   HOVINGA H, 1984, VERVAARDIGINGSTECHNI
   MOORE H, 1982, MANUFACTURING
   PINEY M, 1988, VENTILATION 88
   Shreve RN, 1956, CHEM PROCESS IND
   SPEE T, 1990, STAUB REINHALT LUFT, V50, P361
   SWUSTE P, 1993, ANN OCCUP HYG, V37, P117, DOI 10.1093/annhyg/37.2.117
   SWUSTE P, 1992, 1511 S SDU UITG MIN
   Swuste P., 1994, APPL OCCUPATIONAL EN, V9, P57
   SWUSTE P, 1994, OCCUPATIONAL HYGIENE, V7, P12
   SWUSTE P, 1992, 151 S SDU UITG MIN S
   SWUSTE P, 1994, APPL OCCUPATIONAL EN, V9, P74
   VANCAENEGEM RC, 1979, GROTE WINKLER PRINS
   VANDENKROONENBE.HH, 1983, DESIGN METHODS POSTG
NR 28
TC 3
Z9 3
U1 0
U2 2
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 0925-7535
J9 SAFETY SCI
JI Saf. Sci.
PD JUN-JUL
PY 1997
VL 26
IS 1-2
BP 95
EP 104
DI 10.1016/S0925-7535(96)00020-3
PG 10
WC Engineering, Industrial; Operations Research & Management Science
SC Engineering; Operations Research & Management Science
GA XE987
UT WOS:A1997XE98700011
DA 2019-08-06
ER

PT J
AU Shen, BQ
   Guo, JZ
   Yang, YL
AF Shen, Bingqing
   Guo, Jingzhi
   Yang, Yilong
TI MedChain: Efficient Healthcare Data Sharing via Blockchain
SO APPLIED SCIENCES-BASEL
LA English
DT Article
DE blockchain; healthcare data; electronic health record; data stream;
   healthcare information exchange; data sharing; peer-to-peer;
   decentralization; digest chain
ID INFORMATION EXCHANGE; CLOUD; SYSTEM; PRIVACY; SECURITY; RESOURCE;
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IMPACT; RECORD; SCHEME

AB Healthcare information exchange is an important research topic, which can benefit both healthcare providers and patients. In healthcare data sharing, many cloud-based solutions have been proposed, but the trustworthiness of a third-party cloud service is questionable. Recently, blockchain has been introduced in healthcare record sharing, which does not rely on trusting a third party. However, existing approaches only focus on the records collected from medical examination. They are not efficient in sharing data streams continuously generated from sensors and other monitoring devices. Today, IoT devices have been widely deployed and sensors and mobile applications can monitor patients' body conditions. The collected data are shared to laboratories and institutions for diagnosis and further study. Moreover, existing approaches are too rigid to efficiently support metadata change. In this paper, an efficient data-sharing scheme is proposed, called MedChain, which combines blockchain, digest chain, and structured P2P network techniques to overcome the above efficiency issues in the existing approaches for sharing both types of healthcare data. Based on MedChain, a session-based healthcare data-sharing scheme is devised, which brings flexibility in data sharing. The evaluation results show that MedChain can achieve higher efficiency and satisfy the security requirements in data sharing.

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OI Yang, Yilong/0000-0002-0099-344X

FU MYRG (Multi-Year Research Grant) of University of Macau [MYRG2017-00091-FST]
FX This research was partially funded by the MYRG (Multi-Year Research Grant) of University of Macau, research grant number MYRG2017-00091-FST.

CR Abrar H, 2018, IEEE ACCESS, V6, P19140, DOI 10.1109/ACCESS.2018.2805919
Al Omar A., 2017, MEDIBCHAIN BLOCKCHAI
Ananth C., 2018, J ENG TECHNOL, V6, P42
[Anonymous], 2017, HEALTHC BLOCKCH CUR
[Anonymous], MAJ EXT BARR AD BLOC
Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11
Badawi HF, 2017, FUTURE GENER COMP SY, V66, P59, DOI 10.1016/j.future.2015.11.005
Baden R., 2009, P ACM SIGCOMM 2009 C
Chen YY, 2012, J MED SYST, V36, P3375, DOI 10.1007/s10916-012-9830-6
Fan K, 2018, J MED SYST, V42, DOI 10.1007/s10916-018-0993-7
Farahani B, 2018, FUTURE GENER COMP SY, V78, P659, DOI 10.1016/j.future.2017.04.036
Featherstone I, 2012, INT J MED INFORM, V81, P45, DOI 10.1016/j.ijmedinf.2011.09.002
Goldberger AL, 2000, CIRCULATION, V101, pE215, DOI 10.1161/01.CIR.101.23.e215
Gordon WJ, 2018, COMPUT STRUCT BIOTEC, V16, P224, DOI 10.1016/j.csbj.2018.06.003
Gramoli V., FUTURE GENER COMP SY, DOI [10.1016/j.future.2017.09.023, DOI 10.1016/J.FUTURE.2017.09.023]
Guo R, 2018, IEEE ACCESS, V6, P11676, DOI 10.1109/ACCESS.2018.2801266
Hossain M, 2018, FUTURE GENER COMP SY, V82, P422, DOI 10.1016/j.future.2017.11.020
Hypponen H, 2014, INT J MED INFORM, V83, P1, DOI 10.1016/j.ijmedinf.2013.10.002
KOBLITZ N, 1987, MATH COMPUT, V48, P203, DOI 10.2307/2007884

Li HY, 2018, J MED SYST, V42, DOI 10.1007/s10916-018-0997-3
Liu Y, 2018, FUTURE GENER COMP SY, V78, P1020, DOI 10.1016/j.future.2016.12.027
Lua EK, 2005, IEEE COMMUN SURV TUT, V7, P72, DOI 10.1109/COMST.2005.1610546
MarketsandMarkets Research, IOT HEALTHC MARK COM
Mehmood A, 2018, IEEE ACCESS, V6, P33552, DOI 10.1109/ACCESS.2018.2841972
Merkle R.C, 1987, P C THEOR APPL CRYPT
MGMA, AW BLOCKCH TECHN US
Miller AR, 2014, J HEALTH ECON, V33, P28, DOI 10.1016/j.jhealeco.2013.10.004
Moody GA, 2001, IEEE ENG MED BIOL, V20, P45, DOI 10.1109/51.932724
Patel Vishal, 2018, Health Informatics J, p1460458218769699, DOI 10.1177/1460458218769699
Rahurkar S, 2015, HEALTH AFFAIR, V34, P477, DOI 10.1377/hlthaff.2014.0729
Rinner C, 2016, INT J MED INFORM, V92, P44, DOI 10.1016/j.ijmedinf.2016.05.001
Sahi MA, 2018, IEEE ACCESS, V6, P464, DOI 10.1109/ACCESS.2017.2767561
Sinaci AA, 2013, J BIOMED INFORM, V46, P784, DOI 10.1016/j.jbi.2013.05.009
Sousa J, 2012, 2012 NINTH EUROPEAN DEPENDABLE COMPUTING CONFERENCE (EDCC 2012), P37, DOI 10.1109/EDCC.2012.32
Stoica I., 2001, P 2001 C APPL TECHN
The Economist Intelligence Unit of IBM Institute for Business Value, 2017, HEALTHC RALL BLOCKCH
Walker-Roberts S, 2018, IEEE ACCESS, V6, P25167, DOI 10.1109/ACCESS.2018.2817560
Wang HQ, 2018, IEEE ACCESS, V6, P27818, DOI 10.1109/ACCESS.2018.2838095
Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843
Yang YL, 2018, IEEE ACCESS, V6, P46949, DOI 10.1109/ACCESS.2018.2865535
Yang YL, 2018, INT J BIOL SCI, V14, P907, DOI 10.7150/ijbs.24617
Yao X, 2018, IEEE ACCESS, V6, P3809, DOI 10.1109/ACCESS.2018.2793304
Yue X, 2016, J MED SYST, V40, DOI 10.1007/s10916-016-0574-6
Yuksel B, 2017, FUTURE GENER COMP SY, V68, P1, DOI 10.1016/j.future.2016.08.011
Zhang AQ, 2018, J MED SYST, V42, DOI 10.1007/s10916-018-0995-5
Zissis D, 2012, FUTURE GENER COMP SY, V28, P583, DOI 10.1016/j.future.2010.12.006
NR 46
TC 2
Z9 2
U1 14
U2 14
PU MDPI
PI BASEL
PA ST ALBAN-ANLAGE 66, CH-4052 BASEL, SWITZERLAND
EI 2076-3417
J9 APPL SCI-BASEL
JI Appl. Sci.-Basel
PD MAR 22
PY 2019
VL 9
IS 6
AR 1207
DI 10.3390/app9061207
PG 23
WC Chemistry, Multidisciplinary; Materials Science, Multidisciplinary; Physics, Applied
SC Chemistry; Materials Science; Physics
GA HT2GO
UT WOS:000464381400017

```
OA DOAJ Gold
DA 2019-08-06
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PT J
AU Vaske, OM
   Haussler, D
AF Vaske, Olena Morozova
   Haussler, David
TI Data sharing for pediatric cancers
SO SCIENCE
LA English
DT Editorial Material
C1 [Vaske, Olena Morozova] Univ Calif Santa Cruz, Dept Mol Cell & Dev Biol,
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   [Haussler, David] Univ Calif Santa Cruz, Dept Biomol Engn, Genom Inst, Santa
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NR 0
TC 2
Z9 2
U1 15
U2 15
PU AMER ASSOC ADVANCEMENT SCIENCE
PI WASHINGTON
PA 1200 NEW YORK AVE, NW, WASHINGTON, DC 20005 USA
SN 0036-8075
EI 1095-9203
J9 SCIENCE
JI Science
PD MAR 15
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VL 363
IS 6432
SI SI
BP 1125
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DI 10.1126/science.aax2739
PG 1
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA HP0BC
UT WOS:000461329000001
PM 30872493
OA Bronze
DA 2019-08-06
ER

PT J
AU Dijkers, MP
AF Dijkers, Marcel P.
TI A beginner's guide to data stewardship and data sharing
SO SPINAL CORD
LA English
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DT Review
ID OPEN ACCESS PLATFORMS; FUTURE; DESIGN; POLICY
AB Study design A narrative review of principles, benefits and disadvantages, as well as methods of research data sharing.

Objectives To assist prospective Spinal Cord authors and others with understanding and implementing data sharing, so that various benefits of such sharing can accrue to all spinal cord injury research stakeholders.

Setting International.

Methods The medical research and health care services literature was reviewed nonsystematically for relevant articles, and web sites were explored for information and services offered by various pertinent organizations.

Results Grant makers, professional organizations, research journals, publishers, and other entities in the research field increasingly stress the ethics as well as societal and practical benefits of data sharing, and require researchers to do so within a reasonable time after data collection ends. Sharing data, retrospectively, generally requires much time and resources, but when a data management plan is part of a research proposal from the start, costs are limited, and grant makers allow these costs to be part of a budget. There are many organizations that offer information on or even assist with preparing data for sharing and actual deposit in a data repository.

Conclusions The requirement of data sharing is not likely to go away, and researchers interested in submitting their reports to Spinal Cord would do well to familiarize themselves with the myriad practical issues involved in preparing data for sharing.
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CR Alter GC, 2015, J EMPIR RES HUM RES, V10, P317, DOI 10.1177/1556264615591561
American Psychological Association, 2018, ETH PRINC PSYCH COD
[Anonymous], 2018, DISS SHAR RES RES
[Anonymous], 2018, DATA SCI NIH
[Anonymous], 2018, OPEN ACCESS POLICY
[Anonymous], 2006, DATABASES DATA SETS
[Anonymous], 2007, OECD PRINCIPLES GUID
[Anonymous], 2018, NIH DATA SHARING POL
[Anonymous], 2017, EXTERNAL GUIDANCE IM
[Anonymous], 2014, FAIR DAT PRINC
Babbage DR, 2014, ARCH PHYS MED REHAB, V95, P795, DOI 10.1016/j.apmr.2013.12.014
Biering-Sorensen F, 2015, SPINAL CORD, V53, P265, DOI 10.1038/sc.2014.246
Burton PR, 2015, BIOINFORMATICS, V31, P3241, DOI 10.1093/bioinformatics/btv279
Callahan A, 2017, EXP NEUROL, V295, P135, DOI 10.1016/j.expneurol.2017.05.012
Candela L, 2015, J ASSOC INF SCI TECH, V66, P1747, DOI 10.1002/asi.23358
Charlifue S, 2016, ARCH PHYS MED REHAB, V97, P1805, DOI 10.1016/j.apmr.2016.03.030
Committee on Strategies for Responsible Sharing of Clinical Trial Data Institute of Medicine, 2015, STRAT RESP SHAR CLIN
Culina A, 2018, NAT ECOL EVOL, V2, P420, DOI 10.1038/s41559-017-0458-2
Cummings JA, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0125208
DCC. Digital Curation Centre, 2018, GOOD RES NEEDS GOOD
De Hert S, 2017, EUR J ANAESTH, V34, P1, DOI 10.1097/EJA.0000000000000529
Dechartres A, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0492-3
Dijkers M, 2019, SPINAL CORD, V57, P165, DOI 10.1038/s41393-019-0246-8
Dijkers MP, 2016, IPDMA INDIVIDUAL PAT, V4
Dryad, 2018, DRYAD DIGITAL REPOSI

Dyke SOM, 2016, FACETS, V1, P138, DOI 10.1139/facets-2016-0002
EMAM KHALED EL, 2011, DISPELLING MYTHS SUR
Ferguson AR, 2014, NAT NEUROSCI, V17, P1442, DOI 10.1038/nn.3838
Figshare, 2018, FIGSH CRED ALL YOUR
Giglia E, 2012, Eur J Phys Rehabil Med, V48, P713
Gymrek M, 2016, GIGASCIENCE, V5, DOI 10.1186/s13742-016-0127-4
Haug CJ, 2016, NEW ENGL J MED, V374, P2409, DOI 10.1056/NEJMp1605378
Hesse BW, 2018, AM PSYCHOL, V73, P126, DOI 10.1037/amp0000197
Hlatky MA, 2017, J AM COLL CARDIOL, V69, P1983, DOI 10.1016/j.jacc.2017.03.008
Hopkins C, 2016, J CLIN EPIDEMIOL, V70, P17, DOI 10.1016/j.jclinepi.2015.07.002
Hrynaszkiewicz I, 2010, BRIT MED J, V340, DOI 10.1136/bmj.c181
Hume S, 2016, J BIOMED INFORM, V60, P352, DOI 10.1016/j.jbi.2016.02.016
ICMJE, 2018, HOME
Index, 2018, FITBIR FED INT TRAUM
Ioannidis JPA, 2014, LANCET, V383, P166, DOI 10.1016/S0140-6736(13)62227-8
Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
Kobayashi Shinji, 2018, Yearb Med Inform, V27, P41, DOI 10.1055/s-0038-1641201
Kramer JLK, 2017, NEUROREHAB NEURAL RE, V31, P399, DOI 10.1177/1545968316688801
KRUMHOLZ HM, 2015, BMJ-BRIT MED J, V350, DOI DOI 10.1136/BMJ.H599
Loder E, 2018, BMJ-BRIT MED J, V360, DOI 10.1136/bmj.k710
Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
Martin Erika G, 2017, J Public Health Manag Pract, V23, pe5, DOI 10.1097/PHH.0000000000000388
McDonald L, 2017, BMJ-BRIT MED J, V359, DOI 10.1136/bmj.j4866
McKiernan EC, 2016, ELIFE, V5, DOI 10.7554/eLife.16800
Merson L, 2016, NEW ENGL J MED, V374, P2414, DOI 10.1056/NEJMp1605148
Morey RD, 2016, ROY SOC OPEN SCI, V3, DOI 10.1098/rsos.150547
Munafo MR, 2017, NAT HUM BEHAV, V1, DOI 10.1038/s41562-016-0021
Murray MJ, 2016, BMJ-BRIT MED J, V352, DOI 10.1136/bmj.i849
Naik G, 2017, NATURE, V543, P161, DOI 10.1038/nature.2017.21549
Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374
Noonan VK, 2018, J NEUROTRAUM, V35, P478, DOI 10.1089/neu.2017.5036
Nosek BA, 2012, PERSPECT PSYCHOL SCI, V7, P615, DOI 10.1177/1745691612459058
Piwowar H, 2013, NATURE, V493, P159, DOI 10.1038/493159a
Piwowar HA, 2013, PEERJ, V1, DOI 10.7717/peerj.175
re3data, 2018, HOME
Rouder JN, 2016, BEHAV RES METHODS, V48, P1062, DOI 10.3758/s13428-015-0630-z
Spencer K, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5011
Spinal Cord, 2018, SPINAL CORD
Stuart D, 2018, PRACTICAL CHALLENGES
Sudlow R, 2016, BMC MED RES METHODOL, V16, DOI 10.1186/s12874-016-0171-x
Taichman DB, 2017, ANN INTERN MED, V167, P63, DOI 10.7326/M17-1028
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
Vickers AJ, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d2323
Wellcome Trust, 2018, OUR NEW POL SHAR RES
Wicherts JM, 2006, AM PSYCHOL, V61, P726, DOI 10.1037/0003-066X.61.7.726
NR 70
TC 2
Z9 2
U1 1
U2 1
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND

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J9 SPINAL CORD
JI Spinal Cord
PD MAR
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BP 169
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DI 10.1038/s41393-018-0232-6
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WC Clinical Neurology; Rehabilitation
SC Neurosciences & Neurology; Rehabilitation
GA HN3XZ
UT WOS:000460119800002
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OA Other Gold
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PT J
AU Zhang, Q
   Zhang, QY
   Shi, WS
   Zhong, H
AF Zhang, Quan
   Zhang, Qingyang
   Shi, Weisong
   Zhong, Hong
TI Firework: Data Processing and Sharing for Hybrid Cloud-Edge Analytics
SO IEEE TRANSACTIONS ON PARALLEL AND DISTRIBUTED SYSTEMS
LA English
DT Article
DE Distributed big data processing; edge computing; internet of everything
AB Now we are entering the era of the Internet of Everything (IoE) and billions
of sensors and actuators are connected to the network. As one of the most
sophisticated IoE applications, real-time video analytics is promising to
significantly improve public safety, business intelligence, and healthcare &
life science, among others. However, cloud-centric video analytics requires that
all video data must be preloaded to a centralized cluster or the cloud, which
suffers from high response latency and high cost of data transmission, given the
scale of zettabytes of video data generated by IoE devices. Moreover, video data
is rarely shared among multiple stakeholders due to various concerns, which
restricts the practical deployment of video analytics that takes advantages of
many data sources to make smart decisions. Furthermore, there is no efficient
programming interface for developers and users to easily program and deploy IoE
applications across geographically distributed computation resources. In this
paper, we present a new computing framework, Firework, which facilitates
distributed data processing and sharing for IoE applications via a virtual
shared data view and service composition. We designed an easy-to-use programming
interface for Firework to allow developers to program on Firework. This paper
describes the system design, implementation, and programming interface of
Firework. The experimental results of a video analytics application demonstrate
that Firework reduces up to 19.52 percent of response latency and at least 72.77
percent of network bandwidth cost, compared to a cloud-centric solution.
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FU US National Science Foundation [CNS-1741635]
FX This work is supported in part by US National Science Foundation grant CNS-1741635.
CR Agrawal R, 2000, SIGMOD RECORD, V29, P439
Ananthanarayanan G, 2017, COMPUTER, V50, P58, DOI 10.1109/MC.2017.3641638
[Anonymous], 2014, CISC VIS NETW IND GL
Armbrust M, 2010, COMMUN ACM, V53, P50, DOI 10.1145/1721654.1721672
Bonomi F., 2012, P 1 ED MCC WORKSH MO, P13, DOI DOI 10.1145/2342509.2342513
Cuervo E., 2010, P 8 INT C MOB SYST A, P49, DOI [10.1145/1814433.1814441, DOI 10.1145/1814433.1814441]
Dean J, 2004, USENIX Association Proceedings of the Sixth Symposium on Operating Systems Design and Implementation (OSDE '04), P137
Evans D, 2011, WHITE PAPER, P1, DOI DOI 10.1109/IEEESTD.2007.373646
Fahim A., 2013, P 19 ANN INT C MOB C, P203, DOI [10.1145/2500423.2504576, DOI 10.1145/2500423.2504576]
Fernando N, 2019, IEEE T CLOUD COMPUT, V7, P329, DOI 10.1109/TCC.2016.2560163
Franklin M. J., 2011, SIGMOD, V2011, P61, DOI DOI 10.1145/1989323.1989331
Habak K, 2015, 2015 IEEE 8TH INTERNATIONAL CONFERENCE ON CLOUD COMPUTING, P9, DOI 10.1109/CLOUD.2015.12
Hintjens Pieter, 2013, ZEROMQ MESSAGING MAN
Hunkeler U, 2008, 2008 3RD INTERNATIONAL CONFERENCE ON COMMUNICATION SYSTEM SOFTWARE AND MIDDLEWARE AND WORKSHOPS, VOLS 1 AND 2, P791, DOI 10.1109/COMSWA.2008.4554519
Jain S, 2017, 2017 16TH ACM/IEEE INTERNATIONAL CONFERENCE ON INFORMATION PROCESSING IN SENSOR NETWORKS (IPSN), P119, DOI 10.1145/3055031.3055085
Kemp R., 2012, INT C MOB COMP APPL, V76, P59, DOI DOI 10.1007/978-3-642-29336-8-4
Kreps J., 2011, P NETDB, P1
Little G., 2010, P 23 ANN ACM S US IN, P57, DOI DOI 10.1145/1866029.1866040
Papageorgiou A, 2016, IEEE INT CONGR BIG, P259, DOI 10.1109/BigDataCongress.2016.40
Popovski M., RANDOM CARS DRIVING
Satyanarayanan M, 2009, IEEE PERVAS COMPUT, V8, P14, DOI 10.1109/MPRV.2009.82
Saurez E., 2016, P 10 ACM INT C DISTR, P258, DOI DOI 10.1145/2933267.2933317
Shi C., 2014, P 15 ACM INT S MOB A, P287, DOI DOI 10.1145/2632951.2632958
Shi WS, 2016, IEEE INTERNET THINGS, V3, P637, DOI 10.1109/JIOT.2016.2579198
Shi WS, 2016, COMPUTER, V49, P78, DOI 10.1109/MC.2016.145
Shvachko K, 2010, IEEE S MASS STOR SYS
Simoens P., 2013, P 11 ANN INT C MOB S, P139
Toshniwa A, 2014, SIGMOD'14: PROCEEDINGS OF THE 2014 ACM SIGMOD INTERNATIONAL CONFERENCE ON MANAGEMENT OF DATA, P147, DOI 10.1145/2588555.2595641
Wang J., 2017, P 8 ACM MULT SYST C, P38
Yang DJ, 2012, MOBICOM 12: PROCEEDINGS OF THE 18TH ANNUAL INTERNATIONAL CONFERENCE ON MOBILE COMPUTING AND NETWORKING, P173
Zaharia M, 2013, P 24 ACM S OP SYST P, P423, DOI DOI 10.1145/2517349.2522737
Zaharia Matei, 2010, HOTCLOUD, P10, DOI DOI 10.HTTP://DL.ACM.0RG/CITATI0N.CFM?
Zhang HY, 2017, PROCEEDINGS OF NSDI '17: 14TH USENIX SYMPOSIUM ON NETWORKED SYSTEMS DESIGN AND IMPLEMENTATION, P377
Zhang Q, 2016, PROCEEDINGS OF 2016 FOURTH IEEE WORKSHOP ON HOT TOPICS IN WEB SYSTEMS AND TECHNOLOGIES (HOTWEB), P20, DOI 10.1109/HotWeb.2016.12
Zhang Q, 2016, PR INT CONF AUTONOM, P35, DOI 10.1109/ICAC.2016.27
Zhang T, 2015, P 21 ANN INT C MOB C, P426, DOI DOI 10.1145/2789168.2790123

   Zhang Y, 2012, IEEE INFOCOM SER, P2140, DOI 10.1109/INFCOM.2012.6195597
NR 37
TC 2
Z9 2
U1 5
U2 16
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1314 USA
SN 1045-9219
EI 1558-2183
J9 IEEE T PARALL DISTR
JI IEEE Trans. Parallel Distrib. Syst.
PD SEP 1
PY 2018
VL 29
IS 9
BP 2004
EP 2017
DI 10.1109/TPDS.2018.2812177
PG 14
WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic
SC Computer Science; Engineering
GA GQ2AE
UT WOS:000441445500007
DA 2019-08-06
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PT J
AU Eckstein, L
   Chalmers, D
   Critchley, C
   Jeanneret, R
   McWhirter, R
   Nielsen, J
   Otlowski, M
   Nicol, D
AF Eckstein, Lisa
   Chalmers, Donald
   Critchley, Christine
   Jeanneret, Ruthie
   McWhirter, Rebekah
   Nielsen, Jane
   Otlowski, Margaret
   Nicol, Dianne
TI Australia: regulating genomic data sharing to promote public trust
SO HUMAN GENETICS
LA English
DT Review
ID BROAD CONSENT; BIOBANKING; SAMPLES; LINE; CARE
AB The regulation of genomic data sharing in Australia is a confusing mix of common law, legislation, ethical guidelines, and codes of practice. Beyond privacy laws, which only apply to genomic data that meets the definition of personal information, the key regulatory lever is the National Health and Medical Research Council (NHMRC) National Statement for Ethical Conduct in Human Research (National Statement) (2007). Compliance with the National Statement is a requirement for institutions to apply to the NHMRC for funding, and includesamong other thingsrequirements for review of most genomic research by

Human Research Ethics Committees. The sections of the National Statement specifying requirements for research with human genomic data are currently under review, including proposed new requirements addressing the return of genetic research findings and oversight of transfer agreements. Ensuring the willingness of Australians to donate their genomic information and participate in medical research will require clarification and harmonisation of the applicable regulatory framework, along with reforms to ensure that these regulations reflect the conditions necessary to promote ongoing public trust in researchers and institutions.

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OI McWhirter, Rebekah E/0000-0002-9409-8074; Nicol, Dianne/0000-0002-6553-2839

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CR Aitken M, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0153-x
[Anonymous], 2018, AUSTR COD RESP COND
[Anonymous], 2015, APP GUID
[Anonymous], 2015, APEC PRIV FRAM
[Anonymous], 2018, I CERT ETH REV PROC
[Anonymous], 1977, 7 ALRC
[Anonymous], 2018, ETH COND RES ABR TOR
[Anonymous], 2016, PC12INFORMATION PRIV
[Anonymous], 2013, AAPT MELB IT OWN MOT
[Anonymous], 2017, TENSIONS TRAUMAS HLT
[Anonymous], 2018, NAT APPR SINGL REV M
[Anonymous], 2015, SWINBURNE NATL TECHN
[Anonymous], 2017, APEC CROSS BORD PRIV
[Anonymous], 2017, GEN DAT PROT REG GUI
Australian Government National Health and Medical Research Council, 2007, NAT STAT ETH COND HU
Australian Law Reform Commission, 2014, 123 ALRC
Australian Law Reform Commission and Australian Health Ethics Committee of the National Health and Medical Research Council, 2003, 96 ALRC, V96
Berkman BE, 2014, PERS MED, V11, P285, DOI 10.2217/pme.14.3
Chalmers D, 2015, J LAW MED ETHICS, V43, P703, DOI 10.1111/jlme.12313
Chalmers D, 2014, J BIOETHIC INQ, V11, P301, DOI 10.1007/s11673-014-9552-1
Critchley C, 2017, PUBLIC UNDERST SCI, V26, P671, DOI 10.1177/0963662515623925
Critchley C, 2015, PUBLIC HEALTH GENOM, V18, P160, DOI 10.1159/000375441
De Smit E, 2016, AUSTRALAS MED J, V9, P33, DOI 10.4066/AMJ.2015.2587
Dixon-Woods M, 2011, SOC SCI MED, V73, P1452, DOI 10.1016/j.socscimed.2011.08.031
Dodds Susan, 2002, Monash Bioeth Rev, V21, pS43
Forrest L, 2018, J COMMUN GENET, V9, P57, DOI 10.1007/s12687-017-0323-7
Fraser HE, 2007, MED J AUSTRALIA, V187, P7

```
   Furness PN, 2004, J MED ETHICS, V30, P561, DOI 10.1136/jme.2003.003368
   Garrison NA, 2016, GENET MED, V18, P663, DOI 10.1038/gim.2015.138
   Gillott J, 2014, BIOSCIENCE GOVERNANC, P97
   Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162
   Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
   Johns AL, 2017, MED LAW, V36, P7
   Lipworth W, 2009, J LAW MED, V17, P119
   McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
   McWhirter R, 2015, MONASH BIOETH REV, V33, P203, DOI 10.1007/s40592-015-0037-
8
   McWhirter RE, 2014, J PERS MED, V4, DOI 10.3390/jpm4040459
   Otlowski M, 2013, GENETIC PRIVACY
   Rush A, 2017, RES ETHICS
   Sanderson SC, 2016, EUR J HUM GENET, V24, P14, DOI 10.1038/ejhg.2015.118
   Stegmayr B, 2002, BRIT MED J, V325, P634, DOI 10.1136/bmj.325.7365.634
   Tomlinson T, 2015, JAMA-J AM MED ASSOC, V313, P417, DOI
10.1001/jama.2014.16363
   White VM, 2016, INTERN MED J, V46, P1023, DOI 10.1111/imj.13191
NR 43
TC 2
Z9 2
U1 1
U2 4
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
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J9 HUM GENET
JI Hum. Genet.
PD AUG
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VL 137
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SI SI
BP 583
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WC Genetics & Heredity
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AU Edelstein, M
   Lee, LM
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   Heymann, DL
   Harper, DR
AF Edelstein, Michael
   Lee, Lisa M.
   Herten-Crabb, Asha
   Heymann, David L.
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Harper, David R.
TI Strengthening Global Public Health Surveillance through Data and Benefit Sharing
SO EMERGING INFECTIOUS DISEASES
LA English
DT Review

AB Equitable sharing of public health surveillance data can help prevent or mitigate the effect of infectious diseases. Equitable data sharing includes working toward more equitable sharing of the public health benefits that data sharing brings and requires the engagement of those providing the data, those interpreting and using the data generated by others, those facilitating the data-sharing process, and those deriving and contributing to the benefit. An expert consultation conducted by Chatham House outlined 7 principles to encourage the process of equitable data sharing: 1) building trust, 2) articulating the value, 3) planning for data sharing, 4) achieving quality data, 5) understanding the legal context, 6) creating data-sharing agreements, and 7) monitoring and evaluation. Sharing of public health surveillance data is best done taking into account these principles, which will help to ensure data are shared optimally and ethically, while fulfilling stakeholder expectations and facilitating equitable distribution of benefits.

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FU Bill and Melinda Gates Foundation
FX This manuscript highlights the high-level principles identified as part of a project called "Strengthening Data Sharing for Public Health" conducted by the Chatham House Centre on Global Health Security and funded by the Bill and Melinda Gates Foundation.

CR Anema A, 2014, LANCET INFECT DIS, V14, P1035, DOI 10.1016/S1473-3099(14)70953-3
Bengtsson L, 2011, PLOS MED, V8, DOI 10.1371/journal.pmed.1001083
Brackstone G., 1999, SURV METHODOL, V25, P139
Centers for Disease Control and Prevention, 2011, DAT SEC CONF GUID HI
Chatham House Centre on Global Health Security, GUID SHAR DAT BEN PU
Chunara R, 2015, SCI REP-UK, V5, DOI 10.1038/srep09540
Crook P., 2013, PUBLIC HLTH ENGLAND
Dye C, 2016, B WORLD HEALTH ORGAN, V94, P158, DOI 10.2471/BLT.16.170860
Edelstein M., 2016, ONLINE DATA OFFER HO
Edelstein M, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0100309
Emerson C., DATA SHARING ADV GLO
European Centre for Disease Prevention and Control, LONG TERM SURV STRAT
Finnemore M, 1998, INT ORGAN, V52, P887, DOI 10.1162/002081898550789
Heymann DL, 2004, EMERG INFECT DIS, V10, P173, DOI 10.3201/eid1002.031038
International Organization of Public Health Institutes, 2016, PUBL HLTH SURV CALL
Jamison DT, 2006, DISEASE CONTROL PRIORITIES IN DEVELOPING COUNTRIES, 2ND EDITION, P1
Knobler S., 2004, LEARNING SARS PREPAR
Lan L., 2005, INT PUBLIC MANAGEMEN, V6
Lee LM, 2012, AM J PUBLIC HEALTH, V102, P38, DOI 10.2105/AJPH.2011.300297
Lee LM, 2011, AM J PREV MED, V41, P636, DOI 10.1016/j.amepre.2011.08.015
McNabb SJN, 2014, LANCET RESP MED, V2, P436, DOI 10.1016/S2213-2600(14)70102-X

```
   Mykhalovskiy E, 2006, CAN J PUBLIC HEALTH, V97, P42
   Nordic Outbreak Investigation Team C, 2013, EUROSURVEILLANCE, V18, P20520,
DOI [10.2807/1560-7917, DOI 10.2807/1560-7917.ES2013.18.27.20520, 10.2807/1560-
7917.ES2013.18.27.20520]
   Phommasack Bounlay, 2013, Emerg Health Threats J, V6, DOI
10.3402/ehtj.v6i0.19944
   Royal Society, 2017, MACH LEARN POW PROM
   Rubel A, 2012, KENNEDY INST ETHIC J, V22, P1
   Sane J., OVERCOMING BARRIERS
   Santa-Olalla P, 2013, AM J TROP MED HYG, V89, P688, DOI [10.4269/ajimh.13-
0267, 10.4269/ajtmh.13-0267]
   UK Data Archive, RES DAT LIF CYCL
   United Nations, ANN FIN REP GLOB HLT
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Vayena E, 2015, PLOS COMPUT BIOL, V11, DOI 10.1371/journal.pcbi.1003904
   Velasco E, 2014, MILBANK Q, V92, P7, DOI 10.1111/1468-0009.12038
   WHO, 2005, INT HLTH REG
   Wong John, 2004, SARS EPIDEMIC CHALLE
   World health Organization, 2011, PAND INFL PREPAREDNE
   World Health Organization, 2010, STRENGTH WHO GLOB IN
   World Health Organization, 2017, MEASL SURV DAT
NR 38
TC 2
Z9 2
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U2 12
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PI ATLANTA
PA 1600 CLIFTON RD, ATLANTA, GA 30333 USA
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J9 EMERG INFECT DIS
JI Emerg. Infect. Dis
PD JUL
PY 2018
VL 24
IS 7
BP 1324
EP 1330
DI 10.3201/eid2407.151830
PG 7
WC Immunology; Infectious Diseases
SC Immunology; Infectious Diseases
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PT J
AU Willett, DL
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   Youngblood, JE
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   Basit, MA
AF Willett, Duwayne L.
   Kannan, Vaishnavi
   Chu, Ling
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   Velasco, Ferdinand T.
   Clark, John D.
   Fish, Jason S.
   Ortuzar, Adolfo R.
   Youngblood, Josh E.
   Bhat, Deepa G.
   Basit, Mujeeb A.
TI SNOMED CT Concept Hierarchies for Sharing Definitions of Clinical Conditions Using Electronic Health Record Data
SO APPLIED CLINICAL INFORMATICS
LA English
DT Article
DE SNOMED CT; ICD-10; electronic health records and systems; disease management; health information exchanges; registries; translational research
ID MEDICAL-RECORDS; TRIAL; CARE; INFORMATICS; REGISTRIES; KNOWLEDGE; FRAMEWORK; NETWORK; ALERTS
AB Background Defining clinical conditions from electronic health record (EHR) data underpins population health activities, clinical decision support, and analytics. In an EHR, defining a condition commonly employs a diagnosis value set or grouper. For constructing value sets, Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) offers high clinical fidelity, a hierarchical ontology, and wide implementation in EHRs as the standard interoperability vocabulary for problems. Objective This article demonstrates a practical approach to defining conditions with combinations of SNOMED CT concept hierarchies, and evaluates sharing of definitions for clinical and analytic uses. Methods We constructed diagnosis value sets for EHR patient registries using SNOMED CT concept hierarchies combined with Boolean logic, and shared them for clinical decision support, reporting, and analytic purposes. Results A total of 125 condition-defining standard SNOMED CT diagnosis value sets were created within our EHR. The median number of SNOMED CT concept hierarchies needed was only 2 (25th-75th percentiles: 1-5). Each value set, when compiled as an EHR diagnosis grouper, was associated with a median of 22 International Classification of Diseases (ICD)-9 and ICD-10 codes (25th-75th percentiles: 8-85) and yielded a median of 155 clinical terms available for selection by clinicians in the EHR (25th-75th percentiles: 63-976). Sharing of standard groupers for population health, clinical decision support, and analytic uses was high, including 57 patient registries (with 362 uses of standard groupers), 132 clinical decision support records, 190 rules, 124 EHR reports, 125 diagnosis dimension slicers for self-service analytics, and 111 clinical quality measure calculations. Identical SNOMED CT definitions were created in an EHR-agnostic tool enabling application across disparate organizations and EHRs. Conclusion SNOMED CT-based diagnosis value sets are simple to develop, concise, understandable to clinicians, useful in the EHR and for analytics, and shareable. Developing curated SNOMED CT hierarchy-based condition definitions for public use could accelerate cross-organizational population health efforts, smarter EHR feature configuration, and clinical-translational research employing EHR-derived data.
C1 [Willett, Duwayne L.; Chu, Ling; Clark, John D.; Fish, Jason S.; Basit, Mujeeb A.] Univ Texas Southwestern Med Ctr Dallas, Dept Internal Med, Dallas, TX USA.

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CR Abramson EL, 2016, APPL CLIN INFORM, V7, P994, DOI 10.4338/ACI-2016-04-RA-0069
Adamusiak T, 2014, JMIR MED INF, V2, P20, DOI 10.2196/medinform.3172
Ancker JS, 2017, BMC MED INFORM DECIS, V17, DOI 10.1186/s12911-017-0430-8
[Anonymous], 2017, SNOMED CT EXPR
[Anonymous], 2017, SNOMED CT BROWS
[Anonymous], 2017, SNOMED CT BAS
[Anonymous], 2017, SNOMED CT LOG MOD
[Anonymous], 2017, SNOMED CT CONC MOD
Avorn J, 2010, ARCH INTERN MED, V170, P858, DOI 10.1001/archinternmed.2010.125
Benson T, 2016, PRINCIPLES HLTH INTE, pxxix
Blumenthal D, 2010, NEW ENGL J MED, V363, P501, DOI 10.1056/NEJMp1006114
Bowman Sue, 2005, J AHIMA, V76, P60
Boxwala AA, 2011, J AM MED INFORM ASSN, V18, pI132, DOI 10.1136/amiajnl-2011-000334
Buchanan J, 2017, APPL CLIN INFORM, V8, P180, DOI 10.4338/ACI-2016-04-IE-0054
CMS. gov, 2017, 2018 ICD 10 CM CTR M
Cornet R, 2008, BMC MED INFORM DECIS, V8, DOI 10.1186/1472-6947-8-S1-S2
D'Amore John D, 2011, AMIA Annu Symp Proc, V2011, P285
Falck S, 2013, INT J MED INFORM, V82, P996, DOI 10.1016/j.ijmedinf.2013.07.003
FitzHenry F, 2015, APPL CLIN INFORM, V6, P536, DOI 10.4338/ACI-2014-12-CR-0121
Fleurence RL, 2014, J AM MED INFORM ASSN, V21, P578, DOI 10.1136/amiajnl-2014-002747
Friedman CP, 2010, SCI TRANSL MED, V2, DOI 10.1126/scitranslmed.3001456
Fung K W, 2012, SNOMED CT CAN HELP I
Gottesman O, 2013, GENET MED, V15, P761, DOI 10.1038/gim.2013.72
Halpern Y, 2016, J AM MED INFORM ASSN, V23, P731, DOI 10.1093/jamia/ocw011
Harry E, 2018, NEJM CATALYST NEJM
HL7, 2010, HL7 MEAN US NPRM NOT
Hoffman JM, 2016, J AM MED INFORM ASSN, V23, P796, DOI 10.1093/jamia/ocw027
Hojen AR, 2014, APPL CLIN INFORM, V5, P127, DOI 10.4338/ACI-2013-09-RA-0071
Hojen AR, 2012, METHOD INFORM MED, V51, P529, DOI 10.3414/ME11-02-0023
Hooks C DS, 2018, HL7 BOSTON CHILDRENS
Hsiao Chun-Ju, 2014, Natl Health Stat Report, P1
Kannan V, 2017, METHOD INFORM MED, V56, pE74, DOI 10.3414/ME16-02-0031
Khatipov E, 2014, AMIA ANN S P, P1459
Kruse Clemens Scott, 2016, JMIR Med Inform, V4, pe19, DOI 10.2196/medinform.5525
Leavy M, 2014, REGISTRIES EVALUATIN
Lenfant C, 2003, NEW ENGL J MED, V349, P868, DOI 10.1056/NEJMsa035507
Maddox TM, 2017, CIRCULATION, V135, pE826, DOI 10.1161/CIR.0000000000000480
McCoy AB, 2012, J AM MED INFORM ASSN, V19, P346, DOI 10.1136/amiajnl-2011-000185

```
   McEvoy D, 2018, BMJ QUAL SAF, V27, P40, DOI 10.1136/bmjqs-2017-006707
   Mennemeyer ST, 2016, J AM MED INFORM ASSN, V23, P375, DOI
10.1093/jamia/ocv103
   Morley KI, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0110900
   Motheral BR, 1997, CLIN THER, V19, P346, DOI 10.1016/S0149-2918(97)80122-1
   Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI
10.1136/jamia.2009.000893
   National Library of Medicine (NLM) NLoM, VAL SET AUTH CTR VSA
   Reich C, 2012, J BIOMED INFORM, V45, P689, DOI 10.1016/j.jbi.2012.05.002
   Richesson RL, 2017, J AM MED INFORM ASSN, V24, P996, DOI 10.1093/jamia/ocx016
   Richesson Rachel L, 2016, EGEMS (Wash DC), V4, P1232, DOI 10.13063/2327-
9214.1232
   Robb-Smith A. H. T., 2011, HIST STAT CLASSIFICA
   Rodrigues J-M, 2015, SEMANTIC ALIGNMENT I
   SNOMED_International, 2017, SNOMED CT US ED
   Solomon M, 2016, PERSPECT HLTH INF MA, V13, P1
   Sulaiman IM, 2017, METHOD INFORM MED, V56, P330, DOI 10.3414/ME16-02-0027
   WEED LL, 1968, NEW ENGL J MED, V278, P593, DOI 10.1056/NEJM196803142781105
   Winnenburg Rainer, 2013, AMIA Annu Symp Proc, V2013, P1497
   World Health Organization, 2017, WHO ICD 11 REV INT C
   Wright A, 2012, J AM MED INFORM ASSN, V19, P555, DOI 10.1136/amiajnl-2011-
000521
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J9 APPL CLIN INFORM
JI Appl. Clin. Inform.
PD JUL
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VL 9
IS 3
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WC Medical Informatics
SC Medical Informatics
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TI Ethical concerns on sharing genomic data including patients' family
   members
SO BMC MEDICAL ETHICS
LA English
DT Article
DE Genomic research; Data sharing; Human research protection; Patients and
   family members; ELSI
ID CANCER SUSCEPTIBILITY; PARTICIPANTS; PRIVACY; VIEWS; GENE
AB Background: Platforms for sharing genomic and phenotype data have been
developed to promote genomic research, while maximizing the utility of existing
datasets and minimizing the burden on participants. The value of genomic
analysis of trios or family members has increased, especially in rare diseases
and cancers. This article aims to argue the necessity of protection when sharing
data from both patients and family members.
   Main text: Sharing patients' and family members' data collectively raises an
ethical tension between the value of datasets and the rights of participants,
and increases the risk of re-identification. However, current data-sharing
policies have no specific safeguards or provisions for familial data sharing. A
quantitative survey conducted on 10,881 general adults in Japan indicated that
they expected stronger protection mechanisms when their family members' clinical
and/or genomic data were shared together, as compared to when only their data
were shared. A framework that respects decision-making and the right of
withdrawal of participants, including family members, along with ensuring
usefulness and security of data is needed. To enable this, we propose
recommendations on ancillary safeguards for familial data sharing according to
the stakeholders, namely, initial researchers, genomic researchers, data
submitters, database operators, institutional review boards, and the public and
participants.
   Conclusions: Families have played significant roles in genetic research, and
its value is re-illuminated in the era of genomic medicine. It is important to
make progress in data sharing while simultaneously protecting the privacy and
interests of patients and families, and return its benefits to them.
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FU Ministry of Education, Culture, Sports, Science and Technology of Japan
   (MEXT); Japan Agency for Medical Research and Development (AMED)'s
   "Project for Development of Innovative REsearch on Cancer Treatment
   (P-DIRECT)"; Japan Agency for Medical Research and Development (AMED)'s
   "Project for Cancer REsearch And Therapeutic Evolution (P-CREATE)"; JSPS
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CR Beskow LM, 2004, AM J MED GENET A, V130A, P424, DOI 10.1002/ajmg.a.30234
Budin-Ljosne I, 2014, EUR J HUM GENET, V22, P317, DOI 10.1038/ejhg.2013.131
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Chandler MR, 2016, HUM MUTAT, V37, P835, DOI 10.1002/humu.23017
Doernberg SN, 2016, JAMA-J AM MED ASSOC, V316, P1149, DOI 10.1001/jama.2016.7970
Erlich Y, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001983
FitzGerald LM, 2013, CANCER EPIDEM BIOMAR, V22, P1520, DOI 10.1158/1055-9965.EPI-13-0345
Global Alliance for Genomics and Health, 2016, Science, V352, P1278, DOI 10.1126/science.aaf6162
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hudson TJ, 2010, NATURE, V464, P993, DOI 10.1038/nature08987
Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
Kaye J, 2012, ANNU REV GENOM HUM G, V13, P415, DOI 10.1146/annurev-genom-082410-101454
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Majumder MA, 2016, PLOS BIOL, V14, DOI 10.1371/journal.pbio.2000206
McGuire AL, 2006, SCIENCE, V312, P370, DOI 10.1126/science.1125339
National Bioscience Database Center, NBDC HUM DAT SHAR GU
National Cancer Institute, GEN CANC
National Institutes of Health:, GEN DAT SHAR POL
Noetzli L, 2015, NAT GENET, V47, P535, DOI 10.1038/ng.3253
OECD, 2007, OECD PRINC GUID ACC
Pereira S, 2014, GENES-BASEL, V5, P739, DOI 10.3390/genes5030739
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
Roberts NJ, 2016, CANCER DISCOV, V6, P166, DOI 10.1158/2159-8290.CD-15-0402
Sawyer SL, 2016, CLIN GENET, V89, P275, DOI 10.1111/cge.12654
Schulz E, 2014, NAT COMMUN, V5, DOI 10.1038/ncomms6191
Shringarpure SS, 2015, AM J HUM GENET, V97, P631, DOI 10.1016/j.ajhg.2015.09.010
Taichman DB, 2017, ANN INTERN MED, V167, P63, DOI 10.7326/M17-1028
Takashima K, 2016, EUROPEAN C HUMAN GEN
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
NR 30
TC 2
Z9 2
U1 1
U2 8
PU BIOMED CENTRAL LTD
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PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
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J9 BMC MED ETHICS
JI BMC Med. Ethics
PD JUN 18
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AR 61
DI 10.1186/s12910-018-0310-5

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PG 6
WC Ethics; Medical Ethics; Social Sciences, Biomedical
SC Social Sciences - Other Topics; Medical Ethics; Biomedical Social
   Sciences
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   Fullerton, Kathleen
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   Stoutenburg, Suzette
   Hall, Jason
   Crum, Melvin
   Garcia, Macarena C.
   Iademarco, Michael F.
   Richards, Chesley L.
TI Modernizing Centers for Disease Control and Prevention Informatics Using
   Surveillance Data Platform Shared Services
SO PUBLIC HEALTH REPORTS
LA English
DT Article
DE public health surveillance; public health informatics; interoperability;
   change management
C1 [Lee, Brian; Richards, Chesley L.] Ctr Dis Control & Prevent, Off Publ Hlth
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```
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CR [Anonymous], 2015, CONN HLTH CAR NAT SH
   [Anonymous], 2014, SURV STRAT STRAT IMP
   Executive Office of the President of the United States, 2012, FED INF TECHN
SHAR S
   Fielding RT, 2014, HYPERTEXT TRANSFER P
   Hardt D., 2012, OAUTH 2 0 AUTHORIZAT
   Health Level Seven International, FAST HEALTHC INT RES
   Jellison J, 2016, COLLABORATIVE DESIGN
   Knapp Jake, 2016, SPRINT SOLVE BIG PRO
   Mac Kenzie WR, 2016, PUBLIC HEALTH REP, V131, P742, DOI
10.1177/0033354916670871
   Public Health Surveillance Story Tracker, JIR SYST DASHB
   Public Health Surveillance Wiki Confluence, PLATFORM
   Richards CL, 2014, PUBLIC HEALTH REP, V129, P472, DOI
10.1177/003335491412900603
   Scrum Alliance, SCRUM GUIDE
   Surveillance Data Platform, GITHUB REP CDCS SURV
   Surveillance Leadership Board Platform Workgroup, DES PRINC
   Surveillance Leadership Board Platform Workgroup, SERV DEF
   Thacker Stephen B, 2012, MMWR Suppl, V61, P3
   The Office of the National Coordinator for Health Information Technology,
2014, CONN HLTH CAR NAT 10
NR 18
TC 2
Z9 2
U1 0
U2 1
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 0033-3549
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SC Public, Environmental & Occupational Health
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PT S
AU Zhang, HR
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AF Zhang, Haoran
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Xi, Tianqi
Zheng, Jianqin
Haung, Dou
Shibasaki, Ryosuke
Yan, Yamin
Liang, Yongtu
BE Wang, H
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Wu, J
Yang, Y
Li, H
TI MaaS in Bike-Sharing: Smart Phone GPS Data Based Layout Optimization and Emission Reduction Potential Analysis
SO CLEANER ENERGY FOR CLEANER CITIES
SE Energy Procedia
LA English
DT Proceedings Paper
CT Applied Energy Symposium and Forum - Low-Carbon Cities and Urban Energy Systems (CUE)
CY JUN 05-07, 2018
CL Shanghai, PEOPLES R CHINA
SP Appl Energy, Appl Energy Innovat Inst, Tongji Univ, China Assoc Sci & Technol, HOME Program, Malardalen Univ, Future Energy Profile, Shanghai Key Lab Urban Regenerat & Spatial Optimizat Technol, MOE Joint Lab Int Cooperat Eco Urban Design, Sichuan Univ, Shanghai Univ Electric Power, BEEUE, Int Clean Energy Talent Program, UNiLAB
DE Bike-sharing; Mobility as a Service; Layout optimization; Emission reduction potential
ID PARTICLE SWARM; BEHAVIOR
AB As a representation of smart and green city development, bike-sharing system is one of the hottest topic in the fields of transportation, public health, urban planning, and so on. With the development of Mobility as a Service (MaaS), emerging technologies such as mobile data mining give some new solutions for optimizing bike-sharing system and predicting the emission reduction. Here, we propose a bike-sharing layout optimization and emission reduction potential analysis structure under the concept of MaaS. A human travel mode detection method and a geometry-based probability model are proposed to support the particle swarm optimization process. We implement a comparison study to analyze the computational efficiency. Taking Setagaya ward, Tokyo as the study case with about 3 million GPS trajectories, the result shows that with the increase of station number from 30 to 90, the adoption of bike-sharing system can reduce about 3.1-3.8 thousand tonnes of CO2 emission. Copyright (C) 2018 Elsevier Ltd. All rights reserved.
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FU JST, Strategic International Collaborative Research Program (SICORP); Leading Initiative for Excellent Young Researchers (LEADER) Program [17H01784]; Japan Ministry of Education, Culture, Sports, Science and Technology (MEXT)
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CR Chen Q, 2015, J ADV TRANSPORT, V49, P884, DOI 10.1002/atr.1311
Kennedy J, 1995, 1995 IEEE INTERNATIONAL CONFERENCE ON NEURAL NETWORKS PROCEEDINGS, VOLS 1-6, P1942, DOI 10.1109/ICNN.1995.488968
Li PL, 2018, APPL ENERG, V211, P820, DOI 10.1016/j.apenergy.2017.11.022
Mendes R, 2004, IEEE T EVOLUT COMPUT, V8, P204, DOI [10.1109/TEVC.2004.826074, 10.1109/tevc.2004.826074]
Niu B, 2007, APPL MATH COMPUT, V185, P1050, DOI 10.1016/j.amc.2006.07.026
Shaheen SA, 2010, TRANSP RES RECORD, P159, DOI 10.3141/2143-20
Zhang H., 2018, APPL SOFT COMPUTING
Zhang HR, 2018, APPL ENERG, V220, P527, DOI 10.1016/j.apenergy.2018.03.105
Zhang YP, 2018, APPL ENERG, V220, P296, DOI [10.1016/j.epenergy.2018.03.101, 10.1016/j.apenergy.2018.03.101]
NR 9
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Z9 2
U1 0
U2 0
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J9 ENRGY PROCED
PY 2018
VL 152
BP 649
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DI 10.1016/egypro.2018.09.225
PG 6
WC Energy & Fuels; Environmental Sciences
SC Energy & Fuels; Environmental Sciences & Ecology
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PT J
AU Xia, WY
Wan, ZY
Yin, ZJ
Gaupp, J

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   Liu, YT
   Clayton, EW
   Kantarcioglu, M
   Vorobeychik, Y
   Malin, BA
AF Xia, Weiyi
   Wan, Zhiyu
   Yin, Zhijun
   Gaupp, James
   Liu, Yongtai
   Clayton, Ellen Wright
   Kantarcioglu, Murat
   Vorobeychik, Yevgeniy
   Malin, Bradley A.
TI It's all in the timing: calibrating temporal penalties for biomedical
   data sharing
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
DE biomedical data science; data sharing; policy; economics of data;
   genomics
ID BIG DATA; GENOME
AB Biomedical science is driven by datasets that are being accumulated at an
unprecedented rate, with ever-growing volume and richness. There are various
initiatives to make these datasets more widely available to recipients who sign
Data Use Certificate agreements, whereby penalties are levied for violations. A
particularly popular penalty is the temporary revocation, often for several
months, of the recipient's data usage rights. This policy is based on the
assumption that the value of biomedical research data depreciates significantly
over time; however, no studies have been performed to substantiate this belief.
This study investigates whether this assumption holds true and the data science
policy implications.
   This study tests the hypothesis that the value of data for scientific
investigators, in terms of the impact of the publications based on the data,
decreases over time. The hypothesis is tested formally through a mixed linear
effects model using approximately 1200 publications between 2007 and 2013 that
used datasets from the Database of Genotypes and Phenotypes, a data-sharing
initiative of the National Institutes of Health.
   The analysis shows that the impact factors for publications based on Database
of Genotypes and Phenotypes datasets depreciate in a statistically significant
manner. However, we further discover that the depreciation rate is slow, only 10%
per year, on average.
   The enduring value of data for subsequent studies implies that revoking usage
for short periods of time may not sufficiently deter those who would violate
Data Use Certificate agreements and that alternative penalty mechanisms may need
to be invoked.
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FU National Institutes of Health [R01HG006844, RM1HG009034, U01HG006385, U01HG006378]; National Library of Medicine Training Grant [T15 LM007450]
FX This research was sponsored, in part, by the following grants from the National Institutes of Health: R01HG006844, RM1HG009034, U01HG006385, U01HG006378, and the the National Library of Medicine Training Grant T15 LM007450. The authors also wish to thank the following employees of the NIH for providing some of the core of the dataset used in this study, as well as helpful discussions on modeling and initial findings: Mike Feolo, Masato Kimura, Kristofor Langlais, Dina Paltoo, and Laura Rodriguez.
CR Acland A, 2014, NUCLEIC ACIDS RES, V42, pD7, DOI 10.1093/nar/gkt1146
Adler-Milstein J, 2015, HEALTH AFFAIR, V34, P2174, DOI 10.1377/hlthaff.2015.0992
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Borgman CL, 2010, RES DATA WHO WILL SH
Burton PR, 2007, NATURE, V447, P661, DOI 10.1038/nature05911
Garfield E, 2006, JAMA-J AM MED ASSOC, V295, P90, DOI 10.1001/jama.295.1.90
Grajales FJ, 2014, J MED INTERNET RES, V16, DOI 10.2196/jmir.2912
Hayden EC, 2014, NATURE, V507, P294, DOI 10.1038/507294a
Kumar S, 2015, J AM MED INFORM ASSN, V22, P1137, DOI 10.1093/jamia/ocv056
Mailman MD, 2007, NAT GENET, V39, P1181
Margolis R, 2014, J AM MED INFORM ASSN, V21, P957, DOI 10.1136/amiajnl-2014-002974
Murdoch TB, 2013, JAMA-J AM MED ASSOC, V309, P1351, DOI 10.1001/jama.2013.393
National Academies of Sciences Engineering and Medicine, 2017, FOST INT RES
National Institutes of Health, COMPL STAT POL GOV D
National Science Foundation, DISS SHAR RES RES
NIH, 2014, NIH GEN DAT SHAR POL
*NIH, 2003, FIN NIH STAT SHAR RE
NIH, 2007, POL SHAR DAT OBT NIH
Pacheco CM, 2013, AM J PUBLIC HEALTH, V103, P2152, DOI 10.2105/AJPH.2013.301480
Paltoo DN, 2014, NAT GENET, V46, P934, DOI 10.1038/ng.3062
Patient Centered Outcomes Research Institute, 2016, DAT ACC DAT SHAR POL
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Piwowar HA, 2011, NATURE, V473, P285, DOI 10.1038/473285a
Rodriguez LL, 2013, SCIENCE, V339, P275, DOI 10.1126/science.1234593
West JD, 2010, COLL RES LIBR, V71, P236, DOI 10.5860/0710236
Xia W, DRYAD DIGITAL REPOSI
NR 26
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PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
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IS 1
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WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
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SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
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PT J
AU Conrado, DJ
   Karlsson, MO
   Romero, K
   Sarr, C
   Wilkins, JJ
AF Conrado, Daniela J.
   Karlsson, Mats O.
   Romero, Klaus
   Sarr, Celine
   Wilkins, Justin J.
TI Open innovation: Towards sharing of data, models and workflows
SO EUROPEAN JOURNAL OF PHARMACEUTICAL SCIENCES
LA English
DT Review
DE Open innovation; Data sharing; Pharmacometric models; Modelling
   workflows; Drug development
ID CANCER-RESEARCH; MANAGEMENT; HEALTH
AB Sharing of resources across organisations to support open innovation is an
old idea, but which is being taken up by the scientific community at increasing
speed, concerning public sharing in particular. The ability to address new
questions or provide more precise answers to old questions through merged
information is among the attractive features of sharing. Increased efficiency
through reuse, and increased reliability of scientific findings through enhanced
transparency, are expected outcomes from sharing. In the field of
pharmacometrics, efforts to publicly share data, models and workflow have
recently started.
   Sharing of individual-level longitudinal data for modelling requires solving
legal, ethical and proprietary issues similar to many other fields, but there
are also pharmacometric-specific aspects regarding data formats, exchange
standards, and database properties. Several organisations (CDISC, C-Path, IMI,
ISoP) are working to solve these issues and propose standards. There are also a
number of initiatives aimed at collecting disease-specific databases-Alzheimer's
Disease (ADNI, CAMD), malaria (WWARN), oncology (PDS), Parkinson's Disease
(PPMI), tuberculosis (CPTR, TB-PACTS, ReSeqTB)-suitable for drug-disease
modelling. Organized sharing of pharmacometric executable model code and
associated information has in the past been sparse, but a model repository
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(DDMoRe Model Repository) intended for the purpose has recently been launched. In addition several other services can facilitate model sharing more generally. Pharmacometric workflows have matured over the last decades and initiatives to more fully capture those applied to analyses are ongoing.

In order to maximize both the impact of pharmacometrics and the knowledge extracted from clinical data, the scientific community needs to take ownership of and create opportunities for open innovation.

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CR Aarts AA, 2015, SCIENCE, V349, DOI 10.1126/science.aac4716
Begley CG, 2012, NATURE, V483, P531, DOI 10.1038/483531a
Berthold MR, 2008, STUD CLASS DATA ANAL, P319, DOI 10.1007/978-3-540-78246-9_38
Brumfield M, 2014, NAT REV DRUG DISCOV, V13, P785, DOI 10.1038/nrd4436
Button KS, 2013, NAT REV NEUROSCI, V14, P365, DOI 10.1038/nrn3475
Ebrahim S, 2014, JAMA-J AM MED ASSOC, V312, P1024, DOI 10.1001/jama.2014.9646
European Medicines Agency (EMA), 2014, EUR MED AG POL PUBL
Gorgolewski KJ, 2016, PLOS BIOL, V14, DOI 10.1371/journal.pbio.1002506
Grasela T. H., 2007, PHARMACOMETRICS, P901
Green AK, 2015, ONCOLOGIST, V20, P464, DOI 10.1634/theoncologist.2014-0431
ISoP, 2016, ISOP SURV
Jumbe NL, 2016, NEW ENGL J MED, V374, P2415, DOI 10.1056/NEJMp1605441
Keizer RJ, 2011, COMPUT METH PROG BIO, V101, P72, DOI 10.1016/j.cmpb.2010.04.018
Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
Loukides G, 2010, P NATL ACAD SCI USA, V107, P7898, DOI 10.1073/pnas.0911686107
Ludascher B, 2006, CONCURR COMP-PRACT E, V18, P1039, DOI 10.1002/cpe.994
Macleod MR, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002273
Marek K, 2011, PROG NEUROBIOL, V95, P629, DOI 10.1016/j.pneurobio.2011.09.005
Marshall SF, 2016, CPT-PHARMACOMET SYST, V5, P93, DOI 10.1002/psp4.12049
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Piwowar HA, 2013, PEERJ, V1, DOI 10.7717/peerj.175
Prinz F, 2011, NAT REV DRUG DISCOV, V10, P10, DOI DOI 10.1038/NRD3439-C1.(712-712)
Stephenson D, 2015, J PARKINSON DIS, V5, P581, DOI 10.3233/JPD-150570
Strom BL, 2016, NEW ENGL J MED, V375, P1608, DOI 10.1056/NEJMp1610336
TransCelerate, 2013, DAT DE ID AN IND PAT
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Wang SV, 2016, CLIN PHARMACOL THER, V99, P325, DOI 10.1002/cpt.329
Weiner Michael W, 2015, Alzheimers Dement, V11, pe1, DOI 10.1016/j.jalz.2014.11.001
Wilhelm EE, 2014, JAMA-J AM MED ASSOC, V311, P1201, DOI 10.1001/jama.2014.850
Wilkins J., CLIN PHARM IN PRESS
Wilkins JJ, 2005, COMPUT METH PROG BIO, V78, P259, DOI 10.1016/j.cmpb.2005.02.003
Wolstencroft K, 2013, NUCLEIC ACIDS RES, V41, pW557, DOI 10.1093/nar/gkt328
Xie Y., 2014, IMPLEMENTING REPROD

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PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
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J9 EUR J PHARM SCI
JI Eur. J. Pharm. Sci.
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PY 2017
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SI SI
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WC Pharmacology & Pharmacy
SC Pharmacology & Pharmacy
GA FM7TI
UT WOS:000415283100012
PM 28684136
DA 2019-08-06
ER

PT J
AU Verropoulou, G
   Tsimbos, C
AF Verropoulou, Georgia
   Tsimbos, Cleon
TI Disability trends among older adults in ten European countries over
   2004-2013, using various indicators and Survey of Health, Ageing and
   Retirement in Europe (SHARE) data
SO AGEING & SOCIETY
LA English
DT Article
DE disability trends; Global Activity Limitation Indicator (GALI);
   activities of daily living; instrumental activities of daily living;
   mobility difficulties
ID LATE-LIFE DISABILITY; UNITED-STATES; INSTRUMENTAL ACTIVITIES;
   GENDER-DIFFERENCES; SELF-REPORTS; AGE 65; POPULATION; PEOPLE;
   LIMITATIONS; PREVALENCE
AB In the context of the prospective increase in the numbers of older adults in
Europe and of conflicting findings regarding recent disability trends, the
present study uses cross-sectional data from four waves of the Survey of Health,
Ageing and Retirement in Europe (SHARE), covering the period 2004-2013, and aims
at the assessment of trends in disability by sex and broad age group (50-64 and
65 and over) for the ten countries participating in all waves, based on four
different measures: limitations in activities of daily living (ADLs),
limitations in instrumental ADLs, mobility difficulties and the Global Activity
Limitation Indicator. The analysis uses logistic regression models adjusted for
age and, subsequently, also for chronic conditions. The findings indicate
improvements both in mild/moderate activity restrictions and in functional
limitations for several countries, especially among men and women aged 65 and
over. Regarding severe disability (ADLs) there is mostly a lack of any
significant trend and only a few declines. In several instances, the observed
trends are linked to changes in chronic conditions; significant improvements net
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of chronic conditions are found mainly in Sweden but also in the Netherlands, Austria, Germany, Italy and France. Overall, the estimated trends often differentiate by country, age group and sex while they depend upon the specificities of the measures used in the analysis.
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FU European Commission [QLK6-CT-2001-00360, SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812, 211909, 227822, 261982]; German Ministry of Education and Research; US National Institute on Aging [U01_AG09740-13S2, P01_ AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_ BSR06-11, OGHA_04-064]; European Union - programme of 'Thalis - Panteion - Investigating Crucial Interdisciplinary Linkages in Ageing Societies' part of the Operational Programme of 'Education and Lifelong Learning' [MIS380266]
FX This paper uses data from SHARE Waves 1, 2, 4 and 5 (doi: 10.6103/SHARE.w1.260, 10.6103/SHARE.w2.260 , 10.6103/SHARE.w4.111, 10.6103/SHARE.w5.100, respectively); see Borsch-Supan et al. (2013) for methodological details. The SHARE data collection has been primarily funded by the European Commission through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812) and FP7 (SHARE-PREP: No211909, SHARE-LEAP: No227822, SHARE M4: No261982). Additional funding from the German Ministry of Education and Research, the US National Institute on Aging (U01_AG09740-13S2, P01_ AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, IAG_ BSR06-11, OGHA_04-064) and from various national funding sources is gratefully acknowledged (see www.share-project.org). Further, the European Union provided partial funding to the present study through the co-funded programme of 'Thalis - Panteion - Investigating Crucial Interdisciplinary Linkages in Ageing Societies' which is part of the Operational Programme of 'Education and Lifelong Learning' (MIS380266). Finally, the authors would like to thank two anonymous referees for their constructive criticism and help in improving this paper. No statement of ethical approval is required.
CR Altmets K, 2010, EUROPEAN J PUBLIC HL, V21, P49
   Arber S, 1999, SOC SCI MED, V48, P61, DOI 10.1016/S0277-9536(98)00289-5
   Bhattacharya J, 2008, MED CARE, V46, P92, DOI 10.1097/MLR.0b013e3181484335
   Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
   Bonneux L, 2012, 112 ENEPRI
   CAMBOIS E., 2012, EUROPEAN J PUBLIC HL, V23, P575
   Cambois E, 2008, EUR J AGEING, V5, P287, DOI 10.1007/s10433-008-0097-1
   Crimmins EM, 1997, POPUL DEV REV, V23, P555, DOI 10.2307/2137572
   De Luca G, 2005, SURVEY HLTH AGEING R, P88
   Dunlop DD, 2002, ARCH PHYS MED REHAB, V83, P964, DOI 10.1053/apmr.2002.32817
   Egidi V., 2003, GENUS, VLIX, P169
   Fonda S., 2004, DOCUMENTATION PHYS F
   Freedman VA, 2004, DEMOGRAPHY, V41, P417, DOI 10.1353/dem.2004.0022
   Freedman VA, 2002, JAMA-J AM MED ASSOC, V288, P3137, DOI 10.1001/jama.288.24.3137
   Freedman VA, 2013, DEMOGRAPHY, V50, P661, DOI 10.1007/s13524-012-0167-z
   Giannakouris K., 2008, POPULATION SOCIAL CO
   Gilmour Heather, 2006, Health Rep, V16 Suppl, P21
   Goldman N, 2003, J CLIN EPIDEMIOL, V56, P148, DOI 10.1016/S0895(02)00580-2

Griffith L, 2010, AGE AGEING, V39, P738, DOI 10.1093/ageing/afq105
Grundy E, 2006, EUR J POPUL, V22, P215, DOI 10.1007/s10680-006-9005-6
Jagger C., 2012, 20125 EHLEIS
Jagger C, 2007, HLTH EXPECTANCY CALC
Jagger C, 2010, J CLIN EPIDEMIOL, V63, P892, DOI 10.1016/j.jclinepi.2009.11.002
JETTE AM, 1994, SOC SCI MED, V38, P937, DOI 10.1016/0277-9536(94)90426-X
KATZ S, 1983, J AM GERIATR SOC, V31, P721, DOI 10.1111/j.1532-5415.1983.tb03391.x
KATZ S, 1963, JAMA-J AM MED ASSOC, V185, P914, DOI 10.1001/jama.1963.03060120024016
KATZ S, 1970, GERONTOLOGIST, V10, P20, DOI 10.1093/geront/10.1_Part_1.20
KLEVMARKEN A, 2005, SURVEY HLTH AGING RE, P28
LAWTON MP, 1969, GERONTOLOGIST, V9, P179, DOI 10.1093/geront/9.3_Part_1.179
Lutz W, 2001, NATURE, V412, P543, DOI 10.1038/35087589
Lutz W., 2005, VIENNA YB POPULATION, V2005, P219
MacIntyre S, 1996, SOC SCI MED, V42, P617, DOI 10.1016/0277-9536(95)00335-5
Manton KG, 2001, P NATL ACAD SCI USA, V98, P6354, DOI 10.1073/pnas.111152298
Martin LG, 2014, DISABIL HEALTH J, V7, pS4, DOI 10.1016/j.dhjo.2013.06.007
Martin LG, 2011, POP STUD-J DEMOG, V65, P289, DOI 10.1080/00324728.2011.604730
Martin LG, 2010, HEALTH AFFAIR, V29, P725, DOI 10.1377/hlthaff.2008.0746
Melvin J, 2014, DEMOGR RES, V31, P497, DOI 10.4054/DemRes.2014.31.17
Moe JO, 2011, EUR J AGEING, V8, P49, DOI 10.1007/s10433-011-0179-3
Parker MG, 2007, GERONTOLOGIST, V47, P150, DOI 10.1093/geront/47.2.150
Parker M, 2008, EUR J AGEING, V5, P299, DOI 10.1007/s10433-008-0096-2
Parker MG, 2005, J GERONTOL A-BIOL, V60, P1351, DOI 10.1093/gerona/60.10.1351
Robine JM, 2013, ARCH PUBLIC HEALTH, V71, DOI 10.1186/0778-7367-71-2
Robine JM, 2003, EUR J PUBLIC HEALTH, V13, P6, DOI 10.1093/eurpub/13.suppl_1.6
Schoeni RF, 2006, POP STUD-J DEMOG, V60, P39, DOI 10.1080/00324720500462280
Schoeni RF, 2008, MILBANK Q, V86, P47, DOI 10.1111/j.1468-0009.2007.00513.x
Seeman TE, 2010, AM J PUBLIC HEALTH, V100, P100, DOI 10.2105/AJPH.2008.157388
SHARE, 2013, SHARE REL GUID 2 6 0
SHARE, 2015, SHARE REL GUID 1 0 0
SHARE, 2015, SHARE REL GUID 1 1 1
Skinner KM, 2005, J AMBUL CARE MANAG, V28, P102
Sulander T, 2006, INT J EPIDEMIOL, V35, P1255, DOI 10.1093/ije/dyl183
Oyen H, 2006, SOZ PRAVENTIV MED, V51, P153, DOI 10.1007/s00038-006-0035-y
VERBRUGGE LM, 1994, SOC SCI MED, V38, P1, DOI 10.1016/0277-9536(94)90294-1
Wahrendorf M, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0071893
Woo J, 1998, J GERONTOL A-BIOL, V53, pM102, DOI 10.1093/gerona/53A.2.M102
World Health Organization, 2001, INT CLASS FUNCT DIS

NR 56
TC 2
Z9 2
U1 1
U2 13
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WC Gerontology
SC Geriatrics & Gerontology
GA FK0IL
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PT J
AU Raza, S
Hall, A
AF Raza, Sobia
Hall, Alison
TI Genomic medicine and data sharing
SO BRITISH MEDICAL BULLETIN
LA English
DT Review
DE genomics; data sharing; clinical care; policy
ID GENETICS; VARIANTS; RESOURCE
AB Introduction: Effective data sharing does not occur in the UK despite being essential for the delivery of high-quality genomic services to patients across clinical specialities and to optimize advances in genomic medicine.

Sources of data: Original papers, reviews, guidelines, policy papers and web-resources.

Areas of agreement: Data sharing for genomic medicine requires appropriate infrastructure and policies, together with acceptance by health professionals and the public of the necessity of data sharing for clinical care.

Areas of controversy: There is ongoing debate around the different technical approaches and safeguards that could be used to facilitate data sharing while minimizing the risks to individuals of identification. Lack of consensus undermines trust and confidence.

Growing points: Ongoing policy developments around genomics and health data create opportunities to ensure systems and policies are in place to support proportionate, effective and safeguarded data sharing.

Areas timely for developing research: Mechanisms to improve public trust.
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[Anonymous], 2017, PROMOTING GENE TESTI
[Anonymous], 2016, ONE WAY MIRROR PUBLI
[Anonymous], 2016, IMPR OUTC THROUGH PE
Ayday E, 2015, COMPUTER, V48, P58, DOI 10.1109/MC.2015.59
Ball MP, 2012, P NATL ACAD SCI USA, V109, P11920, DOI 10.1073/pnas.1201904109
Boycott KM, 2013, NAT REV GENET, V14, P681, DOI 10.1038/nrg3555
Chatzimichali EA, 2015, HUM MUTAT, V36, P941, DOI 10.1002/humu.22842
General Medical Council, 2017, CONF GOOD PRACT HAND
Girdea M, 2013, HUM MUTAT, V34, P1057, DOI 10.1002/humu.22347
Gradishar W, 2017, ONCOLOGIST, V22, P797, DOI 10.1634/theoncologist.2016-0431
Harrison SM, 2017, GENET MED, V19, P1096, DOI 10.1038/gim.2017.14
Kaye J, 2014, MED LAW REV, V22, P64, DOI 10.1093/medlaw/fwt027
Kohler S, 2009, AM J HUM GENET, V85, P457, DOI 10.1016/j.ajhg.2009.09.003

```
   Landrum MJ, 2016, NUCLEIC ACIDS RES, V44, pD862, DOI 10.1093/nar/gkv1222
   Lek M, 2016, NATURE, V536, P285, DOI 10.1038/nature19057
   Manrai AK, 2016, NEW ENGL J MED, V375, P655, DOI 10.1056/NEJMsa1507092
   Miller NA, 2015, GENOME MED, V7, DOI 10.1186/s13073-015-0221-8
   National Data Guardian for Health and Care, 2013, INF SHAR NOT SHAR IN
   National Data Guardian for Health and Care, 2016, REV DAT SEC CONS OPT
   Ohm P, 2010, UCLA LAW REV, V57, P1701
   Raza S, 2015, PHG FDN ASS CLIN GEN
   Rehm HL, 2017, NAT REV GENET, V18, P259, DOI 10.1038/nrg.2016.162
   Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
   Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
   Saunders CJ, 2012, SCI TRANSL MED, V4, DOI 10.1126/scitranslmed.3004041
   Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
   Wright Caroline F, 2017, Wellcome Open Res, V2, P15, DOI
10.12688/wellcomeopenres.10942.1
   Wright CF, 2016, NAT REV GENET, V17, P1, DOI 10.1038/nrg.2015.5
   Wright CF, 2015, LANCET, V385, P1305, DOI 10.1016/S0140-6736(14)61705-0
NR 30
TC 2
Z9 2
U1 2
U2 5
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 0007-1420
EI 1471-8391
J9 BRIT MED BULL
JI Br. Med. Bull.
PD SEP
PY 2017
VL 123
IS 1
BP 35
EP 45
DI 10.1093/bmb/ldx024
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WC Medicine, General & Internal
SC General & Internal Medicine
GA FJ6GI
UT WOS:000412854400004
PM 28910995
OA Bronze, Green Published
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ER

PT J
AU Petrova, M
   Barclay, M
   Barclay, SS
   Barclay, SIG
AF Petrova, Mila
   Barclay, Matthew
   Barclay, Sam S.
   Barclay, Stephen I. G.
TI Between "the best way to deliver patient care" and "chaos and low
   clinical value": General Practitioners' and Practice Managers' views on
   data sharing
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SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Health information exchange [MeSH]; Electronic health records [MeSH];
Case management [MeSH]; General pracitce [MeSH]; Health knowledge;
Attitudes; Practice [MeSH]
ID HEALTH INFORMATION EXCHANGE; MULTIPLE IMPUTATION; PILOT PROGRAM; RECORD
DATA; SYSTEMS; IMPACT; USAGE

AB Objective: In the UK, General Practitioners and Practice Managers are key to enabling health information exchange (typically referred to as ` data sharing'). This study aimed to survey GPs and PMs for familiarity, engagement with and perceptions of patient data sharing.

Methods: Cross-sectional survey. All 107 general practices in England's second largest Clinical Commissioning Group, Cambridgeshire & Peterborough CCG. Descriptive statistics; hierarchical logistic regression; thematic analysis.

Results: 405 (64%) responses were received -from 338 (62%) GPs and 67 (71%) PMs. Familiarity and engagement were highest for local frail elderly and end of life care projects (> 76% had used). The greatest difference in use concerned the now suspended national care. data initiative: PMs had odds of reporting use 75 times higher than GP partners (95% CI 27-211). Patient confusion was the most pronounced challenge and improved coordination the most pronounced expected benefit. Frequency of discussions with patients varied with IT competence (OR 4.2 for most competent users relative to least, 95% CI 1.7-10.7) and clinical system (OR 0.3, 95% CI 0.1-0.5). Patient reservations were reported more frequently by respondents who rated their IT competence as highest (OR 3.3, 95% CI 1.5-7.6), perceived more data sharing challenges (OR for a 1-point increase in challenges perception score 3.4, 95% CI 2.1-5.6) and by PMs (relative to GP partners, OR 18.0, 95% CI 7.9-41.3).

Conclusions: Familiarity with and use of data sharing projects was high among GPs and PMs. Both their individual and organisational characteristics were associated with the reported frequency of discussions and patients' responses. Improved awareness of the impact of provider characteristics and attitudes on patients' decisions about data sharing may enhance the equity and autonomy of those decisions.

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FU National Institute for Health Research (NIHR); Cambridgeshire and
Peterborough NHS Foundation Trust; Health Innovation and Education
Cluster (HIEC); Cambridge University Health Partners (CUHP)
FX This paper presents independent research funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research & Care (CLAHRC) East of England, at Cambridgeshire and Peterborough NHS Foundation Trust, as well as the Health Innovation and Education Cluster (HIEC) hosted by Cambridge University Health Partners (CUHP). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. None of the funders has had any involvement in the conduct and representation of this work.

CR Adler-Milstein J, 2013, HEALTH AFFAIR, V32, P1486, DOI
10.1377/hlthaff.2013.0124
[Anonymous], 2016, MAKING IT WORK HARNE

[Anonymous], 2013, INFORM SHARE NOT SHA
Bailey JE, 2013, ANN EMERG MED, V62, P16, DOI 10.1016/j.annemergmed.2013.01.006
Bates DW, 2003, NEW ENGL J MED, V348, P2526, DOI 10.1056/NEJMsa020847
Ben-Assuli O, 2015, HEALTH INFORM J, V21, P73, DOI 10.1177/1460458213503646
Ben-Assuli O, 2013, BMC MED INFORM DECIS, V13, DOI 10.1186/1472-6947-13-49
Bramwell D, 2015, BRIT J GEN PRACT, V65, P374, DOI 10.3399/bjgp15X685909
Codagnone C, 2013, BENCHMARKING DEPLOYM
Cohen GR, 2016, J AM MED INFORM ASSN, V23, pE146, DOI 10.1093/jamia/ocv147
Congress of the United States Congressional Budget Office, 2008, USITC PUBL, V2976
Eden KB, 2016, INT J MED INFORM, V88, P44, DOI 10.1016/j.ijmedinf.2016.01.004
England Integration Pioneers, 2015, EN INF SHAR US MAP H
Erens B, 2015, EARLY EVALUATION INT
Fontaine P, 2010, J AM BOARD FAM MED, V23, P655, DOI 10.3122/jabfm.2010.05.090192
Frisse ME, 2007, J BIOMED INFORM, V40, pS27, DOI 10.1016/j.jbi.2007.08.004
Frisse ME, 2012, J AM MED INFORM ASSN, V19, P328, DOI [10.1136/amiajnl-2011-000394, 10.1136/amiajnl-2011000394]
Graetz I, 2014, MED CARE, V52, P1037, DOI 10.1097/MLR.0000000000000245
Greene Jan, 2016, Manag Care, V25, P22
Hafen E, 2014, METHOD INFORM MED, V53, P82, DOI 10.3414/ME13-02-0051
Hersh W., 2015, USITC PUBL
Johnson KB, 2011, J AM MED INFORM ASSN, V18, P690, DOI 10.1136/amiajnl-2011-000308
Marchibroda JM, 2007, J BIOMED INFORM, V40, pS11, DOI 10.1016/j.jbi.2007.08.008
Martin S, 2016, PRESSURE WHAT COMMON
Miller RH, 2007, HEALTH AFFAIR, V26, pW568, DOI 10.1377/hlthaff.26.5.w568
Morris TP, 2014, BMC MED RES METHODOL, V14, DOI 10.1186/1471-2288-14-75
Mynors G, 2012, GUIDE HLTH RECORDS A
National End of Life Care Programme, 2012, MAK CAS CHANG EL PAL
National Information Board, 2014, PERS HLTH CAR 2020 U
NHS, 2014, 5 YEAR FORW VIEW
NHS England, 2016, PARTN ROYAL COLL GEN
Padrez KA, 2016, BMJ QUAL SAF, V25, P414, DOI 10.1136/bmjqs-2015-004489
Park H, 2015, INT J MED INFORM, V84, P658, DOI 10.1016/j.ijmedinf.2015.05.008
Park H, 2013, INT J MED INFORM, V82, P98, DOI 10.1016/j.ijmedinf.2012.05.001
Patients Know Best Blog, GUID HLTH REC ACC HI
Petrova M., 2016, BMJ SUPPORT PALLIAT
Pisano F, 2015, J EVAL CLIN PRACT, V21, P103, DOI 10.1111/jep.12255
Rubin D. B., 1987, MULTIPLE IMPUTATION
Rudin RS, 2014, ANN INTERN MED, V161, P803, DOI 10.7326/M14-0877
Shade SB, 2012, INT J MED INFORM, V81, pE1, DOI 10.1016/j.ijmedinf.2012.07.003
Shapiro JS, 2016, ANN EMERG MED, V67, P216, DOI 10.1016/j.annemergmed.2015.06.018
Simon SR, 2009, J MED INTERNET RES, V11, DOI 10.2196/jmir.1164
Strauss AT, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/s12911-015-0207-x
Van Buuren S, 1999, STAT MED, V18, P681, DOI 10.1002/(SICI)1097-0258(19990330)18:6<681::AID-SIM71>3.0.CO;2-R
Vest JR, 2014, APPL CLIN INFORM, V5, P219, DOI 10.4338/ACI-2013-10-RA-0083
Vest JR, 2015, J AM MED INFORM ASSN, V22, P435, DOI 10.1136/amiajnl-2014-002760
Vest JR, 2014, AM J MANAG CARE, V20, pESP16
Vest JR, 2013, J MED SYST, V37, DOI 10.1007/s10916-013-9987-7
von Hippel PT, 2007, SOCIOL METHODOL, V37, P83, DOI 10.1111/j.1467-9531.2007.00180.x

Walker J., 2005, HLTH AFF
Weitzman ER, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-39
White I. R., 2011, STAT MED, V30
Woodman J, 2015, BRIT J GEN PRACT, V65, P280, DOI 10.3399/bjgp15X685129
Wyatt J., 2016, HLTH INFORM UNIT PER
Yaraghi N, 2015, J AM MED INFORM ASSN, V22, P1183, DOI 10.1093/jamia/ocv086
Yaraghi N, 2015, J AM MED INFORM ASSN, V22, P1169, DOI 10.1093/jamia/ocv068
Yasnoff WA, 2013, JAMA-J AM MED ASSOC, V309, P989, DOI 10.1001/jama.2013.1474
NR 57
TC 2
Z9 2
U1 0
U2 12
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000, IRELAND
SN 1386-5056
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J9 INT J MED INFORM
JI Int. J. Med. Inform.
PD AUG
PY 2017
VL 104
BP 74
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DI 10.1016/j.ijmedinf.2017.05.009
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WC Computer Science, Information Systems; Health Care Sciences & Services; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA FA3RM
UT WOS:000405362100009
PM 28599819
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ER

PT J
AU Moon, LA
AF Moon, Lisa A.
TI Factors influencing health data sharing preferences of consumers: A critical review
SO HEALTH POLICY AND TECHNOLOGY
LA English
DT Review
DE Informed consent; Release of information; Health information exchange; Consumer attitudes; Consumer health data sharing preferences; Health information exchange public policy
ID INFORMATION EXCHANGE; RECORDS; PERCEPTIONS; ATTITUDES; PRIVACY; ACCESS
AB The purpose of this critical review is to synthesize available literature and identify factors influencing consumer data sharing preferences, while presenting a logic model for legal / public policy development that aligns with consumer expectations for management of ePHI. Eighteen articles were included for the critical review; including 16 studies from three countries. The fourteen cross-sectional studies were evaluated using Olsen and St. George's (2004) Crosssectional Study Design and Data Analysis framework and two qualitative studies were assessed using Kuper, Lingard, Et Levinson (2008) [14] Critically Appraising Qualitative Research strategies. An emerging classification schema of

statistically significant factors identified in this critical review shows that, (1) Trust relationship, (2) Harm Threshold, (3) Balance Risk and Benefits, (4) Transparency of Data Exchange and (5) Access and Control of Data are important when considering how to best include the consumer voice in the development of legal / public policies related to the privacy, security and consent management of ePHI. (C) 2017 Fellowship of Postgraduate Medicine. Published by Elsevier Ltd. All rights reserved.

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CR Ancker JS, 2013, J AM MED INFORM ASSN, V20, P152, DOI 10.1136/amiajnl-2012-001062
Ancker JS, 2012, AM J PREV MED, V43, P76, DOI 10.1016/j.amepre.2012.02.027
Annas GJ, 2003, NEW ENGL J MED, V348, P1486, DOI 10.1056/NEJMlim035027
Caine K, 2013, J AM MED INFORM ASSN, V20, P7, DOI 10.1136/amiajnl-2012-001023
Caldwell SE, 2012, HEALTH RES POLICY SY, V10, P10
Campion TR, 2013, INT J MED INFORM, V82, P810, DOI 10.1016/j.ijmedinf.2013.05.001
Dhopeshwarkar RV, 2012, ANN FAM MED, V10, P428, DOI 10.1370/afm.1396
Dimitropoulos Linda, 2011, Am J Manag Care, V17, pSP111
Dimitropoulos L, 2009, HEALTH AFFAIR, V28, P428, DOI 10.1377/hlthaff.28.2.428
Hripcsak G, 2013, J AM MED INFORM ASS
Kuper A, 2008, BMJ-BRIT MED J, P337
Li M, 2010, L N INST COMP SCI SO, V50, P89
Luchenski S, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-40
Marquard JL, CRYING WOLF CONSUMER
Merz J., 2014, PRIVACY TRANSPARENCY
Mitchell M., 2009, COMPLEXITY GUIDED TO
Morcol G., 2005, Public Administration Quarterly, V29, P297
Morcol G., 2010, EMERGENCE COMPLEXITY, V12, P52
O'Donnell HC, 2011, J GEN INTERN MED, V26, P1019, DOI 10.1007/s11606-011-1733-6
Olsen C, 2004, COLL ENTR EXAM BOARD
Park H, 2013, INT J MED INFORM, V82, P98, DOI 10.1016/j.ijmedinf.2012.05.001
Patel VN, 2012, J MED SYST, V36, P1043, DOI 10.1007/s10916-010-9566-0
Patel VN, 2011, INFORM HEALTH SOC CA, V36, P233, DOI 10.3109/17538157.2011.554930
Patel VN, 2011, AM J MANAG CARE, V17, pE104
Ramos SR, 2014, STUD HEALTH TECHNOL, V201, P418, DOI 10.3233/978-1-61499-415-2-418
Schwartz PH, 2015, J GEN INTERN MED, V30, pS25, DOI 10.1007/s11606-014-3054-z
Teixeira Paul A, 2011, Patient Educ Couns, V84, pe9, DOI 10.1016/j.pec.2010.07.013
Wen K, 2010, J MED INTERNET RES, V12, P4

NR 28
TC 2
Z9 2
U1 1
U2 8
PU ELSEVIER SCI LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, OXON, ENGLAND
SN 2211-8837
J9 HEALTH POLICY TECHN
JI Health Policy Technol.
PD JUN

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PY 2017
VL 6
IS 2
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PG 19
WC Health Policy & Services
SC Health Care Sciences & Services
GA EY5AD
UT WOS:000403988700007
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ER

PT J
AU Zhu, CS
   Pinsky, PF
   Moler, JE
   Kukwa, A
   Mabie, J
   Rathmell, JM
   Riley, T
   Prorok, PC
   Berg, CD
AF Zhu, Claire S.
   Pinsky, Paul F.
   Moler, James E.
   Kukwa, Andrew
   Mabie, Jerome
   Rathmell, Joshua M.
   Riley, Tom
   Prorok, Philip C.
   Berg, Christine D.
TI Data sharing in clinical trials: An experience with two large cancer
   screening trials
SO PLOS MEDICINE
LA English
DT Editorial Material
ID OPEN-ACCESS; LUNG; MORTALITY; PROSTATE; PROJECT
AB Broad sharing of clinical trial data is important for ensuring
reproducibility, transparency, and maximal use of the data by the research
community. However, in practice, such data sharing typically requires planning,
effort, and resources.
   Here, we describe a web-based data sharing system, the Cancer Data Access
System (CDAS), developed for two large cancer screening trials: the Prostate,
Lung, Colorectal and Ovarian (PLCO) cancer screening trial and the National Lung
Screening Trial (NLST).
   Deidentified individual participant data were organized into standard
datasets readily downloadable from CDAS via a simple web-based application
process that involves minimal scientific review. CDAS provides a "one-stop shop"
for access requests, review, and data downloads.
   Since the launch of CDAS in November 2012 and through October 2016, 215
requests were received for PLCO data, of which 199 (93%) were approved, and 240
requests were received for NLST, of which 216 (90%) were approved.
   The estimated cost of CDAS was around US$300,000 for the initial development,
plus additional maintenance and user-support costs of about US$26,000 per month.
Because of its modular nature, additional studies can be added to CDAS with
relatively little additional cost.
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C1 [Zhu, Claire S.; Pinsky, Paul F.; Prorok, Philip C.] NCI, Div Canc Prevent,
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FU NCI [HHSN261201300008I]
FX NCI contract HHSN261201300008I to Information Management Systems
   partially funded the project being described here. The funders had no
   role in the study design, data collection and analysis, decision to
   publish, or preparation of the manuscript (outside of the fact that
   several authors are employees of NCI).
CR Aberle DR, 2011, NEW ENGL J MED, V365, P395, DOI 10.1056/NEJMoa1102873
   Andriole GL, 2012, J NATL CANCER I, V104, P125, DOI 10.1093/jnci/djr500
   Bertagnolli MM, 2017, NEW ENGL J MED, V376, P1178, DOI 10.1056/NEJMsb1702054
   Buys SS, 2011, JAMA-J AM MED ASSOC, V305, P2295, DOI 10.1001/jama.2011.766
   Coady SA, 2017, NEW ENGLAND J MED
   Giffen CA, 2015, BIOPRESERV BIOBANK, V13, P271, DOI 10.1089/bio.2014.0050
   Green AK, 2015, ONCOLOGIST, V20, P464, DOI 10.1634/theoncologist.2014-0431
   Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
   Krumholz HM, 2016, NEW ENGL J MED, V375, P403, DOI 10.1056/NEJMp1607342
   Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374
   Oken MM, 2011, JAMA-J AM MED ASSOC, V306, P1865, DOI 10.1001/jama.2011.1591
   Pencina MJ, 2016, AM HEART J, V172, P64, DOI 10.1016/j.ahj.2015.11.002
   Rathi V, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7570
   Schoen RE, 2012, NEW ENGL J MED, V366, P2345, DOI 10.1056/NEJMoa1114635
   Strom BL, 2016, NEW ENGL J MED, V375, P1608, DOI 10.1056/NEJMp1610336
   Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
   Zhu CS, 2013, JNCI-J NATL CANCER I, V105, P1684, DOI 10.1093/jnci/djt281
NR 17
TC 2
Z9 2
U1 0
U2 4
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1549-1676
J9 PLOS MED
JI PLos Med.
PD MAY
PY 2017
VL 14
IS 5
AR e1002304
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WC Medicine, General & Internal
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PT J
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AU Fiore, LD
Brophy, MT
Ferguson, RE
Shannon, C
Turek, SJ
Pierce-Murray, K
Ajjarapu, S
Huang, GD
Lee, CSE
Lavori, PW
AF Fiore, L. D.
Brophy, M. T.
Ferguson, R. E.
Shannon, C.
Turek, S. J.
Pierce-Murray, K.
Ajjarapu, S.
Huang, G. D.
Lee, C. S. E.
Lavori, P. W.
TI Data Sharing, Clinical Trials, and Biomarkers in Precision Oncology: Challenges, Opportunities, and Programs at the Department of Veterans Affairs
SO CLINICAL PHARMACOLOGY & THERAPEUTICS
LA English
DT Editorial Material
AB Cancer genomic research reveals that a similar cancer clinical phenotype (e.g., non-small cell lung cancer) can arise from various mutations in tumor DNA. Thus, organ of origin is not a definitive classification. Further, targeted therapy for cancer patients (precision oncology) capitalizes on knowledge of individual patient mutational status to deliver treatment directed against the protein products of these mutations with the goal of reducing toxicity and enhancing efficacy relative to traditional nontargeted chemotherapy.
C1 [Fiore, L. D.; Brophy, M. T.; Ferguson, R. E.; Shannon, C.; Turek, S. J.; Pierce-Murray, K.; Ajjarapu, S.; Huang, G. D.; Lee, C. S. E.; Lavori, P. W.] VA Boston Healthcare Syst, Boston, MA 02130 USA.
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FU None [VA999999]
CR Fiore Louis D, 2016, Biomark Cancer, V8, P9, DOI 10.4137/BIC.S37548
Fiore LD, 2011, CLIN TRIALS, V8, P183, DOI [10.1177/1740774511398368, 10.1177/1740774510395635]
Shrager J, 2014, NAT REV CLIN ONCOL, V11, P109, DOI 10.1038/nrclinonc.2013.244
NR 3
TC 2
Z9 2
U1 0
U2 5
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0009-9236
EI 1532-6535
J9 CLIN PHARMACOL THER
JI Clin. Pharmacol. Ther.
PD MAY
PY 2017

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VL 101
IS 5
BP 586
EP 589
DI 10.1002/cpt.660
PG 4
WC Pharmacology & Pharmacy
SC Pharmacology & Pharmacy
GA ES6LK
UT WOS:000399659000009
PM 28182272
OA Other Gold, Green Published
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PT J
AU Lawler, M
   Maughan, T
AF Lawler, Mark
   Maughan, Tim
TI From Rosalind Franklin to Barack Obama: Data Sharing Challenges and
   Solutions in Genomics and Personalised Medicine
SO NEW BIOETHICS-A MULTIDISCIPLINARY JOURNAL OF BIOTECHNOLOGY AND THE BODY
LA English
DT Article
DE personalised medicine; big data; data sharing; genomics; cancer;
   bioethics
ID CANCER; PRIVACY; RIGHTS
AB The collection, storage and use of genomic and clinical data from patients
and healthy individuals is a key component of personalised medicine enterprises
such as the Precision Medicine Initiative, the Cancer Moonshot and the 100,000
Genomes Project. In order to maximise the value of this data, it is important to
embed a culture within the scientific, medical and patient communities that
supports the appropriate sharing of genomic and clinical information. However,
this aspiration raises a number of ethical, legal and regulatory challenges that
need to be addressed. The Global Alliance for Genomics and Health, a worldwide
coalition of researchers, healthcare professionals, patients and industry
partners, is developing innovative solutions to support the responsible and
effective sharing of genomic and clinical data. This article identifies the
challenges that a data sharing culture poses and highlights a series of
practical solutions that will benefit patients, researchers and society.
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FU Medical Research Council - Cancer Research UK (MRC-CRUK)
FX ML is supported through a Medical Research Council - Cancer Research UK
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CR Abul-Husn NS, 2016, SCIENCE, V354, DOI 10.1126/science.aaf7000
   Dewey FE, 2016, SCIENCE, V354, DOI 10.1126/science.aaf6814
   Embi PJ, 2016, NEW ENGL J MED, V374, P1896, DOI 10.1056/NEJMc1602586
   European Commission, 2012, PROP REG EUR PARL CO
   Global Alliance for Genomics and Health, 2015, CONS POL
```

```
   Global Alliance for Genomics and Health, 2015, SEC INFR STAND IMPL
   Global Alliance for Genomics and Health, 2013, WHIT PAP CREAT GLOB
   Global Alliance for Genomics and Health, 2015, PRIV SEC POL
   Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI
10.1126/science.aaf6162
   Grossman RL, 2016, NEW ENGL J MED, V375, P1109, DOI 10.1056/NEJMp1607591
   Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
   Knoppers BM, 2014, GENOME MED, V6, DOI 10.1186/gm530
   Lawler M, 2015, CANCER DISCOV, V5, P1133, DOI 10.1158/2159-8290.CD-15-0821
   Lawler M, 2014, LANCET ONCOL, V15, P258, DOI 10.1016/S1470-2045(13)70552-7
   Lin Z, 2004, SCIENCE, V305, P183, DOI 10.1126/science.1095019
   Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
   Patrinos GP, 2012, HUM MUTAT, V33, P1503, DOI 10.1002/humu.22144
   Rogith D, 2014, J AM MED INFORM ASSN, V21, pE320, DOI 10.1136/amiajnl-2013-
002579
   Siu LL, 2016, NAT MED, V22, P464, DOI 10.1038/nm.4089
   Siva N, 2015, LANCET, V385, P103, DOI 10.1016/S0140-6736(14)62453-3
   Turner EH, 2008, NEW ENGL J MED, V358, P252, DOI 10.1056/NEJMsa065779
   WATSON JD, 1953, NATURE, V171, P737, DOI 10.1038/171737a0
NR 22
TC 2
Z9 2
U1 0
U2 4
PU TAYLOR & FRANCIS LTD
PI ABINGDON
PA 2-4 PARK SQUARE, MILTON PARK, ABINGDON OR14 4RN, OXON, ENGLAND
SN 2050-2877
EI 2050-2885
J9 NEW BIOETH
JI New Bioeth.
PY 2017
VL 23
IS 1
SI SI
BP 64
EP 73
DI 10.1080/20502877.2017.1314883
PG 10
WC Ethics
SC Social Sciences - Other Topics
GA FV9PM
UT WOS:000424920600008
PM 28517986
OA Green Published, Bronze
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ER

PT J
AU Wan, ZY
   Vorobeychik, Y
   Kantarcioglu, M
   Malin, B
AF Wan, Zhiyu
   Vorobeychik, Yevgeniy
   Kantarcioglu, Murat
   Malin, Bradley
TI Controlling the signal: Practical privacy protection of genomic data
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sharing through Beacon services

SO BMC MEDICAL GENOMICS

LA English

DT Article

DE Genomic databases; Beacon service; Data sharing; Privacy; Perturbation; iDASH challenge

ID PRECISION MEDICINE; GENETICS

AB Background: Genomic data is increasingly collected by a wide array of organizations. As such, there is a growing demand to make summary information about such collections available more widely. However, over the past decade, a series of investigations have shown that attacks, rooted in statistical inference methods, can be applied to discern the presence of a known individual's DNA sequence in the pool of subjects. Recently, it was shown that the Beacon Project of the Global Alliance for Genomics and Health, a web service for querying about the presence (or absence) of a specific allele, was vulnerable. The Integrating Data for Analysis, Anonymization, and Sharing (iDASH) Center modeled a track in their third Privacy Protection Challenge on how to mitigate the Beacon vulnerability. We developed the winning solution for this track.

Methods: This paper describes our computational method to optimize the tradeoff between the utility and the privacy of the Beacon service. We generalize the genomic data sharing problem beyond that which was introduced in the iDASH Challenge to be more representative of real world scenarios to allow for a more comprehensive evaluation. We then conduct a sensitivity analysis of our method with respect to several state-of-the-art methods using a dataset of 400,000 positions in Chromosome 10 for 500 individuals from Phase 3 of the 1000 Genomes Project. All methods are evaluated for utility, privacy and efficiency.

Results: Our method achieves better performance than all state-of-the-art methods, irrespective of how key factors (e.g., the allele frequency in the population, the size of the pool and utility weights) change from the original parameters of the problem. We further illustrate that it is possible for our method to exhibit subpar performance under special cases of allele query sequences. However, we show our method can be extended to address this issue when the query sequence is fixed and known a priori to the data custodian, so that they may plan stage their responses accordingly.

Conclusions: This research shows that it is possible to thwart the attack on Beacon services, without substantially altering the utility of the system, using computational methods. The method we initially developed is limited by the design of the scenario and evaluation protocol for the iDASH Challenge; however, it can be improved by allowing the data custodian to act in a staged manner.

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FU NIH; NIH [R01HG006844, RM1HG009034, U01HG006385, U01HG006378]

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CR Altshuler DM, 2015, NATURE, V526, P68, DOI 10.1038/nature15393
Aronson SJ, 2015, NATURE, V526, P336, DOI 10.1038/nature15816
Ball MP, 2014, GENOME MED, V6, DOI 10.1186/gm527

Boycott KM, 2013, NAT REV GENET, V14, P681, DOI 10.1038/nrg3555
Collins FS, 2015, NEW ENGL J MED, V372, P793, DOI 10.1056/NEJMp1500523
Craig DW, 2011, NAT REV GENET, V12, P730, DOI 10.1038/nrg3067
Dwork C, 2015, ANN IEEE SYMP FOUND, P650, DOI 10.1109/FOCS.2015.46
Felch J., 2008, LOS ANGELES TIMES
Frazer KA, 2007, NATURE, V449, P851, DOI 10.1038/nature06258
Gottesman O, 2013, GENET MED, V15, P761, DOI 10.1038/gim.2013.72
Green ED, 2011, NATURE, V470, P204, DOI 10.1038/nature09764
Gymrek M, 2013, SCIENCE, V339, P321, DOI 10.1126/science.1229566
Hayden EC, 2013, NATURE, V498, P16, DOI 10.1038/498017a
Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
Hull SC, 2008, AM J BIOETHICS, V8, P62, DOI 10.1080/15265160802478404
Kaufman DJ, 2009, AM J HUM GENET, V85, P643, DOI 10.1016/j.ajhg.2009.10.002
Knoppers BM, 2014, GENOME MED, V6, DOI 10.1186/gm530
Koboldt DC, 2013, CELL, V155, P27, DOI 10.1016/j.cell.2013.09.006
Mailman MD, 2007, NAT GENET, V39, P1181
Phillips AM, 2016, APPL TRANSL GENOM, V8, P16, DOI 10.1016/j.atg.2016.01.001
Raisaro JL, 2017, J AM MED INFORM ASSN, V24, P799, DOI 10.1093/jamia/ocw167
Rehm HL, 2013, NAT REV GENET, V14, P295, DOI 10.1038/nrg3463
Sanderson SC, 2016, EUR J HUM GENET, V24, P14, DOI 10.1038/ejhg.2015.118
Sankararaman S, 2009, NAT GENET, V41, P965, DOI 10.1038/ng.436
Shringarpure SS, 2015, AM J HUM GENET, V97, P631, DOI 10.1016/j.ajhg.2015.09.010
Stephens ZD, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002195
Taber KAJ, 2014, JAMA INTERN MED, V174, P275, DOI 10.1001/jamainternmed.2013.12048
Torres-Espanol M, 2016, HUM MUTAT, V37, P1106, DOI 10.1002/humu.23022
Wan ZY, 2017, AM J HUM GENET, V100, P316, DOI 10.1016/j.ajhg.2016.12.002
Wang R, 2009, CCS'09: PROCEEDINGS OF THE 16TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P534
Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
Zerhouni EA, 2008, SCIENCE, V322, P44, DOI 10.1126/science.1165490
NR 32
TC 2
Z9 2
U1 0
U2 3
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1755-8794
J9 BMC MED GENOMICS
JI BMC Med. Genomics
PY 2017
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SU 2
AR 39
DI 10.1186/s12920-017-0282-1
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WC Genetics & Heredity
SC Genetics & Heredity
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PT J
AU Mursaleen, LR
Stamford, JA
Jones, DA
Windle, R
Isaacs, T
AF Mursaleen, Leah Rose
Stamford, Jon Andrew
Jones, David Ashford
Windle, Richard
Isaacs, Tom
TI Attitudes Towards Data Collection, Ownership and Sharing Among Patients with Parkinson's Disease
SO JOURNAL OF PARKINSONS DISEASE
LA English
DT Article
DE Parkinson's disease; data collection; data sharing; data ownership; anonymity; communication

AB Background: The ownership and sharing of patient medical data is an increasingly contentious subject in medicine generally but also within the field of Parkinson's disease (PD). Despite being the providers of the medical data, patients are rarely consulted as to its usage.

Objective: The objective of this paper is to establish patient attitudes to ownership of their own medical data and the sharing thereof.

Methods: We report here the results of an online survey of people with Parkinson's. A total of 310 people took part in the 'sharing data' component of the survey, answering some or all of the questions for which they were eligible.

Results: Most respondents (208/306) were aged between 55 and 74 years. 55% of the sample were female and the mean number of years diagnosed was 7.1. Although 93% of respondents were willing to share data, only 41% were currently doing so and a further 8% did not know whether they were sharing any information in this way. There was a significant association between age and data sharing (p = 0.006). However, no clear relationship was found between data sharing and the number of years diagnosed, sex, medication class or health confidence. There was also no consensus among patients on ownership of, access to and usage of their research data.

Conclusion: The lack of consensus on data ownership and general absence of clear demographic predictors of data sharing implies impaired communication pathways. We suggest that strategies directed towards improved communication may help to clarify data ownership and promote data sharing.

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CR Duncan D, 2008, ASSESS EVAL HIGH EDU, V33, P301
Heart T, 2013, INT J MED INFORM, V82, pE209, DOI 10.1016/j.ijmedinf.2011.03.002
Ho L, 2013, J AMBUL CARE MANAG, V36, P235, DOI 10.1097/JAC.0b013e3182955af7
Llull E, 2016, FINANCIAL TIMES
Loebbecke C, 2015, J STRATEGIC INF SYST, V24, P149, DOI 10.1016/j.jsis.2015.08.002
Lupton D, 2016, HEALTH RISK SOC, V17, P473, DOI 10.1080/13698575.2015.1143247
Miller KL, 2016, NEUROREHABILITATION, V39, P465, DOI 10.3233/NRE-161378
Spagnuelo D, 2017, J MED SYST, V41, DOI 10.1007/s10916-016-0653-8
Wasson John, 2014, Fam Pract Manag, V21, P8

```
NR 9
TC 2
Z9 2
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 1877-7171
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J9 J PARKINSON DIS
JI J. Parkinsons Dis.
PY 2017
VL 7
IS 3
BP 523
EP 531
DI 10.3233/JPD-161045
PG 9
WC Neurosciences
SC Neurosciences & Neurology
GA FD1UY
UT WOS:000407323400013
PM 28671139
DA 2019-08-06
ER

PT J
AU Stephens, KA
   Anderson, N
   Lin, CP
   Estiri, H
AF Stephens, Kari A.
   Anderson, Nicholas
   Lin, Ching-Ping
   Estiri, Hossein
TI Implementing partnership-driven clinical federated electronic health
   record data sharing networks
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Information systems; Data sharing; Federated networks; Implementation;
   Electronic health records
ID SOFTWARE-DEVELOPMENT; PUBLIC-HEALTH; PATIENT DATA; MODEL; SUPPORT
AB Objective: Building federated data sharing architectures requires supporting
a range of data owners, effective and validated semantic alignment between data
resources, and consistent focus on end-users. Establishing these resources
requires development methodologies that support internal validation of data
extraction and translation processes, sustaining meaningful partnerships, and
delivering clear and measurable system utility. We describe findings from two
federated data sharing case examples that detail critical factors, shared
outcomes, and production environment results.
   Methods: Two federated data sharing pilot architectures developed to support
network-based research associated with the University of Washington's Institute
of Translational Health Sciences provided the basis for the findings. A spiral
model for implementation and evaluation was used to structure iterations of
development and support knowledge share between the two network development
teams, which cross collaborated to support and manage common stages.
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Results: We found that using a spiral model of software development and multiple cycles of iteration was effective in achieving early network design goals. Both networks required time and resource intensive efforts to establish a trusted environment to create the data sharing architectures. Both networks were challenged by the need for adaptive use cases to define and test utility.

Conclusion: An iterative cyclical model of development provided a process for developing trust with data partners and refining the design, and supported measureable success in the development of new federated data sharing architectures. (C) 2016 Elsevier Ireland Ltd. All rights reserved.

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FX We would like to thank our Institute for Translational Health Sciences colleagues with the Data QUEST and the CICTR projects and the DARTNet Institute. This research was supported by the National Center for Advancing Translational Sciences, Clinical and Translational Science Award for the Institute for Translational Health Sciences UL1TR000423 and Contract #HHSN268200700031C.

CR Anderson N., 2011, J AM MED INFORM ASS, V26
Ash JS, 2008, J AM MED INFORM ASSN, V15, P283, DOI 10.1197/jamia.M2582
Bates D.W., 2016, HLTH AFF MILLWOOD, V29, P614
Boehm B, 2003, COMPUTER, V36, P57, DOI 10.1109/MC.2003.1204376
Boehm B., 2001, J DEFENSE SOFTWARE E, V14, P4
BOEHM BW, 1988, COMPUTER, V21, P61, DOI 10.1109/2.59
Bradshaw Richard L, 2009, AMIA Annu Symp Proc, V2009, P70
DesRoches CM, 2008, NEW ENGL J MED, V359, P50, DOI 10.1056/NEJMsa0802005
Diamond CC, 2009, HEALTH AFFAIR, V28, P454, DOI 10.1377/hlthaff.28.2.454
Evans B., 2009, NOTRE DAME L REV, V585, P619
Gupta A, 2008, NEUROINFORMATICS, V6, P205, DOI 10.1007/s12021-008-9033-y
Hitz P., 2013, CLIN MED RES, V11, P178
Hurd Andy, 2008, Health Manag Technol, V29, P16
Karp DR, 2008, PLOS MED, V5, P1333, DOI 10.1371/journal.pmed.0050190
Kass NE, 2001, AM J PUBLIC HEALTH, V91, P1776, DOI 10.2105/AJPH.91.11.1776
Lazarus R, 2009, J AM MED INFORM ASSN, V16, P18, DOI 10.1197/jamia.M2848
MacKenzie SL, 2012, J AM MED INFORM ASSN, V19, pE119, DOI 10.1136/amiajnl-2011-000508
Magdaleno AM, 2012, J SYST SOFTWARE, V85, P351, DOI 10.1016/j.jss.2011.08.028
Malin B, 2007, ARTIF INTELL MED, V40, P223, DOI 10.1016/j.artmed.2007.04.002
McKinney Maureen, 2009, Hosp Health Netw, V83, P52
Murphy S., 2009, GENOME RES
Murphy S.C., 2002, SECURITY ARCHITECTUR
Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
Nagykaldi S., 2008, INFORM PRIM CARE, V16, P51
National Institutes of Health, 2003, NIH DAT SHAR POL

```
   Nissenbaum H, 1998, LAW PHILOS, V17, P559
   Ohm P., 2009, BROKEN PROMISES PRIV
   Peterson KA, 2012, ANN FAM MED, V10, P560, DOI 10.1370/afm.1434
   Rosenbloom ST, 2008, J AM MED INFORM ASSN, V15, P65, DOI 10.1197/jamia.M2506
   Stephens K.A., 2011, WEB BASED TOOL CATAL
   Stephens K.A., 2012, 2012 AMIA SUMM TRANS
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Weber GM, 2009, J AM MED INFORM ASSN, V16, P624, DOI 10.1197/jamia.M3191
   Westfall JM, 2007, JAMA-J AM MED ASSOC, V297, P403, DOI
10.1001/jama.297.4.403
   Wilcox A., 2014, EGEMS, V2
   Wise P.B., 2016, HEALTHCARE EXEC, V25, P20
   Zerhouni EA, 2007, CLIN PHARMACOL THER, V81, P126, DOI
10.1038/sj.clpt.6100029
NR 37
TC 2
Z9 2
U1 0
U2 5
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
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SN 1386-5056
EI 1872-8243
J9 INT J MED INFORM
JI Int. J. Med. Inform.
PD SEP
PY 2016
VL 93
BP 26
EP 33
DI 10.1016/j.ijmedinf.2016.05.008
PG 8
WC Computer Science, Information Systems; Health Care Sciences & Services;
   Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA DT6JY
UT WOS:000381591700004
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OA Green Published
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PT J
AU Krauss, JC
   Warner, JL
   Maddux, SE
   Brown, JR
   Moldwin, R
   Schorer, AE
   Hughes, KS
   Ambinder, EP
AF Krauss, John C.
   Warner, Jeremy L.
   Maddux, Suzanne E.
   Brown, Jeffrey R.
   Moldwin, Richard
```

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   Schorer, Anna E.
   Hughes, Kevin S.
   Ambinder, Edward P.
TI Data Sharing to Support the Cancer Journey in the Digital Era
SO JOURNAL OF ONCOLOGY PRACTICE
LA English
DT Editorial Material
ID ELECTRONIC HEALTH RECORDS; ONCOLOGY PRACTICE; INFORMATION; IMPROVEMENT;
   SMART; CARE
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CR Alterovitz G, 2015, J AM MED INFORM ASSN, V22, P1173, DOI
10.1093/jamia/ocv045
   American Society of Clinical Oncology, CLIN INF SHAR WORKS
   ASCO Institute for Quality, CHEM TREATM PLAN SUM
   Blayney DW, 2015, J ONCOL PRACT, V11, P174, DOI 10.1200/JOP.2015.004267
   Boyle FM, 2005, J CLIN ONCOL, V23, P916, DOI 10.1200/JCO.2005.09.065
   Campbell Robert James, 2014, J AHIMA, V85, P46
   D'Amore JD, 2014, J AM MED INFORM ASSN, V21, P1060, DOI 10.1136/amiajnl-2014-
002883
   Kruger Grant H, 2011, Anesthesiol Clin, V29, P487, DOI
10.1016/j.anclin.2011.05.004
   Miriovsky BJ, 2012, J CLIN ONCOL, V30, P4243, DOI 10.1200/JCO.2012.42.8011
   Pathak J, 2013, J AM MED INFORM ASSN, V20, pE341, DOI 10.1136/amiajnl-2013-
001939
   Srigley J, 2013, J ONCOL PRACT, V9, pE255, DOI 10.1200/JOP.2012.000818
   Warner JL, 2015, J AM MED INFORM ASSN, V22, P577, DOI 10.1093/jamia/ocu015
   Warner JL, 2013, J ONCOL PRACT, V9, pE96, DOI 10.1200/JOP.2013.000931
   Warner JL, 2015, J ONCOL PRACT
NR 14
TC 2
Z9 2
U1 0
U2 1
PU AMER SOC CLINICAL ONCOLOGY
PI ALEXANDRIA
PA 2318 MILL ROAD, STE 800, ALEXANDRIA, VA 22314 USA
SN 1554-7477
EI 1935-469X
J9 J ONCOL PRACT
JI J. Oncol. Pract.
PD MAR
PY 2016
VL 12
IS 3
BP 201
EP +
DI 10.1200/JOP.2015.007740
PG 8
WC Oncology; Health Care Sciences & Services
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SC Oncology; Health Care Sciences & Services
GA DJ6LV
UT WOS:000374325600008
PM 26759494
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ER

PT J
AU Cherico-Hsii, S
   Bankoski, A
   Singal, P
   Horon, I
   Beane, E
   Casey, M
   Rebbert-Franklin, K
   Sharfstein, J
AF Cherico-Hsii, Sara
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   Singal, Pooja
   Horon, Isabelle
   Beane, Eric
   Casey, Meghan
   Rebbert-Franklin, Kathleen
   Sharfstein, Joshua
TI Sharing Overdose Data Across State Agencies to Inform Public Health
   Strategies: A Case Study
SO PUBLIC HEALTH REPORTS
LA English
DT Article
ID SURVEILLANCE; INTEGRATION; CITY
AB Data sharing and analysis are important components of coordinated and cost-
effective public health strategies. However, legal and policy barriers have made
data from different agencies difficult to share and analyze for policy
development. To address a rise in overdose deaths, Maryland used an innovative
and focused approach to bring together data on overdose decedents across
multiple agencies. The effort was focused on developing discrete intervention
points based on information yielded on decedents' lives, such as vulnerability
upon release from incarceration. Key aspects of this approach included
gubernatorial leadership, a unified commitment to data sharing across agencies
with memoranda of understanding, and designation of a data management team.
Preliminary results have yielded valuable insights and have helped inform policy.
This process of navigating legal and privacy concerns in data sharing across
multiple agencies may be applied to a variety of public health problems
challenging health departments across the country.
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CR Centers for Disease Control and Prevention (US), INJ PREV CONTR PRESC
   Gasner MR, 2014, AM J PUBLIC HEALTH, V104, P993, DOI 10.2105/AJPH.2013.301775
   Jennings JM, 2009, PUBLIC HEALTH REP, V124, P39, DOI
10.1177/00333549091240S207
```

```
   Maryland Department of Health and Mental Hygiene, 2014, RISK OV DEATH FOLL R
   Maryland Department of Health and Mental Hygiene, 2014, MAR VIT STAT PREL RE
   Maryland Department of Health and Mental Hygiene, 2014, DRUG ALC REL INT DEA
   Maryland Department of Health and Mental Hygiene, 2014, MAR OV PREV COUNC HI
   Maryland Office of the Governor. Overdose Prevention Council, 2014, EX ORD 01
01 2014 12
   Paulozzi Leonard J., 2011, Morbidity and Mortality Weekly Report, V60, P1487
   *US DEP HHS, HLTH INF PRIV UND HI
   Weinstock H, 2009, PUBLIC HEALTH REP, V124, P5, DOI
10.1177/00333549091240S202
NR 11
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Z9 2
U1 0
U2 2
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 0033-3549
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J9 PUBLIC HEALTH REP
JI Public Health Rep.
PD MAR-APR
PY 2016
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IS 2
BP 258
EP 263
DI 10.1177/003335491613100209
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA DG9HH
UT WOS:000372392900008
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ER

PT S
AU Spagnuelo, D
   Lenzini, G
AF Spagnuelo, Dayana
   Lenzini, Gabriele
BE Rocha, A
   Correia, AM
   Adeli, H
   Reis, LP
   Teixeira, MM
TI Patient-Centred Transparency Requirements for Medical Data Sharing
   Systems
SO NEW ADVANCES IN INFORMATION SYSTEMS AND TECHNOLOGIES, VOL 1
SE Advances in Intelligent Systems and Computing
LA English
DT Proceedings Paper
CT World Conference on Information Systems and Technologies (WorldCIST)
CY MAR 22-24, 2016
CL Recife, BRAZIL
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DE Requirements; Transparency; Medical Data Sharing Systems
ID PRIVACY; FRAMEWORK; SECURITY; HEALTH
AB We compose, propose, and discuss several requirements to support transparency
in Medical Data Sharing Systems. Transparency is a property that suggests
openness and compliance with policies, practices, and processes employed to
secure data, and it is believed to promote good quality of service in healthcare.
Our requirements indicate how transparency can be realised on modern medical
data sharing systems such as those managing electronic health records.
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Reliabil & Trust SnT, Luxembourg, Luxembourg.
FU FNR/AFR [7842804 TYPAMED]
FX Supported by FNR/AFR project 7842804 TYPAMED
CR Al Faresi A, 2010, P 1 ACM INT HLTH INF, P637
   Benaloh J., 2009, P 2009 ACM WORKSH CL, P103, DOI DOI 10.1145/1655008.1655024
   Cruzes D., 2014, D B 2 4 REQUIREMENTS
   EU, 2012, PROP REG EUR PARL CO
   Ferreira A., 2015, P 3 WORLD C INF SYST
   Fischer-Hubner S, 2014, IFIP ADV INF COMM TE, V421, P77
   Gajanayake R, 2011, IEEE INTERNET COMPUT, V15, P31, DOI 10.1109/MIC.2011.51
   Goodman KW, 2011, J AM MED INFORM ASSN, V18, P77, DOI
10.1136/jamia.2010.008946
   Haas S, 2011, INT J MED INFORM, V80, pE26, DOI 10.1016/j.ijmedinf.2010.10.001
   Hedbom H, 2009, IFIP ADV INF COMM TE, P67
   Henke N, 2011, HLTH INT, V11, P64
   Hu JK, 2010, COMPUT STAND INTER, V32, P274, DOI 10.1016/j.csi.2009.04.005
   Kim KK, 2013, MED CARE, V51, pS66, DOI 10.1097/MLR.0b013e31829b1d9f
   Fernandez-Aleman JL, 2013, J BIOMED INFORM, V46, P541, DOI
10.1016/j.jbi.2012.12.003
   Moe N., 2013, D B 2 1 WORKSH 1 RES
   Office for Civil Right of the Department of Health and USA Human Services,
2015, PRIV SEC EL HLTH REC
   Raizaebagha F., 2015, HLTH INFORM MANAGEME, V44
   Rostad L, 2008, ARES 2008: PROCEEDINGS OF THE THIRD INTERNATIONAL CONFERENCE
ON AVAILABILITY, SECURITY AND RELIABILITY, P935, DOI 10.1109/ARES.2008.185
   Ruotsalainen P, 2011, STUD HEALTH TECHNOL, V169, P497, DOI 10.3233/978-1-
60750-806-9-497
   Seneviratne O, 2014, ANN CONF PRIV SECUR, P121, DOI 10.1109/PST.2014.6890931
   Spagnuelo D., 2015, SECURITY MED DATA SH
   Turilli M, 2009, ETHICS INF TECHNOL, V11, P105, DOI 10.1007/s10676-009-9187-9
NR 22
TC 2
Z9 2
U1 0
U2 1
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 2194-5357
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J9 ADV INTELL SYST
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PG 11
WC Computer Science, Artificial Intelligence; Computer Science, Information
   Systems; Computer Science, Theory & Methods
SC Computer Science
GA BJ0WT
UT WOS:000417258700102
DA 2019-08-06
ER

PT J
AU Hollis, S
   Fletcher, C
   Lynn, F
   Urban, HJ
   Branson, J
   Burger, HU
   Smith, CT
   Sydes, MR
   Gerlinger, C
AF Hollis, Sally
   Fletcher, Christine
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   Urban, Hans-Joerg
   Branson, Janice
   Burger, Hans-Ulrich
   Smith, Catrin Tudur
   Sydes, Matthew R.
   Gerlinger, Christoph
TI Best practice for analysis of shared clinical trial data
SO BMC MEDICAL RESEARCH METHODOLOGY
LA English
DT Article
ID INDIVIDUAL PARTICIPANT DATA; SUBGROUP ANALYSES; PATIENT-LEVEL;
   METAANALYSIS; ASSUMPTIONS; BIAS
AB Background: Greater transparency, including sharing of patient-level data for
further research, is an increasingly important topic for organisations who
sponsor, fund and conduct clinical trials. This is a major paradigm shift with
the aim of maximising the value of patient-level data from clinical trials for
the benefit of future patients and society. We consider the analysis of shared
clinical trial data in three broad categories: (1) reanalysis - further
investigation of the efficacy and safety of the randomized intervention, (2)
meta-analysis, and (3) supplemental analysis for a research question that is not
directly assessing the randomized intervention.
   Discussion: In order to support appropriate interpretation and limit the risk
of misleading findings, analysis of shared clinical trial data should have a
pre-specified analysis plan. However, it is not generally possible to limit bias
and control multiplicity to the extent that is possible in the original trial
design, conduct and analysis, and this should be acknowledged and taken into
account when interpreting results. We highlight a number of areas where specific
considerations arise in planning, conducting, interpreting and reporting
analyses of shared clinical trial data. A key issue is that that these analyses
essentially share many of the limitations of any post hoc analyses beyond the
original specified analyses. The use of individual patient data in meta-analysis
can provide increased precision and reduce bias. Supplemental analyses are
subject to many of the same issues that arise in broader epidemiological
analyses. Specific discussion topics are addressed within each of these areas.
   Summary: Increased provision of patient-level data from industry and
academic-led clinical trials for secondary research can benefit future patients
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and society. Responsible data sharing, including transparency of the research objectives, analysis plans and of the results will support appropriate interpretation and help to address the risk of misleading results and avoid unfounded health scares.

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FU Bayer Pharma AG
FX This paper was the output of a working group formed by EFSPI (European Federation of Statisticians in the Pharmaceutical Industry) and PSI (Statisticians in the Pharmaceutical Industry). No specific funding was provided for the work. Bayer Pharma AG paid the article-processing charge for this article.

CR Ahmed I, 2012, BMJ-BRIT MED J, V344, DOI 10.1136/bmj.d7762
[Anonymous], 1999, STAT MED, V18, P1905
[Anonymous], 2015, ALL TRIALS CAMPAIGN
Benda N, 2011, BIOMETRICAL J, V53, P873, DOI 10.1002/bimj.201100177
Berlin JA, 2002, STAT MED, V21, P371, DOI 10.1002/sim.1023
Brookes ST, 2004, J CLIN EPIDEMIOL, V57, P229, DOI 10.1016/j.jclinepi.2003.08.009
Committee IoMI, 2015, STRAT RESP SHAR CLIN
Debray TPA, 2015, RES SYNTH METHODS, V6, P293, DOI 10.1002/jrsm.1160
Donegan S, 2013, RES SYNTH METHODS, V4, P291, DOI 10.1002/jrsm.1085
Donegan S, 2013, STAT MED, V32, P914, DOI 10.1002/sim.5584
Donegan S, 2012, STAT MED, V31, P3840, DOI 10.1002/sim.5470
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
Epstein M, 2008, PHARMACOEPIDEM DR S, V17, P200, DOI 10.1002/pds.1471
European Federation of Pharmaceutical Industries and Associates (EFPIA)-Pharmaceutical Research and Manufacturers of America (PhRMA), 2015, PRINC RESP CLIN TRIA
European Medicines Agency, 2015, EUR MED AG POL PUBL
European Medicines Agency, 2013, PUBL ACC CLIN TRIAL
Fleming TR, 1995, THER INNOV REGUL S S, V29, p1681S
Hernandez AV, 2006, AM HEART J, V151, P257, DOI 10.1016/j.ahj.2005.04.020

Higgins J, 2012, COCHRANE DB SYST REV, DOI 10.1002/14651858.ED000049
HILL AB, 1965, P ROY SOC MED, V58, P295, DOI 10.1177/003591576505800503
Hoaglin DC, 2011, VALUE HEALTH, V14, P429, DOI 10.1016/j.jval.2011.01.011
Le Noury J, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h4320
Mallinckrod CH, 2013, PHARM STAT, V12, P1, DOI 10.1002/pst.1547
Moher D, 2010, BMJ-BRIT MED J, V340, DOI [10.1136/bmj.c869, 10.1016/j.jclinepi.2010.03.004]
Morris TP, 2014, BMC MED RES METHODOL, V14, DOI 10.1186/1471-2288-14-11
OXMAN AD, 1992, ANN INTERN MED, V116, P78, DOI 10.7326/0003-4819-116-1-78
PROSPERO, 2015, INT PROSP REG SYST R
Riley RD, 2010, BMJ-BRIT MED J, V340, DOI 10.1136/bmj.c221
Sauerbrei W, 2014, STAT MED, V33, P5413, DOI 10.1002/sim.6265
Smith CT, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0097886
Stewart GB, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0046042
Stewart LA, 2015, JAMA-J AM MED ASSOC, V313, P1657, DOI 10.1001/jama.2015.3656
Strom BL, 2014, NEW ENGL J MED, V371, P2052, DOI 10.1056/NEJMp1411794
Sudlow R, BMC MED RES METHODOL
Sutton A, 2008, PHARMACOECONOMICS, V26, P753, DOI 10.2165/00019053-200826090-00006
Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
Thabane L, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-92
Tierney JF, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001855
Tucker K, PROTECTING PATIENT P

NR 39
TC 2
Z9 2
U1 0
U2 0
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1471-2288
J9 BMC MED RES METHODOL
JI BMC Med. Res. Methodol.
PY 2016
VL 16
SU 1
AR 76
DI 10.1186/s12874-016-0170-y
PG 8
WC Health Care Sciences & Services
SC Health Care Sciences & Services
GA EZ9CB
UT WOS:000405025700004
PM 27410240
OA DOAJ Gold, Green Published
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ER

PT S
AU Kim, H
Song, H
Lee, S
Kim, H
Song, I
AF Kim, Hyunsoo
Song, Hoyeong

```
   Lee, Soobin
   Kim, Hyangjung
   Song, Inkwang
GP IEEE
TI A Simple Approach to Share Users' Own Healthcare Data with a Mobile
   Phone
SO 2016 EIGHTH INTERNATIONAL CONFERENCE ON UBIQUITOUS AND FUTURE NETWORKS
   (ICUFN)
SE International Conference on Ubiquitous and Future Networks
LA English
DT Proceedings Paper
CT 8th International Conference on Ubiquitous and Future Networks (ICUFN)
CY JUL 05-08, 2016
CL Vienna, AUSTRIA
SP Tech Univ, IEEE Commun Soc, IEEE, Springer, Samsung Elect, LG Elect, ERICSSON,
LG, MODACOM, ETRI, NIA, SK Telecom, LG U+, KETI, DASAN, Inha Univ, UWB Wireless
Commun Res Ctr, Yonsei Univ, ), Next Generat RFID USN Res Ctr, Kookmin Univ, LED
Convergence Res Ctr, Multi Screen Serv Forum Korea, Kyungpook Natl Univ, Center
for IT Automobile Convergence, Soc Safety Syst Forum Korea, Korean Inst Commun &
Informat Sci, KT
DE Healthcare; Mobile device; Data sharing; Rehabilitation; Authentication
AB Nowadays, many kinds of IT-based healthcare products have been released,
which measure the patients' health status and warn them of potential risk they
might have. In addition, this accumulated data can be sent to remote medical
staff in order for the users to get the proper guidelines or treatments from
them. In this paper, we propose a simple approach which makes sure that the
patients secure the ownership of their own healthcare data and control access of
other people to the data. Moreover, we applied this method into the smartphone-
based rehabilitation application for those who are suffering from shoulder
dysfunction.
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CR Black AD, 2011, PLOS MED, V8, DOI 10.1371/journal.pmed.1000387
   Kish L. J., 2015, NAT BIOTECHNOL, V33, P9
   Koop CE, 2008, IEEE ENG MED BIOL, V27, P29, DOI 10.1109/MEMB.2008.929888
   NAJENSON T, 1971, Scandinavian Journal of Rehabilitation Medicine, V3, P131
   Smith G. R., 1982, BMJ-BRIT MED J, V284, P1224
NR 5
TC 2
Z9 2
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2165-8528
BN 978-1-4673-9991-3
J9 INT CONF UBIQ FUTUR
PY 2016
BP 453
EP 455
PG 3
WC Engineering, Electrical & Electronic
SC Engineering
GA BG6EQ
```

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UT WOS:000390165600104
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ER

PT B
AU Muthukumar, KA
   Nandhini, M
AF Muthukumar, K. A.
   Nandhini, M.
GP IEEE
TI Modified Secret Sharing Algorithm for Secured Medical Data Sharing in
   Cloud Environment
SO 2016 Second International Conference on Science Technology Engineering
   and Management (ICONSTEM)
LA English
DT Proceedings Paper
CT 2nd IEEE International Conference on Science Technology Engineering and
   Management (ICONSTEM)
CY MAR 30-31, 2016
CL Jeppiaar Engn Coll, Chennai, INDIA
SP IEEE
HO Jeppiaar Engn Coll
DE cloud computing; information dispersal algorthim; secret sharing
   algorithm; medical data
AB Cloud computing has become a promising computing paradigm drawing extensive
attention from both academia and industry. Storing, accessing and processing of
data in cloud environment are the cutting edge technology used all over the
world. In modern health care industry cloud computing technology is widely
adopted for storing and sharing medical data. Sensitivity of Medical data needs
to be more secured while sharing the data in cloud environment. Data encryption,
homomorphic encryption, secret sharing technique and data partition technique
are widely used to share the data in cloud computing environment. In this paper,
performance of two algorithms viz., secret sharing algorithm and information
dispersal algorithm are compared and modified secret sharing algorithm is
proposed for medical data sharing.
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CR Aublin P.-L., 2013, 33 IEEE INT C DISTR
   DAWSON E, 1994, COMPUT SECUR, V13, P69, DOI 10.1016/0167-4048(94)90097-3
   Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
   Hitachi Data Systems, 2012, WP429A DG HIT DAT SY
   Nandhini M. Muthukumar, 2016, INT J COMPUTER SCI I, V7
   Onik F. A., 2012, INT J COMPUTER APPL, V49
   RABIN MO, 1989, J ACM, V36, P335, DOI 10.1145/62044.62050
   Sion R., 2007, P NETW DISTR SYST SE
   TEBAA Maha, 2012, P WORLD C ENG 2012 J, VI
NR 9
TC 2
Z9 2
U1 1
U2 8
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-5090-1706-5
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PY 2016
BP 67
EP 71
PG 5
WC Computer Science, Interdisciplinary Applications; Engineering,
   Multidisciplinary
SC Computer Science; Engineering
GA BG4XE
UT WOS:000389234300015
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ER

PT J
AU Knauth, DR
   Meinerz, NE
AF Knauth, Daniela Riva
   Meinerz, Nadia Elisa
TI Reflections on sharing data from healthcare anthropological studies
SO CIENCIA & SAUDE COLETIVA
LA Portuguese
DT Article
DE Ethnography; Results disclosure; Research ethics; Qualitative survey
AB This article discusses the topic of sharing the results of anthropological
studies, such as disseminating research results to health professionals and to
social movements. The starting point is a dialog with a number of successful and
less successful publicizing experiences. This has allowed us to find
negotiations and limits of this practice, and the different dimensions of which
it is a part. We will use examples to develop two lines of questioning regarding
"post-study requirements". The first has to do with the ethical and political
nature of the initiative, and the second problematizes the "interest" in the
results on the part of the various subjects involved in the anthropologic
investigation.
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CR Caldeira T., 1981, CIENCIAS SOCIAIS HOJ, V1, P332
   Minayo MCD, 2008, CIENC SAUDE COLETIVA, V13, P329, DOI 10.1590/S1413-
81232008000200008
   Diniz D, 2008, ETICA PESQUISA TEMAS, P9
   Filho Oliveira, 1999, ENSAIOS ANTROPOLOGIA
   FLEISCHER Soraya, 2010, ETICA REGULAMENTACAO
   Fonseca C, 1995, HORIZ ANTROPOL, V1, P187
   Knauth DR, 2009, FACES HOMOFOBIA CAMP
   Knauth DR, 1996, THESIS ECOLE HAUTES
   Nunes ED, 2008, CIENC SAUDE COLETIVA, V13, P351, DOI 10.1590/S1413-
81232008000200010
   Oliveira LRC, 2004, ANTROPOLOGIA ETICA D, P33
   Sarty C, 2013, ANTROPOLOGIA ETICA D
   Shroeder D., 2008, ETICA PESQUISA TEMAS, P323
   VICTORA Ceres, 2004, ANTROPOLOGIA ETICA D
   Guerriero ICZ, 2008, CIENC SAUDE COLETIVA, V13, P303, DOI 10.1590/S1413-
81232008000200002
NR 14
TC 2
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Z9 2
U1 0
U2 0
PU ABRASCO
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SN 1413-8123
EI 1678-4561
J9 CIENC SAUDE COLETIVA
JI Cienc. Saude Coletiva
PD SEP
PY 2015
VL 20
IS 9
BP 2659
EP 2666
DI 10.1590/1413-81232015209.04672015
PG 8
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA CQ9UP
UT WOS:000360961000007
PM 26331498
OA DOAJ Gold
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ER

PT J
AU Lawson, AB
   Rotejanaprasert, C
   Moraga, P
   Choi, J
AF Lawson, A. B.
   Rotejanaprasert, C.
   Moraga, P.
   Choi, J.
TI A shared neighbor conditional autoregressive model for small area
   spatial data
SO ENVIRONMETRICS
LA English
DT Article
DE conditional autoregressive model; spatial statistics; small area data;
   Bayesian statistics
AB The use of conditional autoregressive (CAR) models for spatial effects is
commonplace, especially when dealing with aggregated count data in health
studies. CAR models are convenient and relatively easy to implement but suffer
from the fact that they have limited flexibility in modeling correlation. We
introduce a new CAR model that can accommodate different neighborhood features
(including shared neighbors). Further, we examine via simulation how this model
performs in comparison with standard CAR models. We also consider the
application to a small area health data example. Copyright (c) 2015 John Wiley &
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```
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CR Assuncao R, 2009, BIOMETRICAL J, V51, P851, DOI 10.1002/bimj.200900056
   Banerjee S., 2015, HIERARCHICAL MODELIN
   BESAG J, 1991, ANN I STAT MATH, V43, P1, DOI 10.1007/BF00116466
   Best N, 2005, STAT METHODS MED RES, V14, P35, DOI 10.1191/0962280205sm388oa
   CALDER C. A., 2002, CASE STUDIES BAYESIA, VVI, P165
   CRESSIE N, 1989, J AM STAT ASSOC, V84, P393, DOI 10.2307/2289922
   Cressie NA, 1993, STAT SPATIAL DATA, V900
   Cressie N, 2008, J COMPUT GRAPH STAT, V17, P726, DOI 10.1198/106186008X340760
   Higdon D., 2002, QUANTITATIVE METHODS, P37, DOI DOI 10.1007/978-1-4471-0657-
9_2
   Hodges JS, 2010, AM STAT, V64, P325, DOI 10.1198/tast.2010.10052
   Lavine ML, 2012, AM STAT, V66, P42, DOI 10.1080/00031305.2012.654746
   Lawson AB, 2000, STAT MED, V19, P2217
   Lee D, 2014, BIOMETRICS, V70, P419, DOI 10.1111/biom.12156
   Moraga P, 2012, COMPUT STAT DATA AN, V56, P1417, DOI
10.1016/j.csda.2011.11.011
   Rodrigues EC, 2012, J MULTIVARIATE ANAL, V109, P88, DOI
10.1016/j.jmva.2012.02.017
   Stern H, 1999, DISEASE MAPPING AND RISK ASSESSMENT FOR PUBLIC HEALTH, P63
   Wall MM, 2004, J STAT PLAN INFER, V121, P311, DOI 10.1016/S0378-
3758(03)00111-3
   White G, 2009, COMPUT STAT DATA AN, V53, P3033, DOI
10.1016/j.csda.2008.08.010
NR 18
TC 2
Z9 2
U1 0
U2 9
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1180-4009
EI 1099-095X
J9 ENVIRONMETRICS
JI Environmetrics
PD SEP
PY 2015
VL 26
IS 6
BP 383
EP 392
DI 10.1002/env.2346
PG 10
WC Environmental Sciences; Mathematics, Interdisciplinary Applications;
   Statistics & Probability
SC Environmental Sciences & Ecology; Mathematics
GA CQ9ZV
UT WOS:000360978100001
DA 2019-08-06
ER

PT J
AU Richardson, V
   Milam, S
   Chrysler, D
```

AF Richardson, Victor
Milam, Sallie
Chrysler, Denise
TI Is Sharing De-identified Data Legal? The State of Public Health Confidentiality Laws and Their Interplay with Statistical Disclosure Limitation Techniques
SO JOURNAL OF LAW MEDICINE & ETHICS
LA English
DT Article; Proceedings Paper
CT National Public Health Law Conference - Intersection of Law, Policy and Prevention
CY OCT, 2014
CL Atlanta, GA
SP Network Public Hlth Law, Ame Soc Law, Med & Eth
AB The multiplicity and age of state confidentiality laws often stymie the flow of public health data. De-identification promises a solution to this problem, but is shadowed by the specter of re-identification attacks. This article examines de-identification's efficacy and legality - ultimately concluding it is a safe and effective data liberation tool.
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RP Richardson, V (reprint author), West Virginia Healthcare Author, Charleston, SC USA.
CR American Statistical Association: Committee on Privacy and Confidentiality, 2011, KEY TERMS DEF
[Anonymous], GUID REG METH DEID P
Cavoukian A., 2011, DISCUSSION PAPERS IN
Centers for Disease Control and Prevention, 2003, HIPAA PRIV RUL PUBL
Ciriani V., 2007, SECURE DATA MANAGEME, V33, P291, DOI [10.1007/978-0-387-27696-0_9, DOI 10.1007/978-0-387-27696-0_9]
Golle P, 2006, 5 ACM WORKSH PRIV EL
*NAT COMM VIT HLTH, 2007, ENH PROT US HLTH DAT
Ohm P, 2010, UCLA LAW REV, V57, P1701
Sweeney L., 2000, 3 CARN MELL U
Ware J. M., PUBLIC HLTH DEP STAT
NR 10
TC 2
Z9 2
U1 1
U2 4
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1073-1105
EI 1748-720X
J9 J LAW MED ETHICS
JI J. Law Med. Ethics
PD SPR
PY 2015
VL 43
SU 1
SI SI
BP 83
EP 86
DI 10.1111/jlme.12224
PG 4

```
WC Ethics; Law; Medical Ethics; Medicine, Legal
SC Social Sciences - Other Topics; Government & Law; Medical Ethics; Legal
   Medicine
GA CF5CS
UT WOS:000352573600020
PM 25846173
DA 2019-08-06
ER

PT J
AU Pisano, F
   Lorenzoni, G
   Sabato, SS
   Soriani, N
   Narraci, O
   Accogli, M
   Rosato, C
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   Folino, F
   Buja, G
   Tona, F
   Baldi, I
   Iliceto, S
   Gregori, D
AF Pisano, Franco
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   Rosato, Carlo
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   Folino, Franco
   Buja, Gianfranco
   Tona, Francesco
   Baldi, Ileana
   Iliceto, Sabino
   Gregori, Dario
CA GISC Study Grp
TI Networking and data sharing reduces hospitalization cost of heart
   failure: the experience of GISC study
SO JOURNAL OF EVALUATION IN CLINICAL PRACTICE
LA English
DT Article
DE evaluation; health services research; public health
ID GENERALIZED ESTIMATING EQUATIONS; DISEASE MANAGEMENT; RANDOMIZED-TRIAL;
   MULTIDISCIPLINARY CARE; HIGH-RISK; OUTCOMES; INTERVENTION; READMISSION;
   PROGRAM
AB Rationale, aims and objectivesHeart failure (HF) is a concerning public
health burden in Western society because, despite the improvement of medical
treatments, it is still associated with adverse outcomes (high morbidity and
mortality), resulting in one of the most expensive chronic disease in Western
countries. Hospital admission particularly is the most expensive cost driver
among the several resources involved in the management of HF. The aim of our
study was to investigate the cost of hospitalization before and after the
enrolment to a new strategy (GISC) in the management of patients with HF.
   MethodsWe enrolled a cohort of 90 patients. Patients were eligible to the
study if they were hospitalized with a new diagnosis of HF or a diagnosis of
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decompensated HF. The enrolment to the study corresponded to the enrolment to the GISC intervention. We calculated the cost for every hospital admission at 6 and 12 months before and after the enrolment using the tariff paid for the diagnosis-related group.

ResultsComparing per-patient cumulative cost before and after the enrolment, we showed that patient's hospitalization was less expensive after the enrolment to the GISC intervention. The strategy resulted in an average cumulative estimated saving of Euro439322.00 (95% CI Euro413890.70; Euro464753.40) at 6 months and of Euro832276.80 (95% CI Euro786863.70; Euro877690.00) at 12 months after the enrolment.

ConclusionsWe found out that the intervention was a cost-saving strategy for follow-up of the patients suffering from HF at 6 and 12 months after the enrolment compared with hospitalizations' cost before the recruitment.

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CR Annema C, 2009, HEART LUNG, V38, P427, DOI 10.1016/j.hrtlng.2008.12.002
Bleumink GS, 2004, EUR HEART J, V25, P1614, DOI 10.1016/j.ehj.2004.06.038
Chaudhry SI, 2007, J CARD FAIL, V13, P709, DOI 10.1016/j.cardfail.2007.06.720
Cleland JGF, 2003, EUR HEART J, V24, P442, DOI 10.1016/S0195-668X(02)00823-0
Coleman K, 2009, HEALTH AFFAIR, V28, P75, DOI 10.1377/hlthaff.28.1.75
Desai AS, 2012, CIRCULATION, V125, P828, DOI 10.1161/CIRCULATIONAHA.111.031179
Gigli G, 2009, J CARDIOVASC MED, V10, P367, DOI 10.2459/JCM.0b013e3283276e1c
Gregori D, 2011, INT J QUAL HEALTH C, V23, P331, DOI 10.1093/intqhc/mzr010
Halekoh U, 2006, J STAT SOFTW, V15, P1
Hesselink G, 2012, ANN INTERN MED, V157, P417, DOI 10.7326/0003-4819-157-6-201209180-00006
Kasper EK, 2002, J AM COLL CARDIOL, V39, P471, DOI 10.1016/S0735-1097(01)01761-2
Kimmelstiel C, 2004, CIRCULATION, V110, P1450, DOI 10.1161/01.CIR.0000141562.22216.00
Komajda M, 2007, EUR HEART J, V28, P1310, DOI 10.1093/eurheartj/ehl443
Krumholz HM, 2002, J AM COLL CARDIOL, V39, P83, DOI 10.1016/S0735-1097(01)01699-0
Ledwidge M, 2003, EUR J HEART FAIL, V5, P381, DOI 10.1016/S1388-9842(02)00235-0
Liao L, 2008, PHARMACOECONOMICS, V26, P447, DOI 10.2165/00019053-200826060-00001
Mazzuoli F, 2012, G ITAL CARDIOL, V13, P615, DOI 10.1714/1133.12490
McAlister FA, 2004, J AM COLL CARDIOL, V44, P810, DOI 10.1016/j.jacc.2004.05.055

McAlister FA, 2001, AM J MED, V110, P378, DOI 10.1016/S0002-9343(00)00743-9
   Nucifora G, 2006, J CARDIOVASC MED, V7, P614, DOI 10.2459/01.JCM.0000237910.34000.58
   Pan W, 2001, BIOMETRICS, V57, P120, DOI 10.1111/j.0006-341X.2001.00120.x
   R.C. Team, 2013, R LANG ENV STAT COMP
   Riegel B, 2002, ARCH INTERN MED, V162, P705, DOI 10.1001/archinte.162.6.705
   Zannad F., 2009, J WORKING GROUPS S5, V11, pv1
NR 24
TC 2
Z9 2
U1 0
U2 1
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1356-1294
EI 1365-2753
J9 J EVAL CLIN PRACT
JI J. Eval. Clin. Pract.
PD FEB
PY 2015
VL 21
IS 1
BP 103
EP 108
DI 10.1111/jep.12255
PG 6
WC Health Care Sciences & Services; Medical Informatics; Medicine, General
   & Internal
SC Health Care Sciences & Services; Medical Informatics; General & Internal
   Medicine
GA CC6AV
UT WOS:000350447800016
PM 25266937
DA 2019-08-06
ER

PT B
AU Bahri, L
   Carminati, B
   Ferrari, E
AF Bahri, Leila
   Carminati, Barbara
   Ferrari, Elena
GP IEEE
TI CARDS - Collaborative Audit and Report Data Sharing for A-Posteriori
   Access Control in DOSNs
SO 2015 IEEE CONFERENCE ON COLLABORATION AND INTERNET COMPUTING (CIC)
LA English
DT Proceedings Paper
CT IEEE Conference Collaboration Internet Computing
CY OCT 28-30, 2015
CL Hangzhou, PEOPLES R CHINA
SP IEEE, IEEE Comp Soc, Zhejiang Univ, ADTIME
DE Collaborative audit; DOSNs; A-posteriori access control; Data
   accountability; Collaborative data sharing
ID TRUST

AB Accountability and transparency have been commonly accepted to deter bad acts and to encourage compliance to rules. For this, auditing has been largely, and since ancient times, adopted to ensure the well running of systems and businesses within which duties are governed by set rules. Recently, an a-posteriori approach to data access control has been investigated for information systems as well across number of critical domains (e.g, healthcare systems). Besides, privacy advocates started calling for the necessity of accountability and transparency in managing users' privacy in nowadays connected and proliferated web data. Following this line of thought, we suggest a system for collaborative a-posteriori access control to data dissemination in decentralized online social networks based on reporting and auditing. We demonstrate the usability of our suggested model using a real OSN graph.

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CR Ala-Kleemola T., 2012, uS Patent, Patent No. [8,112,515, 8112515]
Bahri L., CARDS COLLABORATIVE
Bodriagov O, 2014, INT CONF PERVAS COMP, P622, DOI 10.1109/PerComW.2014.6815278
Buchegger S., 2009, WIR ON DEM NETW SYST, P161
Carminati B, 2009, ACM T INFORM SYST SE, V13, DOI 10.1145/1609956.1609962
Cutillo LA, 2009, IEEE COMMUN MAG, V47, P94, DOI 10.1109/MCOM.2009.5350374
Damen S., 2014, COLL TECHN SYST CTS
Daraghmi EY, 2014, COMPUT HUM BEHAV, V30, P273, DOI 10.1016/j.chb.2013.09.014
Dekker MAC, 2007, ELECTRON NOTES THEOR, V168, P221, DOI 10.1016/j.entcs.2006.08.028
Dewan P., 2010, KNOWLEDGE DATA ENG I
Etalle S, 2007, SACMAT'07: PROCEEDINGS OF THE 12TH ACM SYMPOSIUM ON ACCESS CONTROL MODELS AND TECHNOLOGIES, P11
Ferrari E., 2010, SYNTHESIS LECT DATA
Jahid S., 2012, PERV COMP COMM WORKS, P326
Josang A, 2007, DECIS SUPPORT SYST, V43, P618, DOI 10.1016/j.dss.2005.05.019
Kelly M., 2013, PAYING PRIVACY WHY I
Liu G, 2011, AAAI, P1222
Padayachee K, 2009, COMPUT SECUR, V28, P536, DOI 10.1016/j.cose.2009.03.003
Pava M. L., 2013, ENCY BRITANNICA AUDI
Pearson S., 2011, COMPUTER
Saran C., 2014, T BERNERSLEE DATA SH
Tipton H., 2003, INFORM SECURITY MANA
Weitzner DJ, 2008, COMMUN ACM, V51, P82, DOI 10.1145/1349026.1349043
Yang J, 2015, KNOWL INF SYST, V42, P181, DOI 10.1007/s10115-013-0693-z

NR 23
TC 2
Z9 2
U1 3
U2 3
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-5090-0089-0
PY 2015
BP 36
EP 45
DI 10.1109/CIC.2015.18
PG 10
WC Computer Science, Theory & Methods

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SC Computer Science
GA BF1HK
UT WOS:000380397300005
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ER

PT S
AU Hu, Y
   Peng, C
   Bai, GH
AF Hu, Yan
   Peng, Cong
   Bai, Guohua
GP IEEE
TI SHARING HEALTH DATA THROUGH HYBRID CLOUD FOR SELF-MANAGEMENT
SO 2015 IEEE INTERNATIONAL CONFERENCE ON MULTIMEDIA & EXPO WORKSHOPS
   (ICMEW)
SE IEEE International Conference on Multimedia and Expo Workshops
LA English
DT Proceedings Paper
CT IEEE International Conference on Multimedia & Expo Workshops (ICMEW)
CY JUN 29-JUL 03, 2015
CL Turin, ITALY
DE Chronic disease; information sharing; self-management; cloud computing;
   hybrid cloud
AB Nowadays, patient self-management is encouraged in home-based healthcare,
especially for chronic disease care. Sharing health information could improve
the quality of patient self-management. In this paper, we introduce cloud
computing as a potential technology to provide a more sustainable long-term
solution compared with other technologies. A hybrid cloud is identified as a
suitable way to enable patients to share health information for promoting the
treatment of chronic diseases. And then a prototype on the case of type 2
diabetes is implemented to prove the feasibility of the proposed solution.
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CR Bahga A, 2013, IEEE J BIOMED HEALTH, V17, P894, DOI 10.1109/JBHI.2013.2257818
   Cunningham PJ, 2015, HEALTH AFFAIR, V34, P117, DOI 10.1377/hlthaff.2014.0216
   Currie WL, 2014, INFORM MANAGE-AMSTER, V51, P783, DOI
10.1016/j.im.2014.04.004
   Danaei G, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000058
   Deo S S, 2005, Inform Prim Care, V13, P35
   Hu Y., 2014, HLTH INFORM INT J HI, V3, P11
   Hussain M, 2013, HEALTH TECHNOL-GER, V3, P153, DOI 10.1007/s12553-013-0051-x
   Mahmood Z., 2011, 2011 International Conference on Emerging Intelligent Data
and Web Technologies, P49, DOI 10.1109/EIDWT.2011.16
   Mazhelis O, 2012, INFORM SYST FRONT, V14, P845, DOI 10.1007/s10796-011-9326-9
   Mell P., 2009, NATL I STANDARDS TEC, V53, P50, DOI DOI 10.6028/NIST.SP.800-
145
   Pang ZB, 2015, ENTERP INF SYST-UK, V9, P86, DOI 10.1080/17517575.2013.776118
   Song XG, 2012, 2012 7TH INTERNATIONAL CONFERENCE ON SYSTEM OF SYSTEMS
ENGINEERING (SOSE), P8, DOI 10.1109/SYSoSE.2012.6333450
   Weir CR, 2015, BMC MED INFORM DECIS, V15, DOI 10.1186/s12911-015-0150-x
NR 13
TC 2
Z9 2
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U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2330-7927
BN 978-1-4799-7079-7
J9 IEEE INT CONF MULTI
PY 2015
PG 6
WC Computer Science, Hardware & Architecture; Computer Science, Information
   Systems; Engineering, Electrical & Electronic
SC Computer Science; Engineering
GA BF3DZ
UT WOS:000380531100012
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ER

PT S
AU Melillo, P
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AF Melillo, Paolo
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   Morgan, Stephen P.
   Pecchia, Leandro
BE Lackovic, I
   Vasic, D
TI Automatic Prediction of Falls via Heart Rate Variability and Data Mining
   in Hypertensive Patients: The SHARE Project Experience
SO 6TH EUROPEAN CONFERENCE OF THE INTERNATIONAL FEDERATION FOR MEDICAL AND
   BIOLOGICAL ENGINEERING
SE IFMBE Proceedings
LA English
DT Proceedings Paper
CT 6th European Conference of the
   International-Federation-for-Medical-and-Biological-Engineering (MBEC)
CY SEP 07-11, 2014
CL Dubrovnik, CROATIA
SP Croatian Med & Biol Engn Soc, Int Federat Med & Biol Engn, Minist Sci Educ &
Sports Republ Croatia, Minist Hlth Republ Croatia, Univ Zagreb, Fac Elect Engn &
Comp, European Alliance Med & Biol Engn & Sci, European Cooperat Sci & Technol
DE heart rate variability (HRV); accidental falls; fall risk factors; falls
   prediction; data mining
ID APPROXIMATE ENTROPY; PHYSICAL-ACTIVITY; RISK-ASSESSMENT; HEALTH-CARE;
   QUANTIFICATION; FEATURES; HRV
AB Accidental falls in elderly is a major problem. This paper presents the
preliminary results of a retrospective study investigating association between
Heart Rate Variability (HRV) measures and risk of falling, analyzing 168
clinical 24-hour ECG recording from hypertensive patients, 47 of them
experienced at least one fall in the three months before/after the registration.
Several HRV patterns, based on 68 linear and non-linear HRV measures, were
analyzed in relation to falls using advanced statistical and data mining methods.
   The results demonstrated that there is a significant association between a
depressed HRV and the risk of falling, suggesting that a depressed HRV could be
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a new independent risk factor for falls with an odds ratio of 5.12 (CI 95% 1.42-18.41; p<0.01).

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CR Acharya UR, 2006, MED BIOL ENG COMPUT, V44, P1031, DOI 10.1007/s11517-006-0119-0
Allet L, 2010, SENSORS-BASEL, V10, P9026, DOI 10.3390/s101009026
Breiman L, 2001, MACH LEARN, V45, P5, DOI 10.1023/A:1010933404324
Breiman L., 1984, CLASSIFICATION REGRE
Brennan M, 2001, IEEE T BIO-MED ENG, V48, P1342, DOI 10.1109/10.959330
Camm AJ, 1996, EUR HEART J, V17, P354
Carvajal R, 2005, COMPUT METH PROG BIO, V78, P133, DOI 10.1016/j.cmpb.2005.01.004
Clifford GD, 2005, IEEE T BIO-MED ENG, V52, P630, DOI 10.1109/TBME.2005.844028
Cohen WW, 1995, 12 INT C MACH LEARN
Dabire H, 1998, AM J PHYSIOL-HEART C, V275, pH1290
Design J R., 2010, EVALUATION APPL HEAR
Friedman N, 1997, MACH LEARN, V29, P131, DOI 10.1023/A:1007465528199
Ganyo M, 2011, AGEING SOC, V31, P1350, DOI 10.1017/S0144686X10001443
Gates S, 2008, J REHABIL RES DEV, V45, P1105, DOI 10.1682/JRRD.2008.04.0057
Guideline for the prevention of falls in older persons, 2001, J AM GERIATR SOC, V49, P664, DOI DOI 10.1046/J.1532-5415.2001.49115.X
Hall M., 2009, SIGKDD EXPLORATIONS, V11, P10, DOI [DOI 10.1145/1656274.1656278, 10.1145/1656274.1656278]
Hamacher D, 2011, J R SOC INTERFACE, V8, P1682, DOI 10.1098/rsif.2011.0416
Hautala AJ, 2010, AM J PHYSIOL-HEART C, V298, pH874, DOI 10.1152/ajpheart.00856.2009
Isik M, 2012, EUR GERIATR MED, V3, P9, DOI 10.1016/j.eurger.2011.11.003
KHANDOKER AH, 2009, BIOMED ENG ONLINE, V8
Kosse NM, 2013, INT J MED INFORM, V82, P743, DOI 10.1016/j.ijmedinf.2013.06.001
Melillo P, 2013, IEEE J BIOMED HEALTH, V17, P727, DOI 10.1109/JBHI.2013.2244902
Melillo P, 2012, BMC CARDIOVASC DISOR, V12, DOI 10.1186/1471-2261-12-105
Melillo P, 2011, BIOMED ENG ONLINE, V10, DOI 10.1186/1475-925X-10-96
Melillo P, 2011, MED BIOL ENG COMPUT, V49, P67, DOI 10.1007/s11517-010-0728-5
Niskanen JP, 2004, COMPUT METH PROG BIO, V76, P73, DOI 10.1016/j.cmpb.2004.03.004
Pecchia L, 2011, METHOD INFORM MED, V50, P435, DOI 10.3414/ME10-01-0028
Peel NM, 2011, CAN J AGING, V30, P7, DOI 10.1017/S071498081000070X
Penzel T, 2003, IEEE T BIO-MED ENG, V50, P1143, DOI 10.1109/TBME.2003.817636
Perell KL, 2001, J GERONTOL A-BIOL, V56, pM761, DOI 10.1093/gerona/56.12.M761
PINCUS SM, 1991, P NATL ACAD SCI USA, V88, P2297, DOI 10.1073/pnas.88.6.2297
Quinlan J. R., 1993, C4 5 PROGRAMS MACHIN
Richman JS, 2000, AM J PHYSIOL-HEART C, V278, pH2039
Schoene D, 2014, AGE AGEING, V43, P285, DOI 10.1093/ageing/aft157
Siracuse JJ, 2012, AM J SURG, V203, P335, DOI 10.1016/j.amjsurg.2011.09.018
Tiedemann A, 2008, AGE AGEING, V37, P430, DOI 10.1093/ageing/afn100
Tinetti ME, 2010, JAMA-J AM MED ASSOC, V303, P258, DOI 10.1001/jama.2009.2024
Yang CC, 2010, SENSORS-BASEL, V10, P7772, DOI 10.3390/s100807772
Zbilut JP, 2002, MED ENG PHYS, V24, P53, DOI 10.1016/S1350-4533(01)00112-6
ZEGER SL, 1988, BIOMETRICS, V44, P1049, DOI 10.2307/2531734
Zong W, 2003, COMPUTERS CARDIOLOGY, V2003

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NR 41
TC 2
Z9 2
U1 0
U2 6
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 1680-0737
BN 978-3-319-11127-8
J9 IFMBE PROC
PY 2015
VL 45
BP 42
EP 45
DI 10.1007/978-3-319-11128-5_11
PG 4
WC Engineering, Biomedical; Medical Informatics; Neurosciences
SC Engineering; Medical Informatics; Neurosciences & Neurology
GA BC0RY
UT WOS:000349454200011
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ER

PT J
AU Hayden, EC
AF Hayden, Erika Check
TI Cancer-gene data sharing boosted
SO NATURE
LA English
DT News Item
NR 0
TC 2
Z9 3
U1 0
U2 9
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 0028-0836
EI 1476-4687
J9 NATURE
JI Nature
PD JUN 12
PY 2014
VL 510
IS 7504
BP 198
EP 198
DI 10.1038/510198a
PG 1
WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA AI7AT
UT WOS:000337032400007
PM 24919902
OA Bronze
DA 2019-08-06
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PT S
AU Ammar, N
   Malik, Z
   Rezgui, A
   Alodib, M
AF Ammar, Nariman
   Malik, Zaki
   Rezgui, Abdelmounaam
   Alodib, Mohammed
BE Shakshuki, EM
TI MobiDyC: Private Mobile-Based Health Data Sharing Through Dynamic
   Context Handling
SO 9TH INTERNATIONAL CONFERENCE ON FUTURE NETWORKS AND COMMUNICATIONS
   (FNC'14) / THE 11TH INTERNATIONAL CONFERENCE ON MOBILE SYSTEMS AND
   PERVASIVE COMPUTING (MOBISPC'14) / AFFILIATED WORKSHOPS
SE Procedia Computer Science
LA English
DT Proceedings Paper
CT 11th International Conference on Mobile Systems and Pervasive Computing
   (MobiSPC)
CY AUG 17-20, 2014
CL Niagara Falls, CANADA
DE Privacy; Context; Web service; Cloud; Mobile
AB With the adoption of mobile healthcare applications and the success of cloud
service models, we propose a privacy management framework for mobile health care
applications with support for dynamic privacy management of health data sharing.
Our solution extends the XACML policy language by incorporating user access
context into the privacy policy rule enforcement. We provide an implementation
of our approach that builds on top of the Google App Engine cloud platform. We
also provide a preliminary evaluation that indicates that the overhead incurred
by our approach is minimal. (c) 2014 Elsevier B.V.
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CR Agrawal R., 2007, INTERNATIONAL JOURNA
   Anh D.T.T., 2014, JOURNAL OF SYSTEMS A
   [Anonymous], 2009, THE WEKA DATA MINING
   [Anonymous], 2009, SURVEY CONTEXT AWARE
   Cristofaro E.D., 2013, PARTICIPATORY PRIVAC
   Ferrini R., 2009, INTERNATIONAL CONFER
   Grandison T., 2007, STUDIES IN HEALTH TE
   Hall M., 2009, PROCEEDINGS OF THE I
   Mont M.C., 2006, INTERNATIONAL CONFER
   Pallapa G., 2012, INTERNATIONAL SYMPOS
   Truong H.L., 2009, BREACHES AFFECTING 5
NR 11
TC 2
Z9 2
U1 0
U2 0
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA SARA BURGERHARTSTRAAT 25, PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 1877-0509
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J9 PROCEDIA COMPUT SCI
PY 2014
VL 34
BP 426
EP 433
DI 10.1016/j.procs.2014.07.049
PG 8
WC Computer Science, Information Systems; Computer Science, Theory &
   Methods; Telecommunications
SC Computer Science; Telecommunications
GA BC1CK
UT WOS:000349979900052
OA Other Gold
DA 2019-08-06
ER

PT B
AU Zheng, YX
   Li, LL
   Zhang, L
AF Zheng, Yixin
   Li, Linglong
   Zhang, Lin
GP IEEE
TI Poster Abstract: PiMi Air Community: Getting Fresher Indoor Air by
   Sharing Data and Know-hows
SO PROCEEDINGS OF THE 13TH INTERNATIONAL SYMPOSIUM ON INFORMATION
   PROCESSING IN SENSOR NETWORKS (IPSN' 14)
LA English
DT Proceedings Paper
CT 13th IEEE/ACM International Symposium on Information Processing in
   Sensor Networks (IPSN)
CY APR 15-17, 2014
CL Berlin, GERMANY
SP Assoc Comp Machinery, IEEE, ACM SIGBED, IEEE Comp Soc, Carl Ossietzky Univ
Oldenburg
DE participatory sensing; indoor air quality; human factors
AB PiMiair.org is a participatory indoor air quality data sharing project we
launched in January 2014. Over 200 PiMi air boxes, a low-cost indoor air quality
monitor, were given out to volunteer users across China. The PiMi air boxes
measure the approximate indoor particulate matter concentration, and the ambient
temperate and humidity. When a user accesses the PiMi air box for his personal
air quality data on his smartphone, the data is relayed to the backend PiMi
cloud server for analysis. Accumulating large amount of indoor air quality data
under different circumstances, the PiMi cloud server is able to use statistical
learning methodologies to detect point of interests (POIs) in the data series,
and asks users to label their activities or events at the POIs. Together with
the user-reported physicality information on the indoor environments,
PiMiair.org is able to quantitatively evaluate the impacts of the environment
physicality and human behaviors on the indoor air quality, and mine the
knowledges on how to alleviate indoor air pollution. We believe that by sharing
these knowledge among the community, healthier breathing environments could be
nurtured for the well-being of the public.
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CR Chen YY, 2013, P NATL ACAD SCI USA, V110, P12936, DOI 10.1073/pnas.1300018110
   Linglong Li, 2014, IPSN 2014 BERL APR
   Rim D, 2012, AEROSOL SCI TECH, V46, P494, DOI 10.1080/02786826.2011.639317
NR 3
TC 2
Z9 2
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
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PY 2014
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WC Computer Science, Information Systems; Remote Sensing
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GA BB5AJ
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PT J
AU Yu, H
   Wang, HH
   Wang, C
AF Yu, Hao
   Wang, Haihang
   Wang, Cheng
TI A Sharing Data Model for Wireless Body Sensor Networks in Different
   Application Scenarios of Heterogeneous Platforms
SO AD HOC & SENSOR WIRELESS NETWORKS
LA English
DT Article
DE Body sensor networks; heterogeneous platform; data sharing
ID M-HEALTH
AB Body sensor networks (BSNs) represent an emerging technology which has
attracted much attention recently due to its enormous potential to enable remote,
real-time, continuous and non-invasive monitoring of people in health-care,
entertainment, fitness, sport, and social interaction. At present, the semantic
expressions of BSNs data depend on the specific application scenarios, then have
no unified standard. Such a lack of compatibility in the standard will lead to a
subsequent bottleneck in data sharing of BSNs. This paper presents a model that
addresses the issue, from low-layer data encapsulation to higher layer data
storage, to top-layer application scenarios in BSNs. The physiological data from
BSNs are encapsulated with some metadata, including BSNs context, sensor
position, time and human health state in the model. The proposed model is cross-
platform in terms of sharing physiological data. The results of experiments
validate the effectiveness of data sharing in BSNs under the proposed model.
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```

Dalton A, 2012, IEEE T BIO-MED ENG, V59, P3204, DOI 10.1109/TBME.2012.2204990
Dong L., 2006, P 6 INT C ITS TEL, P987
Espina J., 2008, P 5 INT SUMM SCH S M, P28
Gouttaya N., 2011, P C INF SCI TECHN CI, P13
Gu T, 2011, IEEE T MOBILE COMPUT, V10, P1618, DOI 10.1109/TMC.2011.43
Hanson MA, 2009, SIXTH INTERNATIONAL WORKSHOP ON WEARABLE AND IMPLANTABLE BODY SENSOR NETWORKS, PROCEEDINGS, P181, DOI 10.1109/P3644.47
Joly A., 2009, INT J COMPUTER SCI A, V6, P50
Jovanov E, 2005, P ANN INT IEEE EMBS, P7158, DOI 10.1109/IEMBS.2005.1616158
King R. C., 2010, P INT C BOD SENS NET, P30
Korel BT, 2007, 21ST INTERNATIONAL CONFERENCE ON ADVANCED NETWORKING AND APPLICATIONS WORKSHOPS/SYMPOSIA, VOL 2, PROCEEDINGS, P798
Li HM, 2010, IEEE T INF TECHNOL B, V14, P44, DOI 10.1109/TITB.2009.2028136
Li HB, 2008, EURO WIREL TECHNOL C, P1
Lo B., 2007, P IET SEM ANT PROP B, P26
Loseu V, 2012, P IEEE, V100, P107, DOI 10.1109/JPROC.2011.2161238
Lowe R., 2012, PERV COMP COMM WORKS, P76
Madhusudanan J., 2010, P INT C COMP COMM NE, P1
Meyer M, 2002, DIS MANAGEMENT, V5, P87, DOI DOI 10.1089/109350702320229186
Mirisaee SH, 2009, INTERNATIONAL CONFERENCE ON FUTURE COMPUTER AND COMMUNICATIONS, PROCEEDINGS, P251, DOI 10.1109/ICFCC.2009.84
Nat arajan A, 2007, P 1 ACM SIGMOBILE IN, P19
Pansiot J., 2010, P INT C BOD SENS NET, P153
PEREIRA O. R. E., 2010, P 2010 12 IEEE INT C, P316
Poon CCY, 2006, IEEE COMMUN MAG, V44, P73, DOI 10.1109/MCOM.2006.1632652
Rahman MA, 2011, IEEE T INSTRUM MEAS, V60, P345, DOI 10.1109/TIM.2010.2084190
Wartzek T, 2009, SIXTH INTERNATIONAL WORKSHOP ON WEARABLE AND IMPLANTABLE BODY SENSOR NETWORKS, PROCEEDINGS, P168, DOI 10.1109/P3644.18
Yu H., 2013, J COMPUTATIONAL INFO, V9, P10049
Zhang ZB, 2011, PROC EUR TEST SYMP, P13, DOI 10.1109/ETS.2011.18
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TC 2
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U1 0
U2 0
PU OLD CITY PUBLISHING INC
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PA 628 NORTH 2ND ST, PHILADELPHIA, PA 19123 USA
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J9 AD HOC SENS WIREL NE
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WC Computer Science, Information Systems; Telecommunications
SC Computer Science; Telecommunications
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PT S
AU Singanamalli, A
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AF Singanamalli, Asha
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Feldman, Michael
Madabhushi, Anant
BE Molthen, RC
Weaver, JB
TI Supervised Multi-View Canonical Correlation Analysis: Fused Multimodal Prediction of Disease Diagnosis and PrognosisCancer Synergistic Idea Development Award (PC120857); the QED award from the University City Science Center and Rutgers University, the Ohio Third Frontier Technology development Grant. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. In addition, data collection and sharing for the Alzheimer's Disease Dataset was funded by the Alzheimer's Disease Neuroimaging Initiative (ADNI) (National Institutes of Health Grant U01 AG024904) and DOD ADNI (Department of Defense award number W81XWH-12-2-0012).ADNI is funded by the National Institute on Aging, the National Institute of Biomedical Imaging and Bioengineering, and through generous contributions from a number of associations and companies .Research reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under award numbers R01CA136535-01, R01CA140772-01, and R21CA167811-01; the National Institute of Diabetes and Digestive and Kidney Diseases under award number R01DK098503-02, the DOD Prostate
SO MEDICAL IMAGING 2014: BIOMEDICAL APPLICATIONS IN MOLECULAR, STRUCTURAL, AND FUNCTIONAL IMAGING
SE Proceedings of SPIE
LA English
DT Proceedings Paper
CT Conference on Medical Imaging - Biomedical Applications in Molecular, Structural, and Functional Imaging
CY FEB 16-18, 2014
CL San Diego, CA
SP SPIE, Modus Med Devices Inc, XIFIN Inc, Ventana Med Syst Inc, Intrace Med
ID ALZHEIMERS-DISEASE; PROSTATE-CANCER; BIOMARKER; CLASSIFICATION; SEGMENTATION; SETS
AB While the plethora of information from multiple imaging and non-imaging data streams presents an opportunity for discovery of fused multimodal, multiscale biomarkers, they also introduce multiple independent sources of noise that hinder their collective utility. The goal of this work is to create fused predictors of disease diagnosis and prognosis by combining multiple data streams, which we hypothesize will provide improved performance as compared to predictors from individual data streams. To achieve this goal, we introduce supervised multiview canonical correlation analysis (sMVCCA), a novel data fusion method that attempts to find a common representation for multiscale, multimodal data where class separation is maximized while noise is minimized. In doing so,

sMVCCA assumes that the different sources of information are complementary and thereby act synergistically when combined. Although this method can be applied to any number of modalities and to any disease domain, we demonstrate its utility using three datasets. We fuse (i) 1.5 Tesla (T) magnetic resonance imaging (MRI) features with cerbrospinal fluid (CSF) proteomic measurements for early diagnosis of Alzheimer's disease (n = 30), (ii) 3T Dynamic Contrast Enhanced (DCE) MRI and T2w MRI for in vivo prediction of prostate cancer grade on a per slice basis (n = 33) and (iii) quantitative histomorphometric features of glands and proteomic measurements from mass spectrometry for prediction of 5 year biochemical recurrence postradical prostatectomy (n = 40). Random Forest classifier applied to the sMVCCA fused subspace, as compared to that of MVCCA, PCA and LDA, yielded the highest classification AUC of 0.82 +/- 0.05, 0.76 +/- 0.01, 0.70 +/- 0.07, respectively for the aforementioned datasets. In addition, sMVCCA fused subspace provided 13.6%, 7.6% and 15.3% increase in AUC as compared with that of the best performing individual view in each of the three datasets, respectively. For the biochemical recurrence dataset, Kaplan-Meier curves generated from classifier prediction in the fused subspace reached the significance threshold (p = 0.05) for distinguishing between patients with and without 5 year biochemical recurrence, unlike those generated from classifier predictions of the individual modalities.

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CR Agner SC, 2011, J DIGIT IMAGING, V24, P446, DOI 10.1007/s10278-010-9298-1
[Anonymous], 2008, NEUROIMAGE, V43, P59
Bartlett MS, 1938, P CAMB PHILOS SOC, V34, P33, DOI 10.1017/S0305004100019897

Bellman R., 1961, ADAPTIVE CONTROL PRO, V4
Chan I, 2003, MED PHYS, V30, P2390, DOI 10.1118/1.1593633
Dickerson BC, 2009, NEUROBIOL AGING, V30, P432, DOI 10.1016/j.neurobiolaging.2007.07.022
Fisher RA, 1936, ANN EUGENIC, V7, P179, DOI 10.1111/j.1469-1809.1936.tb02137.x
Golugula A, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-483
Hardoon DR, 2004, NEURAL COMPUT, V16, P2639, DOI 10.1162/0899766042321814
HELOR Y, 2004, HPL2003164R1
Hotelling H, 1936, BIOMETRIKA, V28, P321, DOI 10.1093/biomet/28.3-4.321
Jack CR, 2008, J MAGN RESON IMAGING, V27, P685, DOI 10.1002/jmri.21049
Kern SE, 2012, CANCER RES, V72, P6097, DOI 10.1158/0008-5472.CAN-12-3232
KETTENRING JR, 1971, BIOMETRIKA, V58, P433, DOI 10.1093/biomet/58.3.433
Khaleghi B., 2011, INFORM FUSION
Lanckriet G. R., 2004, P PAC S BIOC, V9, P300
Lee G, 2013, LECT NOTES COMPUT SC, V8151, P396, DOI 10.1007/978-3-642-40760-4_50
Lee G, 2013, I S BIOMED IMAGING, P113
Lee G, 2009, 2009 IEEE INTERNATIONAL SYMPOSIUM ON BIOMEDICAL IMAGING: FROM NANO TO MACRO, VOLS 1 AND 2, P77, DOI 10.1109/ISBI.2009.5192987
Lee JW, 2007, ADV CANCER RES, V96, P269, DOI 10.1016/S0065-230X(06)96010-2
Lewis DP, 2006, BIOINFORMATICS, V22, P2753, DOI 10.1093/bioinformatics/btl475
Madabhushi A, 2011, COMPUT MED IMAG GRAP, V35, P506, DOI 10.1016/j.compmedimag.2011.01.008
McFee B, 2011, IEEE T IMAGE PROCESS, V20, P570, DOI 10.1109/TIP.2010.2068556
Rohlfing T, 2005, PATTERN RECOGN LETT, V26, P2070, DOI 10.1016/j.patrec.2005.03.017
Shaw LM, 2009, ANN NEUROL, V65, P403, DOI 10.1002/ana.21610
Sima C, 2006, BIOINFORMATICS, V22, P2430, DOI 10.1093/bioinformatics/btl407
Singanamalli A., 2013, SPIE MED IMAGING
Sun TK, 2007, APPL MATH COMPUT, V185, P272, DOI 10.1016/j.amc.2006.06.103
Tiwari P, 2011, I S BIOMED IMAGING, P165, DOI 10.1109/ISBI.2011.5872379
Tiwari P, 2010, LECT NOTES COMPUT SC, V6363, P666
Verma R, 2008, ACAD RADIOL, V15, P966, DOI 10.1016/j.acra.2008.01.029
Viswanath S., 2012, J MAGNETIC RESONANCE
Vos E. K., 2013, EUROPEAN UROLOGY
NR 33
TC 2
Z9 2
U1 0
U2 1
PU SPIE-INT SOC OPTICAL ENGINEERING
PI BELLINGHAM
PA 1000 20TH ST, PO BOX 10, BELLINGHAM, WA 98227-0010 USA
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WC Optics; Radiology, Nuclear Medicine & Medical Imaging
SC Optics; Radiology, Nuclear Medicine & Medical Imaging
GA BA9HJ
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DA 2019-08-06
ER

PT J
AU Jousten, A
Lefebvre, M
AF Jousten, Alain
Lefebvre, Mathieu
TI Retirement Incentives in Belgium: Estimations and Simulations Using
SHARE Data
SO ECONOMIST-NETHERLANDS
LA English
DT Article
DE Pensions; Social security; Disability; Early retirement; Unemployment;
Labor force participation
AB The paper studies retirement behavior of wage-earners in Belgium-for the
first time using a rich survey dataset to analyze retirement incentives as faced
by individuals. Specifically, we use SHARE data to estimate a model A la Stock
and Wise (Econom Econ Soc 58(5):1151-1180, 1990). Exploring the data on
individual life-histories from SHARELIFE, we construct a measure of financial
incentive to retire. Our analysis explicitly takes into account the different
take-up rates of the various early retirement exit paths across time and ages.
The results show that financial incentives play a strong role. Health and
education also matter, as do regional differences. Against the general
background of the 2020 strategy, we perform a set of policy simulations and
illustrate the scope but also the limits associated with selective parametric
reforms.
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CR Cremer H, 2009, EUR J POLIT ECON, V25, P174, DOI
10.1016/j.ejpoleco.2008.09.009
Gruber J., 2004, SOCIAL SECURITY PROG
Human Mortality Database, 2012, HUM MORTALITY DATAB
Jousten A., 2010, SOCIAL SECURITY PROG
Jousten A, 2012, NBER CONF R, P251
Kalwij A, 2008, HEALTH ECON, V17, P619, DOI 10.1002/hec.1285
Milligan K, 2012, NBER CONF R, P1
STOCK JH, 1990, ECONOMETRICA, V58, P1151, DOI 10.2307/2938304
van Erp F, 2014, ECONOMIST-NETHERLAND, V162, P167, DOI 10.1007/s10645-014-
9229-5
Van Soest A., 2012, 6698 IZA
Van Soest A., 2009, 15245 NBER
Wise D., 2004, SOCIAL SECURITY RETI
Wise D., 2007, SOCIAL SECURITY PROG
NR 13
TC 2
Z9 2
U1 0
U2 0
PU SPRINGER
PI DORDRECHT
PA VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS
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EI 1572-9982
J9 ECONOMIST-NETHERLAND
JI Economist-Netherlands
PD SEP

```
PY 2013
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IS 3
BP 253
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WC Economics
SC Business & Economics
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PT J
AU Park, KT
   Bensen, R
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   Cox, K
AF Park, K. T.
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TI Geographical Rural Status and Health Outcomes in Pediatric Liver
   Transplantation: An Analysis of 6 Years of National United Network of
   Organ Sharing Data
SO JOURNAL OF PEDIATRICS
LA English
DT Article
ID QUALITY-OF-LIFE; MEDICATION ADHERENCE; FOLLOW-UP; CARE; REGIONALIZATION;
   ACCESS; CHILDREN; DISPARITIES; RESIDENCE; SERVICES
AB Objective To determine whether children in rural areas have worse health than
children in urban areas after liver transplantation (LT).
   Study design We used urban influence codes published by the US Department of
Agriculture to categorize 3307 pediatric patients undergoing LT in the United
Network of Organ Sharing database between 2004 and 2009 as urban or rural.
Allograft rejection, patient death, and graft failure were used as primary
outcome measures of post-LT health. Pediatric end-stage liver disease/model of
end-stage liver disease scores >20 was used to measure worse pre-LT health.
   Results In a multivariate analysis, we found greater rates of allograft
rejection within 6 months of LT (OR 1.27; 95% CI 1.05-1.53) and a lower
occurrence of posttransplantation lymphoproliferative disorder (OR 0.64; 95% CI
0.41-0.99) in patients in rural areas. The difference in allograft rejection was
eliminated at 1 year of LT (OR 1.18; 95% CI 0.98-1.42). Rural location did not
impact other outcome measures.
   Conclusion We conclude that rural location makes a negative impact on patient
health within the first 6 months of LT by increasing the risk for allograft
rejection, although patients in rural areas may have lower rates of developing
posttransplantation lymphoproliferative disorder. Long-term adverse health
effects were not seen. (J Pediatr 2013;162:313-8).
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FX Supported by a grant from the Child Health Research Institute of Stanford University. The authors declare no conflicts of interest.

CR Alonso EM, 2009, AM J TRANSPLANT, V9, P1389, DOI 10.1111/j.1600-6143.2009.02634.x
Alonso EM, 2008, LIVER TRANSPLANT, V14, P460, DOI 10.1002/lt.21352
Alonso EM, 2010, J PEDIATR-US, V156, P270, DOI 10.1016/j.jpeds.2009.08.048
Auchincloss AH, 2002, J RURAL HEALTH, V18, P319, DOI 10.1111/j.1748-0361.2002.tb00894.x
Austin MT, 2006, J GASTROINTEST SURG, V10, P387, DOI 10.1016/j.gassur.2005.10.008
Axelrod DA, 2008, JAMA-J AM MED ASSOC, V299, P202, DOI 10.1001/jama.2007.50
Berg CL, 2009, AM J TRANSPLANT, V9, P907, DOI 10.1111/j.1600-6143.2009.02567.x
Bowling A, 1997, J EPIDEMIOL COMMUN H, V51, P52, DOI 10.1136/jech.51.1.52
Brookhart MA, 2007, ARCH INTERN MED, V167, P847, DOI 10.1001/archinte.167.8.847
Cameron C, 1996, J ADV NURS, V24, P244, DOI 10.1046/j.1365-2648.1996.01993.x
Chan L, 2006, J RURAL HEALTH, V22, P140, DOI 10.1111/j.1748-0361.2006.00022.x
Chen J, 2010, ARCH INTERN MED, V170, P433, DOI 10.1001/archinternmed.2009.538
Chesney MA, 2000, CLIN INFECT DIS, V30, pS171, DOI 10.1086/313849
Church J, 1998, INT J HEALTH SERV, V28, P467, DOI 10.2190/UFPT-7XPW-794C-VJ52
DeVoe JE, 2009, J RURAL HEALTH, V25, P1, DOI 10.1111/j.1748-0361.2009.00192.x
DIMATTEO MR, 1993, HEALTH PSYCHOL, V12, P93, DOI 10.1037/0278-6133.12.2.93
GORDON TA, 1995, ANN SURG, V221, P43, DOI 10.1097/00000658-199501000-00005
Gordon TA, 1998, ANN SURG, V228, P71, DOI 10.1097/00000658-199807000-00011
Granger B, 2008, GASTROEN CLIN BIOL, V32, P589, DOI 10.1016/j.gcb.2008.02.031
Gruen RL, 2002, J EPIDEMIOL COMMUN H, V56, P517, DOI 10.1136/jech.56.7.517
Gruen Rl, 2006, Community Eye Health, V19, P31
Hamilton SM, 1997, ARCH SURG-CHICAGO, V132, P605
Imperato P J, 1996, Am J Med Qual, V11, P193, DOI 10.1177/0885713X9601100407
Jackson BE, 2011, RESP MED, V105, P734, DOI 10.1016/j.rmed.2010.12.019
KANE R, 1979, EVALUATION QUART, V3, P139, DOI 10.1177/0193841X7900300201
Kansagra SM, 2004, JAMA-J AM MED ASSOC, V292, P1717, DOI 10.1001/jama.292.14.1717
Knudson A, 2009, J PUBLIC HEALTH MAN, V15, P232, DOI 10.1097/01.PHH.0000349739.81243.ea
Kosola S, 2012, AM J TRANSPLANT, V12, P420, DOI 10.1111/j.1600-6143.2011.03819.x
Kuhlthau K, 2001, PEDIATRICS, V108, P906, DOI 10.1542/peds.108.4.906
Lee JK, 2006, JAMA-J AM MED ASSOC, V296, P2563, DOI 10.1001/jama.296.21.joc60162
Limbers CA, 2011, PEDIATR TRANSPLANT, V15, P245, DOI 10.1111/j.1399-3046.2010.01453.x
Liu JH, 2008, J RURAL HEALTH, V24, P407, DOI 10.1111/j.1748-0361.2008.00188.x
Livingston EH, 2010, ARCH SURG-CHICAGO, V145, P993, DOI 10.1001/archsurg.2010.218
MAINOUS AG, 1995, J COMMUN HEALTH, V20, P423, DOI 10.1007/BF02260438
Mayer ML, 2008, MATERN CHILD HLTH J, V12, P624, DOI 10.1007/s10995-007-0275-3
Mayer ML, 2009, J PEDIATR SURG, V44, P483, DOI 10.1016/j.jpedsurg.2008.08.015
McAlister VC, 2007, CAN J SURG, V50, P124
McDiarmid SV, 2011, ANN SURG, V254, P145, DOI 10.1097/SLA.0b013e31821ad86a
Morris DS, 2006, J UROLOGY, V176, P242, DOI 10.1016/S0022-5347(06)00512-X

Moscovice I, 2000, J RURAL HEALTH, V16, P168, DOI 10.1111/j.1748-0361.2000.tb00451.x
Muelleman RL, 2010, ACAD EMERG MED, V17, P1390, DOI 10.1111/j.1553-2712.2010.00924.x
Ng VL, 2008, PEDIATRICS, V122, pE1128, DOI 10.1542/peds.2008-1363
Ohl ME, 2011, BMC PUBLIC HEALTH, V11, DOI 10.1186/1471-2458-11-681
Paquette IM, 2011, ANN SURG, V253, P534, DOI 10.1097/SLA.0b013e3182096d68
Park KT, 2011, PEDIATR TRANSPLANT, V15, P300, DOI 10.1111/j.1399-3046.2010.01452.x
Piette JD, 2000, AM J MED, V108, P20, DOI 10.1016/S0002-9343(99)00298-3
Pletcher BA, 2010, J PEDIATR-US, V156, P1011, DOI 10.1016/j.jpeds.2009.12.032
Postier RG, 2007, J GASTROINTEST SURG, V11, P1251
Powe NR, 2003, AM J KIDNEY DIS, V42, P249, DOI 10.1016/S0272-6386(03)00649-8
Redlener Irwin, 2005, Adv Pediatr, V52, P9, DOI 10.1016/j.yapd.2005.03.006
Riall TS, 2007, J GASTROINTEST SURG, V11, P1242, DOI 10.1007/s11605-007-0245-5
Salsberg ES, 2002, HEALTH AFFAIR, V21, P165, DOI 10.1377/hlthaff.21.5.165
Shepherd RW, 2008, AM J TRANSPLANT, V8, P396, DOI 10.1111/j.1600-6143.2007.02068.x
Skinner AC, 2006, J RURAL HEALTH, V22, P36, DOI 10.1111/j.1748-0361.2006.00008.x
Skinner AC, 2007, J RURAL HEALTH, V23, P150, DOI 10.1111/j.1748-0361.2007.00082.x
United States Department of Agriculture, RUR CLASS
Vermeire E, 2001, J CLIN PHARM THER, V26, P331, DOI 10.1046/j.1365-2710.2001.00363.x
Weeks WB, 2006, J RURAL HEALTH, V22, P264, DOI 10.1111/j.1748-0361.2006.00043.x
Weeks WB, 2004, AM J PUBLIC HEALTH, V94, P1762, DOI 10.2105/AJPH.94.10.1762
Wright JD, 2010, OBSTET GYNECOL, V115, P1194, DOI 10.1097/AOG.0b013e3181df94e8

NR 60
TC 2
Z9 3
U1 0
U2 2

PU MOSBY-ELSEVIER
PI NEW YORK
PA 360 PARK AVENUE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0022-3476
EI 1097-6833
J9 J PEDIATR-US
JI J. Pediatr.
PD FEB
PY 2013
VL 162
IS 2
BP 313
EP +
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WC Pediatrics
SC Pediatrics
GA 071GX
UT WOS:000313579900021
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ER

PT J
AU Yardley, S
Brosnan, C
Richardson, J
AF Yardley, Sarah
Brosnan, Caragh
Richardson, Jane
TI Sharing methodology: A worked example of theoretical integration with qualitative data to clarify practical understanding of learning and generate new theoretical development
SO MEDICAL TEACHER
LA English
DT Article
ID MEDICAL-EDUCATION RESEARCH; INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS; HEALTH PSYCHOLOGY; FOCUS GROUPS; EXPERIENCE; STUDENTS; IDENTITY; SCIENCE; ETHICS

AB Background: Theoretical integration is a necessary element of study design if clarification of experiential learning is to be achieved. There are few published examples demonstrating how this can be achieved.

Aims: This methodological article provides a worked example of research methodology that achieved clarification of authentic early experiences (AEEs) through a bi-directional approach to theory and data.

Methods: Bi-directional refers to our simultaneous use of theory to guide and interrogate empirical data and the use of empirical data to refine theory. We explain the five steps of our methodological approach: (1) understanding the context; (2) critique on existing applications of socio-cultural models to inform study design; (3) data generation; (4) analysis and interpretation and (5) theoretical development through a novel application of Metis.

Results: These steps resulted in understanding of how and why different outcomes arose from students participating in AEE. Our approach offers a mechanism for clarification without which evidence-based effective ways to maximise constructive learning cannot be developed. In our example it also contributed to greater theoretical understanding of the influence of social interactions.

Conclusion: By sharing this example of research undertaken to develop both theory and educational practice we hope to assist others seeking to conduct similar research.

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FU Keele University Medical School; Primary Care and Health Sciences Research Institute at Keele University; Association for the Study of Medical Education; North Staffordshire Medical Institute
FX This work was supported by Keele University Medical School and the Primary Care and Health Sciences Research Institute at Keele University. Additional funds were received from the Association for the Study of Medical Education and North Staffordshire Medical Institute.

CR Alderson P, 2002, NURS ETHICS, V9, P508, DOI 10.1191/0969733002ne541oa
Arnseth HC, 2008, PEDAGOG CULT SOC, V16, P289, DOI 10.1080/14681360802346663
Blumer H., 1969, SYMBOLIC INTERACTION
Boulton M., 1994, QUAL HEALTH CARE, V3, P107

Brocki JM, 2006, PSYCHOL HEALTH, V21, P87, DOI 10.1080/14768320500230185
Bunniss S, 2010, MED EDUC, V44, P358, DOI 10.1111/j.1365-2923.2009.03611.x
Cleland JA, 2008, MED EDUC, V42, P800, DOI 10.1111/j.1365-2923.2008.03113.x
Cook DA, 2008, MED EDUC, V42, P128, DOI 10.1111/j.1365-2923.2007.02974.x
Corbin J, 2008, BASICS QUALITATIVE R
Dornan T, 2006, MED TEACH, V28, P13
Dornan T, 2007, MED EDUC, V41, P84, DOI 10.1111/j.1365-2929.2006.02652.x
Engestrom Y, 2005, INTRO VYGOTSKY, P153
Engestrom Y., 2001, J ED WORK, V14, P133, DOI DOI 10.1080/13639080020028747
Eva KW, 2010, MED EDUC, V44, P3, DOI 10.1111/j.1365-2923.2009.03540.x
Eva KW, 2009, MED EDUC, V43, P294, DOI 10.1111/j.1365-2923.2009.03342.x
FREY JH, 1991, SOC SCI J, V28, P175, DOI 10.1016/0362-3319(91)90003-M
Huberman A, 2002, QUALITATIVE RES COMP, P64
Hunter LM, 2008, POPUL ENVIRON, V30, P1, DOI 10.1007/s11111-009-0076-2
KITZINGER J, 1994, SOCIOL HEALTH ILL, V16, P103, DOI 10.1111/1467-9566.ep11347023
Kvale S, 2009, INTERVIEWS LEARNING
Langdridge D., 2009, INTRO RES METHODS DA
Lave J., 1991, SITUATED LEARNING LE
Littlewood S, 2005, BMJ-BRIT MED J, V331, P387, DOI 10.1136/bmj.331.7513.387
Merton RK, 1936, AM SOCIOL REV, V1, P894, DOI 10.2307/2084615
Michell L., 1999, DEV FOCUS GROUP RES, P36, DOI DOI 10.4135/9781849208857.N3
Mishler E. G., 1986, RES INTERVIEWING CON
Monrouxe LV, 2010, MED EDUC, V44, P40, DOI 10.1111/j.1365-2923.2009.03440.x
Monrouxe LV, 2009, QUAL HEALTH RES, V19, P918, DOI 10.1177/1049732309338583
Morgan D. L., 1997, FOCUS GROUPS QUALITA
Morgan DL, 1996, ANNU REV SOCIOL, V22, P129, DOI 10.1146/annurev.soc.22.1.129
National Patient Safety Agency, 2011, INT RES APPL SYST IR
Niemi PM, 1997, MED EDUC, V31, P408, DOI 10.1046/j.1365-2923.1997.00697.x
Norman G, 2009, MED TEACH, V31, P807, DOI 10.1080/01421590903049814
Pawson R, 2004, REALIST SYNTHESIS IN
Pugsley L, 2007, MED EDUC, V41, P726, DOI 10.1111/j.1365-2923.2007.02805.x
QSR International, 2008, NVIVO 8
Radford M, 2006, BRIT EDUC RES J, V32, P177, DOI 10.1080/01411920600568950
Rees CE, 2007, SOC SCI MED, V65, P725, DOI 10.1016/j.socscimed.2007.03.044
Rees CE, 2010, MED EDUC, V44, P334, DOI 10.1111/j.1365-2923.2009.03615.x
Rees CE, 2009, ASSESS EVAL HIGH EDU, V34, P455, DOI 10.1080/02602930802071098
Regehr G, 2010, MED EDUC, V44, P31, DOI 10.1111/j.1365-2923.2009.03418.x
Riessman C. K., 2008, NARRATIVE METHODS HU
Scott J. C., 1998, SEEING STATE CERTAIN
Smith JA, 1996, PSYCHOL HEALTH, V11, P261, DOI 10.1080/08870449608400256
Webster Leonard, 2007, USING NARRATIVE INQU
Wertsch J. V., 1991, VOICES MIND
Williams C, 2007, SOC SCI MED, V65, P1094, DOI 10.1016/j.socscimed.2007.04.033
Yardley S., 2011, UNDERSTANDING AUTHEN
Yardley S, MED ED
Yardley S, AHSE IN PRESS
Yardley S, 2012, MED TEACH, V34, pE102, DOI 10.3109/0142159X.2012.650741
Yardley S, 2010, MED TEACH, V32, P740, DOI 10.3109/0142159X.2010.496007
Ziebland S, 2006, MED EDUC, V40, P405, DOI 10.1111/j.1365-2929.2006.02467.x
NR 53
TC 2
Z9 2
U1 0
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PU INFORMA HEALTHCARE
PI LONDON

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PA TELEPHONE HOUSE, 69-77 PAUL STREET, LONDON EC2A 4LQ, ENGLAND
SN 0142-159X
J9 MED TEACH
JI Med. Teach.
PY 2013
VL 35
IS 3
BP E1011
EP E1019
DI 10.3109/0142159X.2012.733045
PG 9
WC Education, Scientific Disciplines; Health Care Sciences & Services
SC Education & Educational Research; Health Care Sciences & Services
GA 130OQ
UT WOS:000317928300006
PM 23102156
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PT S
AU Moratilla, JM
   Alonso-Calvo, R
   Molina-Vaquero, G
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   Perez-Rey, D
   Maojo, V
AF Moratilla, Juan M.
   Alonso-Calvo, Raul
   Molina-Vaquero, Gema
   Paraiso-Medina, Sergio
   Perez-Rey, David
   Maojo, Victor
BE Lehmann, CU
   Ammenwerth, E
   Nohr, C
TI A Data Model Based on Semantically Enhanced HL7 RIM for Sharing Patient
   Data of Breast Cancer Clinical Trials
SO MEDINFO 2013: PROCEEDINGS OF THE 14TH WORLD CONGRESS ON MEDICAL AND
   HEALTH INFORMATICS, PTS 1 AND 2
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 14th World Congress on Medical and Health Informatics (MEDINFO)
CY AUG 20-23, 2013
CL Copenhagen, DENMARK
DE Semantic Interoperability; Clinical Trials; HL7; INTEGRATE project;
   Breast Cancer; Data repository
AB Breast cancer clinical trial researchers have to handle heterogeneous data
coming from different data sources, overloading biomedical researchers when they
need to query data for retrospective analysis. This paper presents the Common
Data Model (CDM) proposed within the INTEGRATE EU project to homogenize data
coming from different clinical partners. This CDM is based on the Reference
Information Model (RIM) from the Health Level 7 (HL7) version 3. Semantic
capabilities through an SPARQL endpoint were also required to ensure the
sustainability of the platform. For the SPARQL endpoint implementation, a
comparison has been carried out between a Relational SQL database + D2R and a
RDF database. The results show that the first option can store all clinical data
received from institutions participating in the project with a better
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performance. It has been also evaluated by the EU Commission within a patient recruitment demonstrator.
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OI ALONSO CALVO, RAUL/0000-0002-2803-0215
NR 0
TC 2
Z9 2
U1 0
U2 6
PU IOS PRESS
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PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
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J9 STUD HEALTH TECHNOL
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BB1DZ
UT WOS:000341021700239
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PT J
AU Harmon, SHE
   Chen, KH
AF Harmon, Shawn H. E.
   Chen, Kuan-Hsun
TI MEDICAL RESEARCH DATA-SHARING: THE oPUBLIC GOOD' AND VULNERABLE GROUPS
SO MEDICAL LAW REVIEW
LA English
DT Article
DE regulation; medical research; aging; elderly; data-sharing; open science
ID HEALTH-CARE; ALTRUISM; AGE; BIOBANKS; BARRIERS; GENETICS; CONSENT;
   SCIENCE; PART
AB One of the moral tests of governments is how they treat those in the twilight of life (the elderly). As such, it is important not only to take care of the needs of the elderly, but also to place their reality in the forefront of deliberations and actions. Now that we are in the so-called century of biology, we must ensure that the newly transformed and increasingly relied on biosciences not only respond to the needs of the elderly but also reflect the reality of the elderly. While many arguments can be made in support of increased data-sharing in biomedical research (and indeed within and across healthcare systems more generally), there are some persuasive age-based arguments that might serve to encourage science regulators, through both funding structures and the law, to fundamentally reshape the research environment so as to enhance its potential to achieve public goods such as improved health and more effective healthcare systems. In this paper, after noting the new research model arising from

population genomics, with its intense data needs, we advance three age-based arguments, in favour of increased and improved data-sharing, and we conclude with some brief observations about how increased data-sharing might be achieved.

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CR Alexander RD., 1987, BIOL MORAL SYSTEMS
Angrist M, 2009, PERS MED, V6, P691, DOI 10.2217/PME.09.48
[Anonymous], 2010, INT DAT SHAR C HOST
[Anonymous], 2011, ECONOMIST, P13
[Anonymous], 2002, ACT AG POL FRAM
Arzberger P, 2004, DATA SCI J, V3, P135, DOI DOI 10.2481/DSJ.3.135
Backman G, 2008, LANCET, V372, P2047, DOI 10.1016/S0140-6736(08)61781-X
Bar-Tal D., 1985, HUMBOLDT J SOCIAL RE, V13, P3
Batson C. D., 1992, PSA P BIENN M PHIL S, V2, P69
Batson C. D., 1998, HDB SOCIAL PSYCHOL, V2, P282, DOI DOI 10.1002/0471264385.WEI0519
Blumenthal D, 2006, ACAD MED, V81, P137, DOI 10.1097/00001888-200602000-00008
Boles M, 2000, J COMMUN HEALTH, V25, P279, DOI 10.1023/A:1005153909429
Bovenberg J, 2005, GENOMICS SOC POLICY, V1, P1
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI 10.1001/jama.287.4.473
CIALDINI RB, 1990, PSYCHOL BULL, V107, P210, DOI 10.1037/0033-2909.107.2.210
Coggan P, 2011, ECONOMIST
Deaton A., 2010, RES FINDINGS EC AGIN, P235
*DEP HLTH, 2001, NAT SERV FRAM OLD PE
Department of Health, 2003, NAT SERV FRAM OLD PE
Digital Archiving Consultancy, 2005, LARGE SCAL DAT SHAR
EISENBERG N, 1987, PSYCHOL BULL, V101, P91, DOI 10.1037/0033-2909.101.1.91
Elger BS, 2006, EMBO REP, V7, P661, DOI 10.1038/sj.embor.7400740
European Commission, 2007, TOG HLTH STRAT APPR
European Commission, 2007, EUR DEM FUT FACTS FI
European Commission, 2010, SOC SIT EUR UN 2009, P335
European Commission Communication, COM20040304 EUR COMM
European Observatory on the Social Situation, 2008, DEM TRENDS SOC IMP P
EUROPEAN PARLIAMENT, 2009, SEC2009415 EUR COMM, P6
Fuchs VR, 1999, HEALTH AFFAIR, V18, P11, DOI 10.1377/hlthaff.18.1.11
Gibbons M., 1994, NEW PRODUCTION KNOWL
Giordano S, 2005, CAMB Q HEALTHC ETHIC, V14, P83
Gruber J, 2001, 8103 NBER
Hagestad GO, 2006, RES AGING, V28, P638, DOI 10.1177/0164027506291872
Harmon SHE, 2006, HEALTH CARE ANAL, V14, P215, DOI 10.1007/s10728-006-0030-8
Harmon SHE, 2009, EUR J HEALTH LAW, V16, P27, DOI 10.1163/157180909X400213
HILL J, 1984, J SOC BIOL STRUCT, V7, P17, DOI 10.1016/S0140-1750(84)90062-9
HOFFMAN ML, 1981, J PERS SOC PSYCHOL, V40, P121, DOI 10.1037/0022-3514.40.1.121
Hogerzeil HV, 2006, LANCET, V368, P305, DOI 10.1016/S0140-6736(06)69076-4
Kahana E., 1987, SOCIAL JUSTICE RES, V1, P439, DOI DOI 10.1007/BF01048387
Kaiser J, 2002, SCIENCE, V298, P1158, DOI 10.1126/science.298.5596.1158

Kalache A, 1999, Promot Educ, V6, P20, DOI 10.1177/102538239900600406
Kalache A, 2000, Sci Prog, V83 (Pt 1), P33
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Komter A, 2005, SOCIAL SOLIDARITY GI, P116
Krebs D., 1987, SOCIOBIOLOGY PSYCHOL, P81
LEBLANC D, 1987, EDUC GERONTOL, V13, P387, DOI 10.1080/0360127870130502
Leon DA, 2011, INT J EPIDEMIOL, V40, P271, DOI 10.1093/ije/dyr061
Lewes G., 1904, COMTES PHHILOS SCI
Liebrand Wim B. G., 1986, EXPT STUDIES SOCIAL, P113
Lords Science & Technology Committee, 2009, SESS 2008 09 GEN MED
Lovato LC, 1997, CONTROL CLIN TRIALS, V18, P328, DOI 10.1016/S0197-2456(96)00236-X
Macaulay J., 1970, ALTRUISM HELPING BEH
Margolis H., 1982, SELFISHNESS ALTRUISM
Masseria C., 2006, RES NOT MUCH CAR OLD
Mauss M, 1990, GIFT, P50
Midlarsky E, 1991, PROSOCIAL BEHAV REV, P238
Midlarsky E., 1994, ALTRUISM LATER LIFE
Midlarsky E., 2007, ALTRUISM HLTH PERSPE, P56, DOI DOI 10.1093/ACPROF:OSO/9780195182910.001.0001
Nerlich B, 2009, COMMUNICATING BIOL S
NILSTUN T, 1995, SCAND J SOC MED, V23, P81, DOI 10.1177/140349489502300201
Oeppen J, 2002, SCIENCE, V296, P1029, DOI 10.1126/science.1069675
Piliavin J., 1991, GIVING BLOOD
PILIAVIN JA, 1990, ANNU REV SOCIOL, V16, P27, DOI 10.1146/annurev.so.16.080190.000331
Piliavin JA, 1981, EMERGENCY INTERVENTI
Pillemer K., 2000, SOCIAL INTEGRATION 2
Piwowar HA, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0000308
Research Funders, 2011, SHAR RES DAT IMPR PU
Rifkin J, 1998, E ENV MAGAZINE   MAY
Rynning E, 2008, EUR J HEALTH LAW, V15, P297, DOI 10.1163/157180908X338241
Schofield PN, 2009, NATURE, V461, P171, DOI 10.1038/461171a
Schron EB, 1997, J AM GERIATR SOC, V45, P934, DOI 10.1111/j.1532-5415.1997.tb02962.x
Shaffer C, 2007, NAT BIOTECHNOL, V25, P149, DOI 10.1038/nbt0207-149
Smith A, 1790, THEORY MORAL SENTIME, P1
Snyder M, 2000, WHY WE EVALUATE: FUNCTIONS OF ATTITUDES, P365
Sorokin Pitirim A., 2002, WAYS POWER LOVE
The 1000 Genome Project, 2007, IS HUM GEN REF PROJ
Thoits PA, 2001, J HEALTH SOC BEHAV, V42, P115, DOI 10.2307/3090173
Titmuss Richard M, 1973, GIFT RELATIONSHIP
TRIVERS RL, 1971, Q REV BIOL, V46, P35, DOI 10.1086/406755
Uganda Ministry of Health, 2008, REV HSSPII REL HUM R
United Nations, 2011, WORLD POP PROSP 2010
VINE I, 1983, BRIT J SOC PSYCHOL, V22, P1, DOI 10.1111/j.2044-8309.1983.tb00559.x
WALKER A, 1980, J SOC POLICY, V9, P49, DOI 10.1017/S0047279400009545
Walker Jan, 2005, VALUE HLTH CARE INFO
Wanless D, 2006, SECURING GOOD CARE O
WHO, 1998, LIF 21 CENT VIS ALL
WHO, 2002, ACT AG POL FRAM, P42
WHO, 2002, ACT AG POL FRAM, P17
WHO Europe, 2007, EURRC579 WHO EUR
Williams G., 2005, GENOMICS SOC POLICY, V1, P50
Wilson E.O., 1975, P1
World Health Organization, 2007, EV BUS STRENGTH HLTH
Yuille M., 2011, NEW PATHWAY REGULATI

```
   Yuille M, 2010, CELL TISSUE BANK, V11, P241, DOI 10.1007/s10561-009-9150-3
   Ziman J., 2000, REAL SCI WHAT IT IS
NR 95
TC 2
Z9 2
U1 0
U2 22
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 0967-0742
EI 1464-3790
J9 MED LAW REV
JI Med. Law. Rev.
PD FAL
PY 2012
VL 20
IS 4
BP 516
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DI 10.1093/medlaw/fws006
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WC Law; Medicine, Legal
SC Government & Law; Legal Medicine
GA 045BT
UT WOS:000311670300002
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ER

PT J
AU Graber-Naidich, A
   Gorfine, M
   Malone, KE
   Hsu, L
AF Graber-Naidich, Anna
   Gorfine, Malka
   Malone, Kathleen E.
   Hsu, Li
TI Missing genetic information in case-control family data with general
   semi-parametric shared frailty model
SO LIFETIME DATA ANALYSIS
LA English
DT Article
DE Case-control family study; Missing genotypes; Multivariate survival
   analysis; Frailty model
ID MULTIVARIATE SURVIVAL ANALYSIS; REGRESSION-MODELS; BREAST-CANCER;
   LIFE-TABLES; LIKELIHOOD; ASSOCIATION; DESIGNS; DISTRIBUTIONS;
   AGGREGATION; MUTATIONS
AB Case-control family data are now widely used to examine the role of gene-
environment interactions in the etiology of complex diseases. In these types of
studies, exposure levels are obtained retrospectively and, frequently,
information on most risk factors of interest is available on the probands but
not on their relatives. In this work we consider correlated failure time data
arising from population-based case-control family studies with missing genotypes
of relatives. We present a new method for estimating the age-dependent
marginalized hazard function. The proposed technique has two major advantages:
(1) it is based on the pseudo full likelihood function rather than a pseudo
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composite likelihood function, which usually suffers from substantial efficiency loss; (2) the cumulative baseline hazard function is estimated using a two-stage estimator instead of an iterative process. We assess the performance of the proposed methodology with simulation studies, and illustrate its utility on a real data example.

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FU United States-Israel Binational Science Foundation; National Institutes of Health [R01 CA98858, R01 AG14358]; National Institute of Child health and Human Development; National Cancer Institute; Emory University [N01 HD3-3168]; Fred Hutchinson Cancer Research Center [N01 HD2-3166]; Karmanos Cancer Institute at Wayne State University [N01 HD 3-3174]; University of Pennsylvania [N01 HD3-3176]; University of Southern California [N01 HD 3-3175]; Centers for Disease Control and Prevention [Y01 HD7022]
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CR Becher H, 2003, INT J EPIDEMIOL, V32, P38, DOI 10.1093/ije/dyg003
Chatterjee N, 2006, BIOMETRICS, V62, P36, DOI 10.1111/j.1541-0420.2005.00442.x
Chen L, 2009, BIOMETRICS, V65, P1105, DOI 10.1111/j.1541-0420.2008.01184.x
CLAYTON DG, 1978, BIOMETRIKA, V65, P141, DOI 10.2307/2335289
COX DR, 1972, J R STAT SOC B, V34, P187
Duchateau L, 2008, STAT BIOL HEALTH, P1
Fine JP, 2003, J R STAT SOC B, V65, P317, DOI 10.1111/1467-9868.00388
GENEST C, 1986, AM STAT, V40, P280, DOI 10.2307/2684602
GILL RD, 1989, SCAND J STAT, V16, P97
GILL RD, 1985, J ROYAL STAT SOC A, V148, P108
Glidden DV, 1999, BIOMETRIKA, V86, P381, DOI 10.1093/biomet/86.2.381
Gorfine M, 2009, ANN STAT, V37, P1489, DOI 10.1214/08-AOS615
Henderson R, 1999, J R STAT SOC B, V61, P367, DOI 10.1111/1467-9868.00182
Hopper JL, 2003, INT J EPIDEMIOL, V32, P48, DOI 10.1093/ije/dyg018
HOUGAARD P, 1986, BIOMETRIKA, V73, P387, DOI 10.1093/biomet/73.2.387
Hougaard P, 2000, ANAL MULTIVARIATE SU, DOI 10. 1007/978-1-4612-1304-8
Hsu L, 2007, STAT MED, V26, P4657, DOI 10.1002/sim.2870
Hsu L, 2006, BIOSTATISTICS, V7, P387, DOI 10.1093/biostatistics/kxj014
KLEIN JP, 1992, BIOMETRICS, V48, P795, DOI 10.2307/2532345
Kosorok MR, 2004, ANN STAT, V32, P1448, DOI 10.1214/009053604000000535
Malone KE, 2006, CANCER RES, V66, P8297, DOI 10.1158/0008-5472.CAN-06-0503
Malone KE, 2000, CANCER, V88, P1393, DOI 10.1002/(SICI)1097-0142(20000315)88:6<1393::AID-CNCR17>3.0.CO;2-P

```
   Marchbanks PA, 2002, ANN EPIDEMIOL, V12, P213, DOI 10.1016/S1047-
2797(01)00274-5
   MARSHALL AW, 1988, J AM STAT ASSOC, V83, P834, DOI 10.2307/2289314
   MCGILCHRIST CA, 1993, BIOMETRICS, V49, P221, DOI 10.2307/2532615
   NIELSEN GG, 1992, SCAND J STAT, V19, P25
   OAKES D, 1989, J AM STAT ASSOC, V84, P487, DOI 10.2307/2289934
   Ripatti S, 2000, BIOMETRICS, V56, P1016, DOI 10.1111/j.0006-341X.2000.01016.x
   Shih JH, 1995, BIOMETRICS, V51, P1384, DOI 10.2307/2533269
   Shih JH, 2002, BIOMETRICS, V58, P502, DOI 10.1111/j.0006-341X.2002.00502.x
   Vaida F, 2000, STAT MED, V19, P3309, DOI 10.1002/1097-
0258(20001230)19:24<3309::AID-SIM825>3.0.CO;2-9
   Yasui Y, 2004, BIOMETRICS, V60, P199, DOI 10.1111/j.0006-341X.2004.00249.x
   ZEGER SL, 1988, BIOMETRICS, V44, P1049, DOI 10.2307/2531734
   Zhao LP, 1998, BIOMETRIKA, V85, P299, DOI 10.1093/biomet/85.2.299
NR 34
TC 2
Z9 2
U1 0
U2 1
PU SPRINGER
PI DORDRECHT
PA VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS
SN 1380-7870
EI 1572-9249
J9 LIFETIME DATA ANAL
JI Lifetime Data Anal.
PD APR
PY 2011
VL 17
IS 2
BP 175
EP 194
DI 10.1007/s10985-010-9178-5
PG 20
WC Mathematics, Interdisciplinary Applications; Statistics & Probability
SC Mathematics
GA 725RT
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PT J
AU Gondos, A
   Brenner, H
AF Gondos, Adam
   Brenner, Hermann
TI Period Analysis for More Up-to-Date Graft and Patient Survival Estimates
   in Transplantation: An Evaluation Using United Network for Organ Sharing
   Data
SO TRANSPLANTATION
LA English
DT Article
DE Transplantation; Survival analysis; Methodology; Period analysis
ID LONG-TERM SURVIVAL; CANCER SURVIVAL; EMPIRICAL-EVALUATION; RATES;
   REGISTRY; FINLAND; EUROPE; SYSTEM
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AB Background. Traditional, cohort-based survival analysis approaches may provide outdated graft and patient survival estimates in times when clinical progress is rapid. Period analysis, a survival analysis method that uses left truncation and was shown to provide more up-to-date survival estimates than traditional, cohort-based methods in other medical fields, may improve the timeliness of survival monitoring in transplantation.

Methods. Using United Network for Organ Sharing/Organ Procurement and Transplantation Network data, we evaluated, through a series of comparisons, how well most up-to-date 5-year survival estimates potentially derivable by two commonly used cohort-based methods and the period method would have been able to predict the later observed survival of corresponding most recent transplants in the dataset between 1992 to 1994 and 2001 to 2003.

Results. In the analysis of overall survival, period analysis provided a best prediction for 93 of the 100 evaluated point estimates, whereas among 350 evaluated point estimates of age-specific survival, period analysis provided a best estimate on 254 occasions (72.6%), compared with 49 (14.0%) and 82 (23.4%) occasions for the cohort-based approaches. Mean average absolute differences between period estimates and the later observed survival were meaningfully lower than those obtained by traditional methods, indicating that period estimates may provide much better survival predictions for recently transplanted grafts and patients than estimates derivable at the same time by traditional survival analysis approaches.

Conclusion. The timeliness of survival monitoring can be meaningfully improved by the application of period analysis. The use of period analysis for providing more up-to-date survival estimates in transplantation may be encouraged.

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CR Arndt V, 2007, ANN ONCOL, V18, P1734, DOI 10.1093/annonc/mdm188
Brenner H, 2004, EUR J CANCER, V40, P2494, DOI 10.1016/j.ejca.2004.07.022
Brenner H, 2002, INT J EPIDEMIOL, V31, P456, DOI 10.1093/ije/31.2.456
Brenner H, 2002, J CLIN ONCOL, V20, P826, DOI 10.1200/JCO.20.3.826
Brenner H, 2002, LANCET, V360, P1131, DOI 10.1016/S0140-6736(02)11199-8
Brenner H, 2002, EUR J CANCER, V38, P690, DOI 10.1016/S0959-8049(02)00003-5
Brenner H, 2002, AM J EPIDEMIOL, V156, P566, DOI 10.1093/aje/kwf071
Brenner H, 1996, CANCER-AM CANCER SOC, V78, P2004, DOI 10.1002/(SICI)1097-0142(19961101)78:9<2004::AID-CNCR23>3.3.CO;2-6
Brenner H, 2009, EUR J CANCER, V45, P1028, DOI 10.1016/j.ejca.2008.11.005
CRONIN K, 2003, 200302 SRAB NCI STAT
Dickinson DM, 2003, AM J TRANSPLANT, V3, P13, DOI 10.1034/j.1600-6143.3.s4.3.x
Dickinson DM, 2004, AM J TRANSPLANT, V4, P13, DOI 10.1111/j.1600-6135.2004.00395.x

```
   Ellison LF, 2006, ANN EPIDEMIOL, V16, P191, DOI
10.1016/j.annepidem.2005.02.017
   Houterman S, 2006, ANN ONCOL, V17, P709, DOI 10.1093/annonc/mdj139
   Levine GN, 2006, AM J TRANSPLANT, V6, P1228, DOI 10.1111/j.1600-
6143.2006.01277.x
   *SEER STAT SOFTW, 2008, SURV EP END RES PROG
   Steliarova-Foucher E, 2007, ANN ONCOL, V18, P1554, DOI 10.1093/annonc/mdm194
   Talback M, 2004, CANCER CAUSE CONTROL, V15, P967, DOI 10.1007/s10552-004-
2475-0
   Talback M, 2004, EUR J CANCER, V40, P1361, DOI 10.1016/j.ejca.2004.02.004
   *UNOS OPTN, 2006, ANN REP 2005 UNOS, V2009
   *UNOS OPTN, 2007, ANN REP 2006 UNOS
   Verdecchia A, 2007, LANCET ONCOL, V8, P784, DOI 10.1016/S1470-2045(07)70246-2
   Wolfe RA, 2003, AM J TRANSPLANT, V3, P103, DOI 10.1034/j.1600-6143.3.s4.10.x
NR 23
TC 2
Z9 2
U1 0
U2 0
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
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J9 TRANSPLANTATION
JI Transplantation
PD MAR 15
PY 2010
VL 89
IS 5
BP 580
EP 588
DI 10.1097/TP.0b013e3181caa38e
PG 9
WC Immunology; Surgery; Transplantation
SC Immunology; Surgery; Transplantation
GA 571AF
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PM 20173683
DA 2019-08-06
ER

PT J
AU Boughman, JA
AF Boughman, Joann A.
TI Genomewide association studies data sharing: National institutes of
   health policy process
SO AMERICAN JOURNAL OF HUMAN GENETICS
LA English
DT Editorial Material
NR 0
TC 2
Z9 2
U1 0
U2 0
PU UNIV CHICAGO PRESS
PI CHICAGO
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```

```
J9 AM J HUM GENET
JI Am. J. Hum. Genet.
PD MAR
PY 2007
VL 80
IS 3
BP 581
EP 582
DI 10.1086/512166
PG 2
WC Genetics & Heredity
SC Genetics & Heredity
GA 139AB
UT WOS:000244403300022
OA Green Published, Bronze
DA 2019-08-06
ER

PT J
AU Hampton, T
AF Hampton, T
TI Sharing patient health data
SO JAMA-JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION
LA English
DT News Item
NR 0
TC 2
Z9 2
U1 0
U2 0
PU AMER MEDICAL ASSOC
PI CHICAGO
PA 515 N STATE ST, CHICAGO, IL 60610 USA
SN 0098-7484
J9 JAMA-J AM MED ASSOC
JI JAMA-J. Am. Med. Assoc.
PD JAN 28
PY 2004
VL 291
IS 4
BP 415
EP 415
DI 10.1001/jama.291.4.415-a
PG 1
WC Medicine, General & Internal
SC General & Internal Medicine
GA 767EF
UT WOS:000188426700005
DA 2019-08-06
ER

PT J
AU Ouyang, Y
   Guo, B
   Lu, XJ
   Han, Q
   Guo, T
   Yu, ZW
```

AF Ouyang, Yi
Guo, Bin
Lu, Xinjiang
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TI CompetitiveBike: Competitive Analysis and Popularity Prediction of Bike-Sharing Apps Using Multi-Source Data
SO IEEE TRANSACTIONS ON MOBILE COMPUTING
LA English
DT Article
DE Bike-sharing app; mobile app; popularity prediction; competitive analysis; event storyline
ID EMERGENCE; DEMAND
AB In recent years, bike-sharing systems have been widely deployed in many big cities, which provide an economical and healthy lifestyle. With the prevalence of bike-sharing systems, a lot of companies join the bike-sharing market, leading to increasingly fierce competition. To be competitive, bike-sharing companies and app developers need to make strategic decisions and predict the popularity of bike-sharing apps. However, existing works mostly focus on predicting the popularity of a single app, the popularity contest among different apps has not been explored yet. In this paper, we aim to forecast the popularity contest between Mobike and Ofo, two most popular bike-sharing apps in China. We develop CompetitiveBike, a system to predict the popularity contest among bike-sharing apps leveraging multi-source data. We extract two novel types of features: coarse-grained and fine-grained competitive features, and utilize Random Forest model to forecast the future competitiveness. In addition, we view mobile apps competition as a long-term event and generate the event storyline to enrich our competitive analysis. We collect data about two bike-sharing apps and two food ordering & delivery apps from 11 app stores and Sina Weibo, implement extensive experimental studies, and the results demonstrate the effectiveness and generality of our approach.
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FX This work was partially supported by the National Key R&D Program of China (No. 2017YFB1001800), and the National Natural Science Foundation of China (No. 61332005, 61772428, 61725205).
CR Bao J, 2017, KDD'17: PROCEEDINGS OF THE 23RD ACM SIGKDD INTERNATIONAL CONFERENCE ON KNOWLEDGE DISCOVERY AND DATA MINING, P1377, DOI 10.1145/3097983.3098056
Benesty J, 2009, SPRINGER TOP SIGN PR, V2, P1, DOI 10.1007/978-3-642-00296-0_1
Bergen M., 2002, MANAGERIAL DECISION, V23, P157, DOI DOI 10.1002/MDE.1059
Blei DM, 2003, J MACH LEARN RES, V3, P993, DOI 10.1162/jmlr.2003.3.4-5.993
Borodin A., 2005, ONLINE COMPUTATION C
Cao LB, 2012, IEEE T KNOWL DATA EN, V24, P1378, DOI 10.1109/TKDE.2011.129
Cao W., 2015, P 29 AAAI C ART INT, P2518
Carreno LVG, 2013, PROCEEDINGS OF THE 35TH INTERNATIONAL CONFERENCE ON SOFTWARE ENGINEERING (ICSE 2013), P582, DOI 10.1109/ICSE.2013.6606604
Chen C, 2018, IEEE T INTELL TRANSP, V19, P3292, DOI 10.1109/TITS.2017.2771231

Chen LB, 2016, UBICOMP'16: PROCEEDINGS OF THE 2016 ACM INTERNATIONAL JOINT CONFERENCE ON PERVASIVE AND UBIQUITOUS COMPUTING, P841, DOI 10.1145/2971648.2971652

Chen LB, 2015, PROCEEDINGS OF THE 2015 ACM INTERNATIONAL JOINT CONFERENCE ON PERVASIVE AND UBIQUITOUS COMPUTING (UBICOMP 2015), P571, DOI 10.1145/2750858.2804291

DeMaio P, 2009, J PUBLIC TRANSPORT, V12, P41, DOI DOI 10.5038/2375-0901.12.4.3

DeSarbo WS, 2006, STRATEGIC MANAGE J, V27, P101, DOI 10.1002/smj.505

Di Sorbo A, 2016, FSE'16: PROCEEDINGS OF THE 2016 24TH ACM SIGSOFT INTERNATIONAL SYMPOSIUM ON FOUNDATIONS OF SOFTWARE ENGINEERING, P499, DOI 10.1145/2950290.2950299

Fu Bin, 2013, P 19 ACM SIGKDD INT, P1276, DOI [DOI 10.1145/2487575.2488202, 10.1145/2487575.2488202]

Fu YJ, 2016, IEEE T MOBILE COMPUT, V15, P2851, DOI 10.1109/TMC.2016.2516020

Garg R, 2013, MIS QUART, V37, P1253, DOI 10.25300/MISQ/2013/37.4.12

Ghose A, 2014, MANAGE SCI, V60, P1470, DOI 10.1287/mnsc.2014.1945

Girardello A., 2010, P 12 INT C HUM COMP, P431, DOI [10.1145/1851600.1851698, DOI 10.1145/1851600.1851698]

Goodfellow I, 2016, DEEP LEARNING

Gu XD, 2015, IEEE INT CONF AUTOM, P760, DOI 10.1109/ASE.2015.57

Guo B., 2017, P ACM INT MOB WEAR U, V1

Guo B, 2017, IEEE COMMUN SURV TUT, V19, P2526, DOI 10.1109/COMST.2017.2726686

Guo B, 2015, ACM COMPUT SURV, V48, DOI 10.1145/2794400

He W, 2013, INT J INFORM MANAGE, V33, P464, DOI 10.1016/j.ijinfomgt.2013.01.001

Jiang H, 2013, BMC OPHTHALMOL, V13, DOI 10.1186/1471-2415-13-66

Jin J, 2016, ENG APPL ARTIF INTEL, V49, P61, DOI 10.1016/j.engappai.2015.12.005

Koller D., 2009, PROBABILISTIC GRAPHI

Lin C.-Y., 2004, ACL WORKSH TEXT SUMM, V8

Lin C, 2012, WOR CONG SOFTW ENG, P172, DOI 10.1109/WCSE.2012.41

Liu J., 2016, P 22 ACM SIGKDD INT, P1005

Liu JM, 2017, KDD'17: PROCEEDINGS OF THE 23RD ACM SIGKDD INTERNATIONAL CONFERENCE ON KNOWLEDGE DISCOVERY AND DATA MINING, P957, DOI 10.1145/3097983.3098180

Liu JM, 2015, IEEE DATA MINING, P883, DOI 10.1109/ICDM.2015.99

Lu XJ, 2016, UBICOMP'16: PROCEEDINGS OF THE 2016 ACM INTERNATIONAL JOINT CONFERENCE ON PERVASIVE AND UBIQUITOUS COMPUTING, P1052, DOI 10.1145/2971648.2971749

Malmi E., 2014, UBICOMP 14 ADJUNCT, P391

Martin W, 2017, IEEE T SOFTWARE ENG, V43, P817, DOI 10.1109/TSE.2016.2630689

Nassirtoussi AK, 2014, EXPERT SYST APPL, V41, P7653, DOI 10.1016/j.eswa.2014.06.009

Oliver NM, 2000, IEEE T PATTERN ANAL, V22, P831, DOI 10.1109/34.868684

Ouyang Y, 2017, PERS UBIQUIT COMPUT, V21, P97, DOI 10.1007/s00779-016-0977-x

Panichella S, 2015, 2015 31ST INTERNATIONAL CONFERENCE ON SOFTWARE MAINTENANCE AND EVOLUTION (ICSME) PROCEEDINGS, P281, DOI 10.1109/ICSM.2015.7332474

Pucher J, 2010, PREV MED, V50, pS106, DOI 10.1016/j.ypmed.2009.07.028

Shaheen SA, 2010, TRANSP RES RECORD, P159, DOI 10.3141/2143-20

Singla Adish, 2015, AAAI, P723

Tkachenko M, 2017, IEEE T KNOWL DATA EN, V29, P771, DOI 10.1109/TKDE.2016.2640281

Wang Y., 2017, P 26 INT JOINT C ART, P2978

Xu KQ, 2011, DECIS SUPPORT SYST, V50, P743, DOI 10.1016/j.dss.2010.08.021

Yu ZW, 2016, IEEE T HUM-MACH SYST, V46, P151, DOI 10.1109/THMS.2015.2446953

Zhang DQ, 2011, COMPUTER, V44, P21, DOI 10.1109/MC.2011.65

```
   Zhang Z, 2013, ACM TRANS MANAG INF, V3, DOI 10.1145/2407740.2407744
   Zhu HS, 2015, IEEE T CYBERNETICS, V45, P1303, DOI 10.1109/TCYB.2014.2349954
NR 50
TC 1
Z9 1
U1 1
U2 1
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1314 USA
SN 1536-1233
EI 1558-0660
J9 IEEE T MOBILE COMPUT
JI IEEE. Trans. Mob. Comput.
PD AUG
PY 2019
VL 18
IS 8
BP 1760
EP 1773
DI 10.1109/TMC.2018.2868933
PG 14
WC Computer Science, Information Systems; Telecommunications
SC Computer Science; Telecommunications
GA IG2MA
UT WOS:000473630100004
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ER

PT J
AU Toland, AE
   Brody, LC
   Couch, FJ
   Culver, JO
   Eccles, DM
   Foulkes, WD
   Goldgar, DE
   Hogervorst, F
   Houdayer, C
   Levy-Lahad, E
   Monteiro, AN
   Nathanson, KL
   Neuhausen, SL
   Plon, SE
   Sharan, SK
   Spurdle, AB
   Szabo, C
   Tavtigian, SV
   Wolfsberg, TG
AF Toland, Amanda E.
   Brody, Lawrence C.
   Couch, Fergus J.
   Culver, Julie O.
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   Foulkes, William D.
   Goldgar, David E.
   Hogervorst, Frans
   Houdayer, Claude
```

Levy-Lahad, Ephrat
Monteiro, Alvaro N.
Nathanson, Katherine L.
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Plon, Sharon E.
Sharan, Shyam K.
Spurdle, Amanda B.
Szabo, Csilla
Tavtigian, Sean V.
Wolfsberg, Tyra G.
CA BIC Steering Comm
TI Lessons learned from two decades of BRCA1 and BRCA2 genetic testing: the evolution of data sharing and variant classification
SO GENETICS IN MEDICINE
LA English
DT Editorial Material
ID UNKNOWN CLINICAL-SIGNIFICANCE; BREAST-CANCER INFORMATION; SEQUENCE VARIANTS; RECOMMENDATIONS
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```
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FU Intramural Research Program of the National Human Genome Research
   Institute
FX Support to carry out the production of this work was provided by the
   Intramural Research Program of the National Human Genome Research
   Institute.
CR Bever L, 2017, WASHINGTON POST
   Buchtel KM, 2018, J GENET COUNS, V27, P131, DOI 10.1007/s10897-017-0130-7
   Chen Z, 2018, GENET MED, V20, P428, DOI 10.1038/gim.2017.118
   Davies K, 1996, BREAKTHROUGH RACE FI
   Easton DF, 2007, AM J HUM GENET, V81, P873, DOI 10.1086/521032
   Eccles DM, 2015, ANN ONCOL, V26, P2057, DOI 10.1093/annonc/mdv278
   Foulkes WD, 2016, NAT REV CLIN ONCOL, V13, P41, DOI
10.1038/nrclinonc.2015.173
   FRIEND S, 1995, NAT GENET, V11, P238, DOI 10.1038/ng1195-238
   Goldgar DE, 2004, AM J HUM GENET, V75, P535, DOI 10.1086/424388
   Greenblatt MS, 2008, HUM MUTAT, V29, P1273, DOI 10.1002/humu.20889
   Harrison SM, 2017, GENET MED, V19, P1096, DOI 10.1038/gim.2017.14
   Kurian AW, 2017, J CLIN ONCOL, V35, P2232, DOI 10.1200/JCO.2016.71.6480
   Landrum MJ, 2016, NUCLEIC ACIDS RES, V44, pD862, DOI 10.1093/nar/gkv1222
   Levy-Lahad E, 2015, JNCI-J NATL CANCER I, V107, DOI 10.1093/jnci/dju420
   Lincoln SE, 2017, JCO PRECIS ONCOL, V1, DOI 10.1200/PO.16.00020
   Marshall E, 2013, SCIENCE, V342, P27, DOI 10.1126/science.342.6154.27
   Mazoyer S, 1996, NAT GENET, V14, P253, DOI 10.1038/ng1196-253
   Mersch J, 2018, JAMA-J AM MED ASSOC, V320, P1266, DOI 10.1001/jama.2018.13152
   MIKI Y, 1994, SCIENCE, V266, P66, DOI 10.1126/science.7545954
   Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
   Slavin TP, 2018, JNCI-J NATL CANCER I, V110, DOI 10.1093/jnci/djy027
   Spurdle AB, 2012, HUM MUTAT, V33, P2, DOI 10.1002/humu.21628
   Szabo C, 2000, HUM MUTAT, V16, P123, DOI 10.1002/1098-
1004(200008)16:2<123::AID-HUMU4>3.0.CO;2-Y
   Tavtigian SV, 2018, GENET MED, V20, P1054, DOI 10.1038/gim.2017.210
   Thompson BA, 2014, NAT GENET, V46, P107, DOI 10.1038/ng.2854
   Thompson BA, 2013, HUM MUTAT, V34, P200, DOI 10.1002/humu.22213
   Tsui LC, 2013, CSH PERSPECT MED, V3, DOI 10.1101/cshperspect.a009472
   Wagner TMU, 1999, HUM MOL GENET, V8, P413, DOI 10.1093/hmg/8.3.413
   Whiley PJ, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0086836
   WOOSTER R, 1995, NATURE, V378, P789, DOI 10.1038/378789a0
NR 30
TC 1
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PU NATURE PUBLISHING GROUP
PI NEW YORK
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J9 GENET MED
JI Genet. Med.
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PY 2019
VL 21
IS 7
BP 1476
EP 1480
DI 10.1038/s41436-018-0370-4
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WC Genetics & Heredity
SC Genetics & Heredity
GA IG0ZD
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PM 30474649
DA 2019-08-06
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AU Morioka, T
   Blyth, BJ
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AF Morioka, Takamitsu
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   Schofield, Paul
   Grosche, Bernd
   Kulka, Ulrike
   Shimada, Yoshiya
   Yamada, Yutaka
   Kakinuma, Shizuko
TI Establishing the Japan-Store house of animal radiobiology experiments
   (J-SHARE), a large-scale necropsy and histopathology archive providing
   international access to important radiobiology data
SO INTERNATIONAL JOURNAL OF RADIATION BIOLOGY
LA English
DT Article; Early Access
DE Animal experiments; archive; tissue specimen; database; pathology
ID RADIATION; EXPOSURE; GENES; AGE
AB Purpose: Projects evaluating the effects of radiation, within the National
Institutes of Quantum and Radiological Science and Technology (QST), National
Institute of Radiological Sciences (NIRS), have focused on risk analyses for
life shortening and cancer prevalence using laboratory animals. Genetic and
epigenetic alterations in radiation-induced tumors have been also analyzed with
the aim of better understanding mechanisms of radiation carcinogenesis. As well
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as the economic and practical limitations of repeating such large-scale experiments, ethical considerations make it vital that we store and share the pathological data and samples of the animal experiments for future use. We are now constructing such an archive called the Japan-Storehouse of Animal Radiobiology Experiments (J-SHARE). Methods: J-SHARE records include information such as detailed experimental protocols, necropsy records and photographs of organs at necropsy. For each animal organs and tumor tissues are dissected, and parts are stored as frozen samples at -80 degrees C. Samples fixed with formalin are also embedded in paraffin blocks for histopathological analyses. Digital copies of stained tissues are being systematically saved using a virtual slide system linked to original records by barcodes. Embedded and frozen tissues are available for molecular analysis. Conclusion: Similar archive systems for radiation biology have also been under construction in the USA and Europe, the Northwestern University Radiation Archive (NURA), and STORE at the BfS, respectively. The J-SHARE will be linked with the sister-archives and made available for collaborative research to institutions and universities all over the world.

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CR Abbott A, 2012, NATURE, V485, P162, DOI 10.1038/485162a
Blyth BJ, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0130666
Haley BM, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0140989
Imaoka T, 2016, RADIAT RES, V185, P505, DOI 10.1667/RR14309.1
Morioka T, 2015, CANCER SCI, V106, P217, DOI 10.1111/cas.12591
Sazykina TG, 2016, J ENVIRON RADIOACTIV, V165, P227, DOI 10.1016/j.jenvrad.2016.10.013
Schofield PN, 2013, J BIOMED SEMANT, V4, DOI 10.1186/2041-1480-4-18
Shang Y, 2017, RADIAT RES, V188, P235, DOI 10.1667/RR14563.1
Showler K, 2017, J RADIAT RES, V58, P183, DOI 10.1093/jrr/rrw097
Sunaoshi M, 2015, MUTAT RES-FUND MOL M, V779, P58, DOI 10.1016/j.mrfmmm.2015.06.004
Takabatake M, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0164194
Tapio S, 2008, RADIAT ENVIRON BIOPH, V47, P183, DOI 10.1007/s00411-007-0149-5
Tapio S, 2010, RADIAT ENVIRON BIOPH, V49, P1, DOI 10.1007/s00411-009-0263-7
Tsuruoka C, 2016, RADIAT RES, V186, P407, DOI 10.1667/RR14499.1
Tran V, 2017, RADIAT ENVIRON BIOPH, V56, P299, DOI 10.1007/s00411-017-0707-4
Wang QO, 2010, RADIAT ENVIRON BIOPH, V49, P317, DOI 10.1007/s00411-010-0270-8
Yamada Y, 2017, RADIAT RES, V187, P210, DOI 10.1667/RR14478.1
Zander Alia, 2019, Int J Radiat Biol, P1, DOI 10.1080/09553002.2019.1572249

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Z9 1
U1 0
U2 0
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PA 2-4 PARK SQUARE, MILTON PARK, ABINGDON OR14 4RN, OXON, ENGLAND
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J9 INT J RADIAT BIOL
JI Int. J. Radiat. Biol.
DI 10.1080/09553002.2019.1625458
EA JUN
EY 2019
PG 6
WC Biology; Nuclear Science & Technology; Radiology, Nuclear Medicine &
   Medical Imaging
SC Life Sciences & Biomedicine - Other Topics; Nuclear Science &
   Technology; Radiology, Nuclear Medicine & Medical Imaging
GA II5OD
UT WOS:000475243200001
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PT J
AU Andruszkiewicz, N
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   Hirji, MM
AF Andruszkiewicz, Nicole
   Ogunniyi, Cassandra
   Carfagnini, Christina
   Branston, Allison
   Hirji, M. Mustafa
TI Utilizing public health core competencies to share data effectively with
   community organizations to promote health equity
SO CANADIAN JOURNAL OF PUBLIC HEALTH-REVUE CANADIENNE DE SANTE PUBLIQUE
LA English
DT Article
DE Data sharing; Health equity; Community partners; Deliberative dialogue;
   Core competencies
ID DELIBERATIVE DIALOGUES
AB Objectives This article utilizes an adapted model for research transfer to
highlight the important role of Local Public Health Agencies (LPHAs) to share
data more effectively with local community organizations to advance health
equity.
   Methods A literature review related to public health data sharing with local
community partners was conducted using Medline, Embase, and CINAHL databases and
grey literature sources with 12 articles included for analysis. Six LPHAs
distributed an online survey to 405 local community organizations to define
their current data uses and needs. Survey and literature review findings
informed a one-day deliberative dialogue event with 19 participants who brought
multiple perspectives together on the bathers and potential solutions for data
sharing.
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Results Results are discussed utilizing the three stages of data sharing: awareness, communication, and collaboration. Awareness of the barriers and needs of community partners related to data, and the public health core competency of assessment and analysis is the first stage. More effective is the second stage, where LPHAs proactively communicate to understand and meet the needs of community partners. Data sharing is the most effective when LPHAs use the third stage of collaboration to work with community partners to mutually benefit from data sharing.

Conclusion When LPHAs utilize their core competencies of assessment and analysis, communication, and collaboration to share data with community partners, they are able to share data more effectively. This allows community partners to modify programs to better serve priority populations and improve population health.

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CR Anderson M, 1999, SOC SCI MED, V49, P1007, DOI 10.1016/S0277-9536(99)00179-3
Baird Kanaan S., 2012, COMMUNITY LEARNING S
Boyko JA, 2012, SOC SCI MED, V75, P1938, DOI 10.1016/j.socscimed.2012.06.016
Brack M., 2015, DATA SHARING PUBLIC
Braun V., 2006, QUALITATIVE RES PSYC, V3, P77, DOI DOI 10.1191/1478088706QP0630A
Canadian Council on Social Development, COMM DAT PROGR
Chircop A, 2015, CRIT PUBLIC HEALTH, V25, P178, DOI 10.1080/09581596.2014.887831
Fosse E., 2018, SCANDINAVIAN J PUB S, V46
Government of Canada, HOM PARTN STRAT COOR
Harper D. R., 2017, GUIDE SHARING DATA B
Institute of Health Economics, 2008, EFF DISS FIND RES
Kothari A, 2016, HEALTH RES POLICY SY, V14, DOI 10.1186/s12961-016-0082-7
Lavis JN, 2009, HEALTH RES POLICY SY, V7, DOI 10.1186/1478-4505-7-S1-S14
Moat KA, 2014, B WORLD HEALTH ORGAN, V92, P20, DOI 10.2471/BLT.12.116806
Moher D, 2009, PLOS MED, V6, DOI 10.1371/journal.pmed.1000097
National Collaborating Centre for Determinants of Health, 2013, LETS TALK PUBL HLTH
Neudorf C, 1998, P 1998 GEOGR INF SYS, P607
Pauly BM, 2017, AIMS PUBLIC HEALTH, V4, P490, DOI 10.3934/publichealth.2017.5.490
Public Health Agency of Canada, 2007, COR COMP PUBL HLTH C
Public Health Agency of Canada, 2012, KNOWL TRANSL KT PLAN
Public Health Research Education and Development (PHRED) Program, 2006, PUBL HLTH COR COMP D
Robert Wood Johnson Foundation, 2015, DAT HLTH LEARN WHAT
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Woolf SH, 2015, ANNU REV PUBL HEALTH, V36, P463, DOI 10.1146/annurev-publhealth-082214-110901
World Health Organization, 2013, CLOS HLTH EQ GAP POL
Wray R., 2013, WE ASK WE CARE TRIHO

NR 26
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U1 0
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PU SPRINGER INTERNATIONAL PUBLISHING AG
PI CHAM
PA GEWERBESTRASSE 11, CHAM, CH-6330, SWITZERLAND
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WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
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PT J
AU Zhang, HR
   Song, X
   Long, Y
   Xia, TQ
   Fang, K
   Zheng, JQ
   Huang, D
   Shibasaki, R
   Liang, YT
AF Zhang, Haoran
   Song, Xuan
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   Zheng, Jianqin
   Huang, Dou
   Shibasaki, Ryosuke
   Liang, Yongtu
TI Mobile phone GPS data in urban bicycle-sharing: Layout optimization and
   emissions reduction analysis
SO APPLIED ENERGY
LA English
DT Article; Proceedings Paper
CT CUE Conference
CY JUN 05-07, 2018
CL Shanghai, PEOPLES R CHINA
DE Bicycle-sharing; Geometry-based probability model; Particle swarm
   optimization; Rebalancing optimization; Potential emission reduction
ID PARTICLE SWARM; REBALANCING PROBLEM; FRAMEWORK; BENEFITS; LOCATION;
   BEHAVIOR; SYSTEMS; IMPACT
AB As a representation of smart and sustainable city development, bicycle-
sharing system is one of the hottest topics in the domains of transportation,
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public health, urban planning, and so on. In this paper, a model is proposed for analyzing the potential reduction in emissions associated with the adoption of a bicycle-sharing system. Methods are proposed for extracting human travel modes from mobile phone GPS trajectories, together with a geometry based probability model, to support particle swarm optimization. A comparison study is implemented to analyze the model's computational efficiency. Based on the resulting optimal layout for the network of bicycle docking stations, and considering demand uncertainty, a multi-scenario integer linear programming model is proposed to optimize rebalancing procedures (i.e., moving bicycles between docking stations according to demand), to determine the detailed design-scale information required. Mobile phone GPS trajectories from approximately 3.7 million local mobilities are used to construct a case study for Setagaya Ward, Tokyo. The results show that, compared with the previous methods, the optimal layout solved by the proposed method could reduce emissions by a further 6.4% and 4.4%. With an increase from 30 to 90 bicycle stations, the adoption of bicycle-sharing can reduce CO2 emissions by approximately 3.1-3.8 thousand tonnes. However, emission reduction will maximally decrease by 21.26% after offset by bicycles production and rebalancing-generated emission.
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CR Askari EA, 2017, CAPACITATED BIKE SHA
Aziz HMA, 2017, TRANSPORTATION, P1
Boyaci B, 2015, EUR J OPER RES, V240, P718, DOI 10.1016/j.ejor.2014.07.020
Garcia-Palomares JC, 2012, APPL GEOGR, V35, P235, DOI 10.1016/j.apgeog.2012.07.002
Chen Q, 2016, J ADV TRANSPORT, V49, P384
Dell'Amico M, 2014, OMEGA-INT J MANAGE S, V45, P7, DOI 10.1016/j.omega.2013.12.001
El-Assi W, 2017, TRANSPORTATION, V44, P589, DOI 10.1007/s11116-015-9669-z
Erdogan G, 2015, EUR J OPER RES, V245, P667, DOI 10.1016/j.ejor.2015.03.043
Fishman F, 2014, URBAN TP CHINA, V33, P148
Gonzalez F, 2016, TRANSPORTATION, V43, P407, DOI 10.1007/s11116-015-9581-6
Gonzalez LL, 2016, OPTIMAL LOCATION BIK
Jordehi AR, 2015, RENEW SUST ENERG REV, V52, P1260, DOI 10.1016/j.rser.2015.08.007

Kato H., 2011, JPN SOC MAT CYCL WAS, V22, P220
Kennedy J, 1995, 1995 IEEE INTERNATIONAL CONFERENCE ON NEURAL NETWORKS PROCEEDINGS, VOLS 1-6, P1942, DOI 10.1109/ICNN.1995.488968
KENNEDY J, 1995, P IEEE INT C NEUR NE, P1942, DOI DOI 10.1109/ICNN.1995.488968
Kloimullner C, 2017, NETWORKS, V69, P270, DOI 10.1002/net.21736
Lee C.-H., 2013, WIREL NETW, V19, P1003
Li PL, 2018, APPL ENERG, V211, P820, DOI 10.1016/j.apenergy.2017.11.022
Long Y, 2018, APPL ENERG, V218, P349, DOI 10.1016/j.apenergy.2018.02.167
Mendes R, 2004, IEEE T EVOLUT COMPUT, V8, P204, DOI [10.1109/TEVC.2004.826074, 10.1109/tevc.2004.826074]
MOE, 2016, GREEN VAL CHAIN PLAT
Mrkajic V, 2015, RENEW SUST ENERG REV, V49, P232, DOI 10.1016/j.rser.2015.04.100
Needell ZA, 2016, NAT ENERGY, V1, DOI [10.1038/NENERGY.2016.112, 10.1038/nenergy.2016.112]
Niu B, 2007, APPL MATH COMPUT, V185, P1050, DOI 10.1016/j.amc.2006.07.026
Pedroso FE, 2016, AM J PUBLIC HEALTH, V106, pe3
Rissel C, 2015, INT J BEHAV NUTR PHY, V12, DOI 10.1186/s12966-015-0294-1
Rossetti T, 2019, TRANSPORTATION, V46, P697, DOI 10.1007/s11116-017-9830-y
Shaheen SA, 2010, TRANSP RES RECORD, P159, DOI 10.3141/2143-20
Shekarchian M, 2017, RENEW SUST ENERG REV, V77, P327, DOI 10.1016/j.rser.2017.04.015
Sun LS, 2018, APPL ENERG, V230, P1014, DOI 10.1016/j.apenergy.2018.09.080
Sundfor HB, 2017, BMC PUBLIC HEALTH, V17, DOI 10.1186/s12889-017-4817-3
Wuerzer T, 2016, INT J SUSTAIN TRANSP, V10, P247, DOI 10.1080/15568318.2014.897403
Yahya BN, 2017, SUSTAINABILITY-BASEL, V9, DOI 10.3390/su9112070
Zhang H, 2018, APPL SOFT COMPUT J
Zhang HR, 2018, APPL ENERG, V220, P527, DOI 10.1016/j.apenergy.2018.03.105
Zhang LH, 2015, J CLEAN PROD, V97, P124, DOI 10.1016/j.jclepro.2014.04.006
Zhang YP, 2018, APPL ENERG, V220, P296, DOI [10.1016/j.epenergy.2018.03.101, 10.1016/j.apenergy.2018.03.101]

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J9 APPL ENERG
JI Appl. Energy
PD MAY 15
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VL 242
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WC Energy & Fuels; Engineering, Chemical
SC Energy & Fuels; Engineering
GA IB1SS
UT WOS:000470045800011
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AU Shah, N
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AF Shah, Nisha
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   Giordano, Giuseppe Nicola
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   Hudson, Michelle
   Pearson, Ewan
   Ruetten, Hartmut
   Kaye, Jane
TI Sharing data for future research-engaging participants' views about data
   governance beyond the original project: a DIRECT Study
SO GENETICS IN MEDICINE
LA English
DT Article
DE data sharing; data governance; type II diabetes; patient involvement;
   ethics
ID BIOBANK RESEARCH; DATA ACCESS; PUBLIC-ATTITUDES; CONSENT; PRINCIPLES;
   OVERSIGHT; OPINIONS; PATIENT; ETHICS

AB Purpose: Biomedical data governance strategies should ensure that data are collected, stored, and used ethically and lawfully. However, research participants' preferences for how data should be governed is least studied. The Diabetes Research on Patient Stratification (DIRECT) project collected substantial amounts of health and genetic information from patients at risk of, and with type II diabetes. We conducted a survey to understand participants' future data governance preferences. Results will inform the postproject data governance strategy.

   Methods: A survey was distributed in Denmark, Sweden, The Netherlands, and the United Kingdom.

   Results: In total 855 surveys were returned. Ninety-seven percent were supportive of sharing data postproject, and 90% were happy to share data with universities, and 56% with commercial companies. The top three priorities for data sharing were highly secure database, DIRECT researchers to monitor data used by other researchers, and researchers cannot identify participants. Respondents frequently suggested that a postproject Data Access Committee should involve a DIRECT researcher, diabetes clinician, patient representative, and a DIRECT participant.

   Conclusion: Preferences of how data should be governed, and what data could be shared and with whom varied between countries. Researchers are considered as key custodians of participant data. Engaging participants aids in designing governance to support their choices.

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CR Bell Elizabeth A, 2014, AMIA Annu Symp Proc, V2014, P1699
Church G, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000665
D'Abramo F, 2015, BMC MED ETHICS, V16, DOI 10.1186/s12910-015-0053-5
Duke CS, 2013, BIOSCIENCE, V63, P483, DOI 10.1525/bio.2013.63.6.10
Ellenberg S. S., 2002, DATA MONITORING COMM
Eurobarometer, 2017, ATT IMP DIG AUT DAIL, DOI [10.2759/835661, DOI 10.2759/835661]
Flicek P, 2007, CISC VIS NETW IND GL
Haga SB, 2011, PUBLIC HEALTH GENOM, V14, P319, DOI 10.1159/000324705
Harron K, 2014, LANCET, V383, P1124, DOI 10.1016/S0140-6736(14)60558-4
Heeney C, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-017-0240-7
Herson J, 2009, CH CRC BIOSTAT SER, V30, P1
Kaufman D, 2008, GENET MED, V10, P331, DOI 10.1097/GIM.0b013e31818bb3ab
Kaye J, 2014, GENOME MED, V6, DOI 10.1186/gm523
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Kim KK, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-017-0185-x
Koivula RW, 2014, DIABETOLOGIA, V57, P1132, DOI 10.1007/s00125-014-3216-x
Langhof H, 2017, EUR J HUM GENET, V25, P293, DOI 10.1038/ejhg.2016.172
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Ludman EJ, 2010, J EMPIR RES HUM RES, V5, P9, DOI 10.1525/jer.2010.5.3.9
Mailman MD, 2007, NAT GENET, V39, P1181
Mascalzoni D, 2015, EUR J HUM GENET, V23, P721, DOI 10.1038/ejhg.2014.197
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
McGuire AL, 2011, GENOME RES, V21, P1001, DOI 10.1101/gr.120329.111
Mori Ipsos, 2015, ONE WAY MIRROR PUBLI
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Page SA, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0130-4
Porteri C, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-81
Riordan F, 2015, INT J MED INFORM, V84, P237, DOI 10.1016/j.ijmedinf.2015.01.008
Sanderson SC, 2017, AM J HUM GENET, V100, P414, DOI 10.1016/j.ajhg.2017.01.021

```
   Shabani M, 2017, BIOPRESERV BIOBANK, V15, P469, DOI 10.1089/bio.2017.0045
   Shabani M, 2016, GENET MED, V18, P892, DOI 10.1038/gim.2015.189
   Shabani M, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002339
   Shabani M, 2015, EMBO MOL MED, V7, P507, DOI 10.15252/emmm.201405002
   Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI
10.1586/14737159.2014.961917
   Smith CT, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0532-z
   Spencer K, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5011
   Tereskerz PM, 2010, ACCOUNT RES, V17, P30, DOI 10.1080/08989620903520313
   Vayena E, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001937
   2011, LANCET, V377, P537, DOI DOI 10.1016/S0140-6736(10)62234-9
NR 39
TC 1
Z9 1
U1 6
U2 7
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
SN 1098-3600
EI 1530-0366
J9 GENET MED
JI Genet. Med.
PD MAY
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VL 21
IS 5
BP 1131
EP 1138
DI 10.1038/s41436-018-0299-7
PG 8
WC Genetics & Heredity
SC Genetics & Heredity
GA HW5CT
UT WOS:000466707400013
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PT J
AU Waithira, N
   Mutinda, B
   Cheah, PY
AF Waithira, Naomi
   Mutinda, Brian
   Cheah, Phaik Yeong
TI Data management and sharing policy: the first step towards promoting
   data sharing
SO BMC MEDICINE
LA English
DT Article
DE Data sharing; Data management; Data sharing policy; Broad consent;
   Ethical
ID HEALTH RESEARCH; CONSENT; MALARIA; VIEWS
AB Background: Health-related research funders, regulators and journals expect
that de-identified individual-level health data be shared widely, with as few
restrictions as possible; yet, in reality, the volume of shared data remains low.
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Main body: Health researchers and other data producers are reluctant to share their data unless they are confident that their datasets are of high quality and reliable, and that they are used in accordance with the values and aims of their institutions. We argue that having an institutional, departmental or group data management and sharing policy is the first step towards encouraging researchers and healthcare professionals to share their data more widely. Our paper outlines the elements of a data management and sharing policy, which should include aims consistent with those of the institution as well as with data management procedures, models of data sharing, request procedures, consent models and cost recovery mechanisms. A policy would help an institution, department or group maximise the use of its data and protect the interests of the institution and its members. We base our recommendations on our experience collecting and curating data for large clinical trials conducted in low- and middle-income countries, facilitating the sharing of datasets with secondary users, whilst teaching data management and conducting empirical research on data sharing. Although the fundamentals of a policy are general, the paper is focused on the low- and middle-income country context.

Conclusion: We argue that having an institutional, departmental or group data management and sharing policy is the first step in promoting data sharing.

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CR [Anonymous], 2017, POL DAT SOFTW MAT MA
Ashley EA, 2014, NEW ENGL J MED, V371, P411, DOI 10.1056/NEJMoa1314981
Bellary Shantala, 2014, Perspect Clin Res, V5, P159, DOI 10.4103/2229-3485.140555
Bezuidenhout Louise, 2018, Glob Bioeth, V29, P39, DOI 10.1080/11287462.2018.1441780
Bezuidenhout LM, 2017, SCI PUBL POLICY, V44, P464, DOI 10.1093/scipol/scw036
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Cheah PY, 2019, NATURE, V565, P294, DOI 10.1038/d41586-019-00118-9
Cheah PY, 2018, BMC MED ETHICS, V19, DOI 10.1186/s12910-018-0326-x
Cheah PY, 2017, LANCET, V390, P1642, DOI 10.1016/S0140-6736(17)31951-7
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Cheah PY, 2015, ARCH DIS CHILD, V100, P438, DOI 10.1136/archdischild-2014-307121
Cheah PY, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-22
Council for International Organizations of Medical Sciences & World Health Organization, 2016, INT ETH GUID HLTH RE
Das D, 2014, MALARIA J, V13, DOI 10.1186/1475-2875-13-217
European Medicines Agency, 2014, EMA2408102013
Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162

```
   International Conference on Harmonisation of Technical Requirements for
Registration of Pharmaceuticals for Human Use, 1996, ICH HARM TRIP GUID G
   Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
   Lim Renly, 2017, Wellcome Open Res, V2, P95, DOI
10.12688/wellcomeopenres.12594.2
   Onyamboko MA, 2014, ANTIMICROB AGENTS CH, V58, P5528, DOI 10.1128/AAC.02682-
14
   Pisani E, 2016, BMJ-BRIT MED J, V355, DOI 10.1136/bmj.i5295
   Serwadda D, 2018, SCIENCE, V359, P642, DOI 10.1126/science.aap8395
   Taichman DB, 2017, LANCET, V389, pE12, DOI 10.1016/S0140-6736(17)31282-5
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NR 24
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SN 1741-7015
J9 BMC MED
JI BMC Med.
PD APR 17
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AR 80
DI 10.1186/s12916-019-1315-8
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PT J
AU Nicholas, J
   Shilton, K
   Schueller, SM
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AF Nicholas, Jennifer
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   Mohr, David C.
TI The Role of Data Type and Recipient in Individuals' Perspectives on
   Sharing Passively Collected Smartphone Data for Mental Health:
   Cross-Sectional Questionnaire Study
SO JMIR MHEALTH AND UHEALTH
LA English
DT Article
DE mHealth; privacy; personal sensing; digital mental health; depression;
   anxiety; mobile phone
ID SCREENING INSTRUMENT; DISORDER; PRIVACY; VALIDATION
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AB Background: The growing field of personal sensing harnesses sensor data collected from individuals' smartphones to understand their behaviors and experiences. Such data could be a powerful tool within mental health care. However, it is important to note that the nature of these data differs from the information usually available to, or discussed with, health care professionals. To design digital mental health tools that are acceptable to users, understanding how personal sensing data can be used and shared is critical.

Objective: This study aimed to investigate individuals' perspectives about sharing different types of sensor data beyond the research context, specifically with doctors, electronic health record (EHR) systems, and family members.

Methods: A questionnaire assessed participants' comfort with sharing six types of sensed data: physical activity, mood, sleep, communication logs, location, and social activity. Participants were asked about their comfort with sharing these data with three different recipients: doctors, EHR systems, and family members. A series of principal component analyses (one for each data recipient) was performed to identify clusters of sensor data types according to participants' comfort with sharing them. Relationships between recipients and sensor clusters were then explored using generalized estimating equation logistic regression models.

Results: A total of 211 participants completed the questionnaire The majority were female (171/211, 81.0%), and the mean age was 38 years (SD 10.32). Principal component analyses consistently identified two clusters of sensed data across the three data recipients: "health information," including sleep, mood, and physical activity, and "personal data," including communication logs, location, and social activity. Overall, participants were significantly more comfortable sharing any type of sensed data with their doctor than with the EHR system or family members (P<.001) and more comfortable sharing "health information" than "personal data" (P<.001). Participant characteristics such as age or presence of depression or anxiety did not influence participants' comfort with sharing sensed data.

Conclusions: The comfort level in sharing sensed data was dependent on both data type and recipient, but not individual characteristics. Given the identified differences in comfort with sensed data sharing, contextual factors of data type and recipient appear to be critically important as we design systems that harness sensor data for mental health treatment and support.

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CR Adams A., 1999, CHI 99 HUM FACT COMP
Barnett I, 2018, NEUROPSYCHOPHARMACOL, V43, P1660, DOI 10.1038/s41386-018-0030-z
Barth A, 2006, 2006 IEEE S SEC PRIV
Beck A. T, 1996, MANUAL BECK DEPRESSI
Beckwith R, 2005, P INT S TECHN SOC 20

BOHN MJ, 1995, J STUD ALCOHOL, V56, P423, DOI 10.15288/jsa.1995.56.423
Boonstra TW, 2018, J MED INTERNET RES, V20, DOI 10.2196/10131
Canzian L, 2015, P 2015 ACM INT JOINT
Chow PI, 2017, J MED INTERNET RES, V19, DOI 10.2196/jmir.6820
Corrigan PW, 2002, CLIN PSYCHOL-SCI PR, V9, P35, DOI 10.1093/clipsy/9.1.35
de Montjoye YA, 2013, SCI REP-UK, V3, DOI 10.1038/srep01376
Dehling T, 2015, JMIR MHEALTH UHEALTH, V3, DOI 10.2196/mhealth.3672
Doryab A, 2014, 2014 AAAI WORKSH MOD
Faurholt-Jepsen M, 2014, PSYCHIAT RES, V217, P124, DOI 10.1016/j.psychres.2014.03.009
Hirschfeld RMA, 2000, AM J PSYCHIAT, V157, P1873, DOI 10.1176/appi.ajp.157.11.1873
Insel TR, 2017, JAMA-J AM MED ASSOC, V318, P1215, DOI 10.1001/jama.2017.11295
Jain SH, 2015, NAT BIOTECHNOL, V33, P462, DOI 10.1038/nbt.3223
Klasnja P, 2009, P 7 INT C PERV COMP
Kroenke K, 2001, J GEN INTERN MED, V16, P606, DOI 10.1046/j.1525-1497.2001.016009606.x
Lin J, 2014, SOUPS 14 P 10 USENIX
Martin K, 2016, J ASSOC INF SCI TECH, V67, P1871, DOI 10.1002/asi.23500
Marwick AE, 2018, INT J COMMUN-US, V12, P1157
Mohr DC, 2017, ANNU REV CLIN PSYCHO, V13, P23, DOI 10.1146/annurev-clinpsy-032816-044949
Ng A, 2018, JMIR MENT HEALTH, V5, DOI 10.2196/10415
Nicholas J, 2017, EUR PSYCHIAT, V44, P210, DOI 10.1016/j.eurpsy.2017.05.023
Nissenbaum H, 2004, WASH LAW REV, V79, P119
Nissenbaum H., 2009, PRIVACY CONTEXT TECH
Osmani V, 2015, IEEE PERVAS COMPUT, V14, P10, DOI 10.1109/MPRV.2015.54
Pentland Alex, 2009, Stud Health Technol Inform, V149, P93
Proudfoot J, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1475
Rabbi Mashfiqui, 2011, Proc ACM Int Conf Ubiquitous Comput, V2011, P385
Saeb Sohrab, 2017, J Med Internet Res, V19, pe118, DOI 10.2196/jmir.6821
Saeb S, 2016, PEERJ, V4, DOI 10.7717/peerj.2537
Saeb S, 2015, J MED INTERNET RES, V17, DOI 10.2196/jmir.4273
Schatz BR, 2015, BIG DATA, V3, P219, DOI 10.1089/big.2015.0021
Shilton K, 2009, COMMUN ACM, V52, P48, DOI 10.1145/1592761.1592778
SKINNER HA, 1982, ADDICT BEHAV, V7, P363, DOI 10.1016/0306-4603(82)90005-3
Spitzer RL, 2006, ARCH INTERN MED, V166, P1092, DOI 10.1001/archinte.166.10.1092
Vitak J, 2016, P 19 ACM C COMO SUPP
Wang R, 2014, PROCESSING OF 2014 INTERNATIONAL CONFERENCE ON MULTISENSOR FUSION AND INFORMATION INTEGRATION FOR INTELLIGENT SYSTEMS (MFI)
Zimmer M, 2018, SOC MEDIA SOC, V4, DOI 10.1177/2056305118768300
NR 41
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J9 JMIR MHEALTH UHEALTH
JI JMIR mHealth uHealth
PD APR 5
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DI 10.2196/12578
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA HU5RL
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PT J
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AF Li, Xuecao
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   Yu, Sha
   Asrar, Ghassem R.
TI Projecting Global Urban Area Growth Through 2100 Based on Historical
   Time Series Data and Future Shared Socioeconomic Pathways
SO EARTHS FUTURE
LA English
DT Article
DE urban area; urbanization; population; GDP; SDG; SSP
ID CONSTRAINED CELLULAR-AUTOMATA; EARTH SYSTEM MODEL; LAND-COVER CHANGE;
   SPATIALLY EXPLICIT; DYNAMICS; SCENARIOS; IMPACTS; URBANIZATION;
   BIODIVERSITY; POPULATION
AB Improved understanding of the potential growth of urban areas at the national
and global levels is needed for sustainable urban development. Current panel
data analysis and local scale modeling are limited in projecting global urban
area growth with large spatial heterogeneities. In this study, we developed
country-specific urban area growth models using the time series data set of
global urban extents (1992-2013) and projected the future growth of urban areas
under five Shared Socioeconomic Pathways (SSPs). Our results indicate the global
urban area would increase roughly 40-67% under five SSPs until 2050 relative to
the base year of 2013, and this trend would continue to a growth ratio of more
than 200% by 2100. The growth of urban areas under relatively unsustainable
development pathways (e.g., regional rivalry SSP3 and inequality SSP4) is
smaller compared to other SSPs. Although developing countries would remain as
leading contributors to the increase of global urban areas in the future, they
may exhibit different temporal patterns, that is, plateaued or monotonically
increasing trends. This variation is primarily attributed to the compounding
effect of the growth in population and gross domestic product. Our urban area
data set presents a first country-level urban area projection under the five
SSPs, spanning from 2013 to 2100. This data set has a great potential to support
various global change studies, for example, urban sprawl simulation, integrated
assessment modeling for sustainable development goals, and investigation of the
impact of urbanization on atmospheric emissions, air quality, and human health.
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FX We acknowledge funding support from the U.S. Department of Energy, Office of Science, as part of research in Multi-Sector Dynamics, Earth and Environmental System Modeling Program, the NASA ROSES LULC Program "NNH11ZDA001N-LCLUC," and the NASA ROSES INCA Program "NNH14ZDA001N-INCA," with additional support for Jiyong Eom from the Ministry of Environment of Korea through the Climate Change Correspondence Program (2004001300002). The historical and future population and GDP data are available in the World Bank Database (http://databank.worldbank.org/) and the Shared Socioeconomic Pathways (SSP) Database (https://tntcat.iiasa.ac.at/SspDb), respectively. The projected global urban area growth under five SSPs by 2100 is available at figshare website (https://doi.org/10.6084/m9.figshare.7817624.v1).We would like to thank two anonymous reviewers for their constructive comments and suggestions. The views and opinions expressed in this paper are those of the authors alone.

CR Alberti M, 2017, P NATL ACAD SCI USA, V114, P8951, DOI 10.1073/pnas.1606034114
[Anonymous], 2018, WORLD URB PROSP 2018
Bond-Lamberty B, 2014, GEOSCI MODEL DEV, V7, P2545, DOI 10.5194/gmd-7-2545-2014
Chen J, 2002, PHOTOGRAMM ENG REM S, V68, P1063
Collins WD, 2015, GEOSCI MODEL DEV, V8, P2203, DOI 10.5194/gmd-8-2203-2015
DeFries RS, 1999, GLOBAL BIOGEOCHEM CY, V13, P803, DOI 10.1029/1999GB900037
Dellink R, 2017, GLOBAL ENVIRON CHANG, V42, P200, DOI 10.1016/j.gloenvcha.2015.06.004
Dong N, 2018, GLOBAL ENVIRON CHANG, V50, P164, DOI 10.1016/j.gloenvcha.2018.04.001
Eom J., 2012, PNNL21073
Foley JA, 2005, SCIENCE, V309, P570, DOI 10.1126/science.1111772
Goldewijk KK, 2010, HOLOCENE, V20, P565, DOI 10.1177/0959683609356587
Gong P, 2012, LANCET, V379, P843, DOI 10.1016/S0140-6736(11)61878-3
Guneralp B, 2017, P NATL ACAD SCI USA, V114, P8945, DOI 10.1073/pnas.1606035114
Han J, 2009, LANDSCAPE URBAN PLAN, V91, P133, DOI 10.1016/j.landurbplan.2008.12.002
He CY, 2016, ENVIRON MODELL SOFTW, V75, P44, DOI 10.1016/j.envsoft.2015.09.015
He CY, 2013, LANDSCAPE URBAN PLAN, V113, P78, DOI 10.1016/j.landurbplan.2013.01.004
Hurtt GC, 2006, GLOBAL CHANGE BIOL, V12, P1208, DOI 10.1111/j.1365-2486.2006.01150.x
Imhoff ML, 2010, REMOTE SENS ENVIRON, V114, P504, DOI 10.1016/j.rse.2009.10.008
Irwin EG, 2001, AGR ECOSYST ENVIRON, V85, P7, DOI 10.1016/S0167-8809(01)00200-6
Jiang LW, 2017, GLOBAL ENVIRON CHANG, V42, P193, DOI 10.1016/j.gloenvcha.2015.03.008
Li X, 2000, INT J GEOGR INF SCI, V14, P131, DOI 10.1080/136588100240886
Li X, 2017, ANN AM ASSOC GEOGR, V107, P1040, DOI 10.1080/24694452.2017.1303357

Li X, 2019, REMOTE SENS ENVIRON, V222, P267, DOI 10.1016/j.rse.2018.12.036
Li XC, 2018, REMOTE SENS ENVIRON, V216, P674, DOI 10.1016/j.rse.2018.07.030
Li XC, 2016, SCI BULL, V61, P1651, DOI 10.1007/s11434-016-1148-1
Li XC, 2016, SCI BULL, V61, P1637, DOI 10.1007/s11434-016-1111-1
Li XC, 2015, REMOTE SENS ENVIRON, V166, P78, DOI 10.1016/j.rse.2015.06.007
Li XC, 2014, INT J GEOGR INF SCI, V28, P1317, DOI 10.1080/13658816.2014.883079
Liu Y., 2003, Computers, Environment and Urban Systems, V27, P637, DOI 10.1016/S0198-9715(02)00069-8
Lu YL, 2015, NATURE, V520, P432, DOI 10.1038/520432a
Melaas EK, 2013, REMOTE SENS ENVIRON, V132, P176, DOI 10.1016/j.rse.2013.01.011
Mertes CM, 2015, REMOTE SENS ENVIRON, V158, P331, DOI 10.1016/j.rse.2014.09.023
Myers N, 2000, NATURE, V403, P853, DOI 10.1038/35002501
O'Neill BC, 2017, GLOBAL ENVIRON CHANG, V42, P169, DOI 10.1016/j.gloenvcha.2015.01.004
Riahi K, 2017, GLOBAL ENVIRON CHANG, V42, P153, DOI 10.1016/j.gloenvcha.2016.05.009
Samir KC, 2017, GLOBAL ENVIRON CHANG, V42, P181, DOI 10.1016/j.gloenvcha.2014.06.004
Sante I, 2010, LANDSCAPE URBAN PLAN, V96, P108, DOI 10.1016/j.landurbplan.2010.03.001
Seto KC, 2012, P NATL ACAD SCI USA, V109, P16083, DOI 10.1073/pnas.1211658109
Small C, 2005, REMOTE SENS ENVIRON, V96, P277, DOI 10.1016/j.rse.2005.02.002
Solecki W, 2013, ENVIRONMENT, V55, P12, DOI 10.1080/00139157.2013.748387
van Vuuren DP, 2017, GLOBAL ENVIRON CHANG, V42, P148, DOI 10.1016/j.gloenvcha.2016.10.009
Wang J., 2019, SCI TOTAL ENV
Wu DQ, 2010, STOCH ENV RES RISK A, V24, P235, DOI 10.1007/s00477-009-0313-3
Yu S, 2014, ENERGY, V67, P284, DOI 10.1016/j.energy.2013.12.072
Zhang GJ, 2013, NAT CLIM CHANGE, V3, P466, DOI [10.1038/nclimate1803, 10.1038/NCLIMATE1803]
Zhou YY, 2018, REMOTE SENS ENVIRON, V219, P206, DOI 10.1016/j.rse.2018.10.015
Zhou YY, 2015, ENVIRON RES LETT, V10, DOI 10.1088/1748-9326/10/5/054011
Zhou YY, 2014, REMOTE SENS ENVIRON, V147, P173, DOI 10.1016/j.rse.2014.03.004
Zhou YY, 2014, APPL ENERG, V113, P1077, DOI 10.1016/j.apenergy.2013.08.034

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PU AMER GEOPHYSICAL UNION
PI WASHINGTON
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J9 EARTHS FUTURE
JI Earth Future
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BP 351
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PG 12
WC Environmental Sciences; Geosciences, Multidisciplinary; Meteorology & Atmospheric Sciences

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SC Environmental Sciences & Ecology; Geology; Meteorology & Atmospheric
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PT J
AU Kalkman, S
   Mostert, M
   Gerlinger, C
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AF Kalkman, Shona
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TI Responsible data sharing in international health research: a systematic
   review of principles and norms
SO BMC MEDICAL ETHICS
LA English
DT Review
DE Big data; Data sharing; Secondary use; Research ethics; Ethical
   governance
ID POLICY; GOVERNANCE; ETHICS
AB BackgroundLarge-scale linkage of international clinical datasets could lead
to unique insights into disease aetiology and facilitate treatment evaluation
and drug development. Hereto, multi-stakeholder consortia are currently
designing several disease-specific translational research platforms to enable
international health data sharing. Despite the recent adoption of the EU General
Data Protection Regulation (GDPR), the procedures for how to govern responsible
data sharing in such projects are not at all spelled out yet. In search of a
first, basic outline of an ethical governance framework, we set out to explore
relevant ethical principles and norms.MethodsWe performed a systematic review of
literature and ethical guidelines for principles and norms pertaining to data
sharing for international health research.ResultsWe observed an abundance of
principles and norms with considerable convergence at the aggregate level of
four overarching themes: societal benefits and value; distribution of risks,
benefits and burdens; respect for individuals and groups; and public trust and
engagement. However, at the level of principles and norms we identified
substantial variation in the phrasing and level of detail, the number and
content of norms considered necessary to protect a principle, and the contextual
approaches in which principles and norms are used.ConclusionsWhile providing
some helpful leads for further work on a coherent governance framework for data
sharing, the current collection of principles and norms prompts important
questions about how to streamline terminology regarding de-identification and
how to harmonise the identified principles and norms into a coherent governance
framework that promotes data sharing while securing public trust.
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FU Innovative Medicines Initiative 2 Joint Undertaking (IMI2) [116055];
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Federation of Pharmaceutical Industries and Associations (EFPIA)
FX This work was supported by the Innovative Medicines Initiative 2 Joint
Undertaking (IMI2) under [grant agreement No. 116055]. This Joint
Undertaking receives support from the European Horizon 2020 research and
innovation programme and European Federation of Pharmaceutical
Industries and Associations (EFPIA).
CR Alfonso F, 2017, NETH HEART J, V25, P297, DOI 10.1007/s12471-017-0974-3
Allen Claudia, 2014, EGEMS (Wash DC), V2, P1057, DOI 10.13063/2327-9214.1057
Andrew NE, 2016, AUST NZ J PUBL HEAL, V40, P436, DOI 10.1111/1753-6405.12576
[Anonymous], 2016, INT ETH GUID HLTH EL
[Anonymous], 2013, DECL HELS ETH PRINC
[Anonymous], 2015, COLL LINK US DAT BIO
[Anonymous], 2013, PRINC RESP CLIN TRIA
[Anonymous], 2011, JOINT STAT PURP PRIN
[Anonymous], 2014, EUR MED AG POL PUBL
[Anonymous], 2014, FRAM RESP SHAR GEN H
[Anonymous], 2009, REC COUNC HUM BIOB G
[Anonymous], 2007, PRINC GUID ACC RES D
[Anonymous], 2016, DECL TAIP ETH CONS R
[Anonymous], 2017, REC COUNC HLTH DAT G
Antman EM, 2015, J AM HEART ASSOC, V4, DOI 10.1161/JAHA.115.002810
Auffray C, 2016, GENOME MED, V8, DOI 10.1186/s13073-016-0323-y
Baker DB, 2016, EGEMS GENERATING EVI, V4, P7, DOI [10.13063/2327-9214.1207, DOI 10.13063/2327-9214.1207]
Banzi R, 2014, EUR J INTERN MED, V25, P681, DOI 10.1016/j.ejim.2014.07.012
Blasimme A, 2018, HEALTH AFFAIR, V37, P702, DOI 10.1377/hlthaff.2017.1558
Bredenoord AL, 2015, REGEN MED, V10, P857, DOI 10.2217/rme.15.42
Carter P, 2015, J MED ETHICS, V41, P404, DOI 10.1136/medethics-2014-102374
Chan Tom, 2016, J Innov Health Inform, V23, P627, DOI 10.14236/jhi.v23i3.909
Childress JF, 2002, J LAW MED ETHICS, V30, P170, DOI 10.1111/j.1748-720X.2002.tb00384.x
Chokshi DA, 2006, B WORLD HEALTH ORGAN, V84, P382, DOI 10.2471/BLT.06.029843
Deverka PA, 2017, GENOME MED, V9, DOI 10.1186/s13073-017-0476-3
Dove ES, 2016, LANCET, V387, P1374, DOI 10.1016/S0140-6736(16)30078-2
Dove ES, 2013, GENOME MED, V5, DOI 10.1186/gm503
Duchange N, 2014, EUR J PAEDIATR NEURO, V18, P597, DOI 10.1016/j.ejpn.2014.04.002
Dyke SOM, 2016, NPJ GENOM MED, V1, DOI 10.1038/npjgenmed.2016.24
Dyke SOM, 2011, GENOME MED, V3, DOI 10.1186/gm276
Floridi L, 2018, KEY ETHICAL CHALLENG, P1
Global Alliance for Genomics and Health (GA4GH), REG ETH TOOLK
GSK, 2014, DAT TRANSP GSK
Hemingway H, 2018, EUR HEART J, V39, P1481, DOI 10.1093/eurheartj/ehx487
Knoppers Bartha Maria, 2017, Current Opinion in Systems Biology, V4, P53, DOI 10.1016/j.coisb.2017.07.001
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Kostkova P, 2016, FRONT PUBLIC HEALTH, V4, DOI 10.3389/fpubh.2016.00007
Kuehn BM, 2014, JAMA-J AM MED ASSOC, V311, P665, DOI 10.1001/jama.2014.884
Laurie G, 2013, EUR J RISK REGUL, V4, P43, DOI 10.1017/Sl867299XO0002786
Laurie G, 2011, HUM GENET, V130, P347, DOI 10.1007/s00439-011-1066-x
LEA NC, 2016, MED, V4, pe22, DOI DOI 10.2196/medinform.5571

Mascalzoni D, 2015, EUR J HUM GENET, V23, P721, DOI 10.1038/ejhg.2014.197
Paltoo DN, 2014, NAT GENET, V46, P934, DOI 10.1038/ng.3062
Phillips M, 2016, NAT BIOTECHNOL, V34, P1102, DOI 10.1038/nbt.3696
Prainsack B, 2013, MED LAW REV, V21, P71, DOI 10.1093/medlaw/fws040
Regulatory and Ethics Working Group Global Alliance for Genomics & Health, 2014, Hugo J, V8, P1, DOI 10.1186/1877-6566-8-1
Rodriguez H, 2009, J PROTEOME RES, V8, P3689, DOI 10.1021/pr900023z
Shenkin SD, 2017, NEUROIMAGE, V153, P399, DOI 10.1016/j.neuroimage.2017.02.030
Tucker K, 2016, BMC MED RES METHODOL, V16, DOI 10.1186/s12874-016-0169-4
Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
NR 51
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U2 3
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PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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Chiu, K
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Chiu, Kellia
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Continella, Andrea
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Holz, Ralph
TI Data sharing practices of medicines related apps and the mobile ecosystem: traffic, content, and network analysis
SO BMJ-BRITISH MEDICAL JOURNAL
LA English
DT Article
ID PRIVACY; HEALTH; SECURITY
AB OBJECTIVES

To investigate whether and how user data are shared by top rated medicines related mobile applications (apps) and to characterise privacy risks to app users, both clinicians and consumers.

DESIGN

Traffic, content, and network analysis.

SETTING

Top rated medicines related apps for the Android mobile platform available in the Medical store category of Google Play in the United Kingdom, United States, Canada, and Australia.

PARTICIPANTS

24 of 821 apps identified by an app store crawling program. Included apps pertained to medicines information, dispensing, administration, prescribing, or use, and were interactive.

INTERVENTIONS

Laboratory based traffic analysis of each app downloaded onto a smartphone, simulating real world use with four dummy scripts. The app's baseline traffic related to 28 different types of user data was observed. To identify privacy leaks, one source of user data was modified and deviations in the resulting traffic observed.

MAIN OUTCOME MEASURES

Identities and characterisation of entities directly receiving user data from sampled apps. Secondary content analysis of company websites and privacy policies identified data recipients' main activities; network analysis characterised their data sharing relations.

RESULTS

19/24 (79%) of sampled apps shared user data. 55 unique entities, owned by 46 parent companies, received or processed app user data, including developers and parent companies (first parties) and service providers (third parties). 18 (33%) provided infrastructure related services such as cloud services. 37 (67%) provided services related to the collection and analysis of user data, including analytics or advertising, suggesting heightened privacy risks. Network analysis revealed that first and third parties received a median of 3 (interquartile range 1-6, range 1-24) unique transmissions of user data. Third parties advertised the ability to share user data with 216 "fourth parties"; within this network (n= 237), entities had access to a median of 3 (interquartile range 1-11, range 1-140) unique transmissions of user data. Several companies occupied central positions within the network with the ability to aggregate and reidentify user data.

CONCLUSIONS

Sharing of user data is routine, yet far from transparent. Clinicians should be conscious of privacy risks in their own use of apps and, when recommending apps, explain the potential for loss of privacy as part of informed consent. Privacy regulation should emphasise the accountabilities of those who control and process user data. Developers should disclose all data sharing practices and allow users to choose precisely what data are shared and with whom.

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   to submit the article for publication.
CR Android Developers, 2018, SYST PERM
   [Anonymous], 2018, MHEALTH DEV EC MHEAL
   Binns R, 2018, WEBSCI'18: PROCEEDINGS OF THE 10TH ACM CONFERENCE ON WEB
SCIENCE, P23, DOI 10.1145/3201064.3201089
   Blenner SR, 2016, JAMA-J AM MED ASSOC, V315, P1051, DOI
10.1001/jama.2015.19426
   Continella A, P 2017 NETW DISTR SY
   Dayer L, 2013, J AM PHARM ASSOC, V53, P172, DOI 10.1331/JAPhA.2013.12202
   Dehling T, 2015, JMIR MHEALTH UHEALTH, V3, DOI 10.2196/mhealth.3672
   Ebeling M., 2016, HEALTHCARE BIG DATA, DOI [10.1057/978-1-137-50221-6, DOI
10.1057/978-1-137-50221-6]
   European Union, 2018, OFFICAL J EUROPEAN U
   Google Inc, 2018, WHO AR GOOGL PARTN
   Grindrod K, 2017, CAN PHARM J, V150, P60, DOI 10.1177/1715163516680226
   Grundy Q, 2017, FINDING PEACE MIND N
   Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
   Huckvale K, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0444-y
   McGrath P., 2018, ABC NEWS
   Muthing J, 2019, J MED INTERNET RES, V21, DOI 10.2196/jmir.9818
   Papageorgiou A, 2018, IEEE ACCESS, V6, P9390, DOI 10.1109/ACCESS.2018.2799522
   Pasquale F., 2015, BLACK BOX SOC, DOI [10.4159/harvard.9780674736061, DOI
10.4159/HARVARD.9780674736061]
   Pedersen T. L, 2018, TIDYGRAPH TIDY API G
   R Core Team, 2016, R LANG ENV STAT COMP
   Razaghpanah A, P 2018 NETW DISTR SY
   Sunyaev A, 2015, J AM MED INFORM ASSN, V22, pE28, DOI 10.1136/amiajnl-2013-
002605
   Vallina-Rodriguez N, 2016, 1 DAT ALG TRANSP WOR
   Wilson D., 2011, NY TIMES, pB1
   Yahoo. Developer Network, 2018, FLURR AN TERMS SERV
NR 25
TC 1
Z9 1
U1 2
U2 2
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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JI BMJ-British Medical Journal
PD MAR 20
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AU Graske, J
   Schmidt, A
   Wolf-Ostermann, K
AF Graeske, Johannes
   Schmidt, Annika
   Wolf-Ostermann, Karin
TI More staff=better quality of life for people with dementia? results of a
   secondary data analysis in German shared-housing arrangements
SO ISRAEL JOURNAL OF HEALTH POLICY RESEARCH
LA English
DT Article
DE Dementia care; Quality of life; Shared-housing arrangements; Staffing
ID CARE; RESIDENTS; OUTCOMES; RELIABILITY; INSTRUMENT
AB BackgroundShared-housing arrangements (SHAs) in Germany are an alternative
care arrangement for people with dementia. They are disconnected from
traditional nursing homes and are often situated in ordinary apartment buildings.
Community health care providers serve persons with dementia in SHAs, and there
is no official regulation regarding the staff-resident ratio. The association
between the staff-resident ratio and the quality of life (QoL) of persons with
dementia has not yet been investigated in SHAs.MethodA cross-sectional study was
performed in SHAs in Berlin, Germany, using ANCOVA models to analyse whether
residents' QoL (QUALIDEM), as assessed by staff in SHAs, can be explained by the
staff-resident ratio, adjusted for residents' sex, age, length of stay,
challenging behaviour (CMAI), cognitive impairment (GDS) and level of care
dependency according to the German statutory health care insurance.ResultsIn
this study, 58 SHAs with 396 residents (mean age 78.4years, 69.4% female)
participated. The staff-resident ratio was 0.2 and 0.6 for registered nurses and
certified nursing assistants, respectively. Associations with QoL were found
predominantly for challenging behaviour and cognitive impairment. The analysis
showed that there was no significant effect of the total staff-resident ratio
(p>0.05) in explaining the variation in residents' QoL (total and subdomains).
In general, the proportion of explained variance was weak (R-
2<0.216).ConclusionsThe present study did not show a significant association
between staffing and residents' QoL in SHAs. However, further investigation is
required regarding the direct interaction between staff and residents. A main
focus should be to educate users about the benefits and disadvantages of shared-
housing arrangements.
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FX The German Federal Ministry of Education and Research funded the WGQual
   study.
CR ANNERSTEDT L, 1993, SOC SCI MED, V37, P1529, DOI 10.1016/0277-9536(93)90187-9
   Banerjee S, 2009, INT J GERIATR PSYCH, V24, P15, DOI 10.1002/gps.2090
   Beerens HC, 2014, J AM MED DIR ASSOC, V15, P54, DOI
10.1016/j.jamda.2013.09.010
   Bickel H, HAUFIGKEIT DEMENZERK
   BMG-Bundesministerium fur Gesundheit, 2009, BER BEIR UB PFLEG
```

Chenoweth L, 2015, NEURODEGENER DIS MAN, V5, P109, DOI [10.2217/nmt.14.55, 10.2217/NMT.14.55]
Cohen-Mansfield J., 1991, INSTRUCTION MANUAL C
COHENMANSFIELD J, 1989, J GERONTOL, V44, pM77, DOI 10.1093/geronj/44.3.M77
Dichter MN, 2014, INT PSYCHOGERIATR, V26, P825, DOI 10.1017/S1041610214000052
Dichter MN, 2013, HEALTH QUAL LIFE OUT, V11, DOI 10.1186/1477-7525-11-91
Ettema TP, 2007, INT J GERIATR PSYCH, V22, P549, DOI 10.1002/gps.1713
Ettema TP, 2007, INT J GERIATR PSYCH, V22, P424, DOI 10.1002/gps.1692
Fischer T, 2011, PFLEGE, V24, P97, DOI 10.1024/1012-5302/a000105
Graske J, 2013, BUNDESGESUNDHEITSBLA, V56, P1410, DOI 10.1007/s00103-013-1825-z
Graske J, 2015, BMC GERIATR, V15, DOI 10.1186/s12877-015-0012-5
Graske J, 2014, QUAL LIFE RES, V23, P549, DOI 10.1007/s11136-013-0504-8
Graske J, 2012, AGING MENT HEALTH, V16, P819, DOI 10.1080/13607863.2012.667782
Graske J, 2012, GERIATR NURS, V33, P204, DOI 10.1016/j.gerinurse.2012.01.001
Grske J, 2014, HEALTH QUAL LIFE OUT, V12, DOI 10.1186/s12955-014-0177-1
Kane RA, 2007, J AM GERIATR SOC, V55, P832, DOI 10.1111/j.1532-5415.2007.01169.x
Klie T., 2017, AMBULANT BETREUTE WO
Luppa M, 2010, AGE AGEING, V39, P31, DOI 10.1093/ageing/afp202
Moise P., 2004, DEMENTIA CARE 9 OECD
REISBERG B, 1982, AM J PSYCHIAT, V139, P1136
Rothgang H., 2017, AMBULANTISIERUNG STA
Spector A, 2006, ALZ DIS ASSOC DIS, V20, P160, DOI 10.1097/00002093-200607000-00007
Verbeek H, 2009, INT PSYCHOGERIATR, V21, P252, DOI 10.1017/S104161020800820X
Wetzels RB, 2010, DEMENT GERIATR COGN, V29, P189, DOI 10.1159/000280437
Wimo A, 2010, WORLD ALZHEIMER REPO
Wolf-Ostermann K, 2012, MONITOR VERSORGUNGSF, V5, P32
Wolf-Ostermann K., 2012, AMBULANT BETREUTE WO, P183
Wolf-Ostermann K., 2013, ZEITSCHRIFT FUR GERO, P1
Wolf-Ostermann K, 2015, J J GERONTO, V1, P7
Wolf-Ostermann K, 2014, APPL NURS RES, V27, P33, DOI 10.1016/j.apnr.2013.11.002
Wolf-Ostermann K, 2012, J CLIN NURS, V21, P3047, DOI 10.1111/j.1365-2702.2012.04305.x
Xu DJ, 2013, ARCH GERONTOL GERIAT, V57, P127, DOI 10.1016/j.archger.2013.03.015
NR 36
TC 1
Z9 1
U1 4
U2 4
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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WC Health Policy & Services; Public, Environmental & Occupational Health
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PT J
AU Lane, ST
   Gates, KM
   Pike, HK
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AF Lane, Stephanie T.
   Gates, Kathleen M.
   Pike, Hallie K.
   Beltz, Adriene M.
   Wright, Aidan G. C.
TI Uncovering General, Shared, and Unique Temporal Patterns in Ambulatory
   Assessment Data
SO PSYCHOLOGICAL METHODS
LA English
DT Article
DE time series analysis; idiographic methods; structural equation modeling;
   daily diary data
ID BORDERLINE PERSONALITY-DISORDER; AFFECTIVE INSTABILITY; MOOD CHANGE;
   DAILY-LIFE; CONNECTIVITY; MODEL; NETWORKS; DYNAMICS; SEARCH; FMRI
AB Intensive longitudinal data provide psychological researchers with the
potential to better understand individual-level temporal processes. While the
collection of such data has become increasingly common, there are a
comparatively small number of methods well-suited for analyzing these data, and
many methods assume homogeneity across individuals. A recent development rooted
in structural equation and vector autoregressive modeling, Subgrouping Group
Iterative Multiple Model Estimation (S-GIMME), provides one method for arriving
at individual-level models composed of processes shared by the sample, a subset
of the sample, and a given individual. As this algorithm was motivated and
validated for use with neuroimaging data, its performance is less understood in
the context of ambulatory assessment data. Here, we evaluate the performance of
the S-GIMME algorithm across various conditions frequently encountered with
daily diary (compared to neuroimaging) data; namely, a smaller number of
variables, a lower number of time points, and smaller autoregressive effects. We
demonstrate, for the first time, the importance of the autoregressive effects in
recovering data-generating connections and directions, and the ability to use S-
GIMME with lengths of data commonly seen in daily diary studies. We demonstrate
the use of S-GIMME with an empirical example evaluating the general, shared, and
unique temporal processes associated with a sample of individuals with
borderline personality disorder (BPD). Finally, we underscore the need for
methods such as S-GIMME moving forward given the increasing use of intensive
longitudinal data in psychological research, and the potential for these data to
provide novel insights into human behavior and mental health.
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CR American Psychiatric Association, 2013, DIAGN STAT MAN MENT
Asparouhov T, 2018, STRUCT EQU MODELING, V25, P359, DOI 10.1080/10705511.2017.1406803
Bachrach RL, 2017, PSYCHOL ADDICT BEHAV, V31, P576, DOI 10.1037/adb0000285
Beltz AM, 2017, MULTIVAR BEHAV RES, V52, P789, DOI 10.1080/00273171.2017.1373014
Beltz AM, 2016, MULTIVAR BEHAV RES, V51, P357, DOI 10.1080/00273171.2016.1151333
Beltz AM, 2013, ADDICT BEHAV, V38, P2052, DOI 10.1016/j.addbeh.2012.12.023
Bollen K. A., 1989, STRUCTURAL EQUATIONS, DOI [10.1002/9781118619179, DOI 10.1002/9781118619179]
Borkenau P, 1998, J RES PERS, V32, P202, DOI 10.1006/jrpe.1997.2206
Bradley R, 2005, J CHILD PSYCHOL PSYC, V46, P1006, DOI 10.1111/j.1469-7610.2004.00401.x
Brown T., 2006, CONFIRMATORY FACTOR
Castro-Schilo L, 2013, MULTIVAR BEHAV RES, V48, P175, DOI 10.1080/00273171.2012.736042
Chatfield C., 2003, ANAL TIME SERIES INT
Critchfield KL, 2008, BRIT J CLIN PSYCHOL, V47, P185, DOI 10.1348/014466507X240731
Ebner-Priemer UW, 2007, PSYCHOL MED, V37, P961, DOI 10.1017/S0033291706009706
Enders CK, 2001, STRUCT EQU MODELING, V8, P128, DOI 10.1207/S15328007SEM0801_7
Fernandez KC, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0178806
Fisher AJ, 2016, ASSESSMENT, V23, P496, DOI 10.1177/1073191116638735
Fisher AJ, 2015, J CONSULT CLIN PSYCH, V83, P825, DOI 10.1037/ccp0000026
Gadassi R, 2016, ARCH SEX BEHAV, V45, P109, DOI 10.1007/s10508-014-0448-2
Gates KM, 2017, MULTIVAR BEHAV RES, V52, P129, DOI 10.1080/00273171.2016.1256187
Gates KM, 2016, FRONT NEUROINFORM, V10, DOI 10.3389/fninf.2016.00045
Gates KM, 2012, NEUROIMAGE, V63, P310, DOI 10.1016/j.neuroimage.2012.06.026
Gates KM, 2010, NEUROIMAGE, V50, P1118, DOI 10.1016/j.neuroimage.2009.12.117
GRANGER CWJ, 1988, J ECONOMETRICS, V39, P199, DOI 10.1016/0304-4076(88)90045-0
GRANGER CWJ, 1969, ECONOMETRICA, V37, P424, DOI 10.2307/1912791
Hallquist MN, 2012, PERSONAL DISORD, V3, P228, DOI 10.1037/a0027953
Hamaker EL, 2002, STRUCT EQU MODELING, V9, P347, DOI 10.1207/S15328007SEM0903_3
Hamaker EL, 2017, CURR DIR PSYCHOL SCI, V26, P10, DOI 10.1177/0963721416666518
Hamaker EL, 2016, ASSESSMENT, V23, P436, DOI 10.1177/1073191116632339
HUBERT L, 1985, J CLASSIF, V2, P193, DOI 10.1007/BF01908075
Hyman SE, 2010, ANNU REV CLIN PSYCHO, V6, P155, DOI 10.1146/annurev.clinpsy.3.022806.091532
Hyvarinen A, 2010, J MACH LEARN RES, V11, P1709
Joreskog K. G, 1986, LISREL VI ANALYSIS O
Karunanayaka P, 2014, HUM BRAIN MAPP, V35, P2055, DOI 10.1002/hbm.22312
KERNBERG OF, 1975, INT J GROUP PSYCHOTH, V25, P251, DOI 10.1080/00207284.1975.11491899
Kim J, 2007, HUM BRAIN MAPP, V28, P85, DOI 10.1002/hbm.20259
Kotov R, 2017, J ABNORM PSYCHOL, V126, P454, DOI 10.1037/abn0000258
Lane ST, 2017, STRUCT EQU MODELING, V24, P768, DOI 10.1080/10705511.2017.1309978
Laurenceau JP, 2005, J FAM PSYCHOL, V19, P86, DOI 10.1037/0893-3200.19.1.86
LEBO MA, 1978, J RES PERS, V12, P205, DOI 10.1016/0092-6566(78)90098-3
Lee CM, 2017, PSYCHOL ASSESSMENT, V29, P253, DOI 10.1037/pas0000320

Lenzenweger MF, 2008, J PERS DISORD, V22, P313, DOI 10.1521/pedi.2008.22.4.313
Liao TW, 2005, PATTERN RECOGN, V38, P1857, DOI 10.1016/j.patcog.2005.01.025
Lilienfeld S. O., 1994, CLIN PSYCHOL-SCI PR, V1, P71
MACCALLUM R, 1986, PSYCHOL BULL, V100, P107, DOI 10.1037/0033-2909.100.1.107
MACCALLUM RC, 1992, PSYCHOL BULL, V111, P490, DOI 10.1037/0033-2909.111.3.490
Miskewicz K, 2015, J PERS DISORD, V29, P486, DOI 10.1521/pedi.2015.29.4.486
Molenaar P. C. M., 2004, MEASUREMENT, V2, P201, DOI DOI 10.1207/S15366359MEA0204_
Molenaar PCM, 2008, DEV PSYCHOBIOL, V50, P60, DOI 10.1002/dev.20262
Molenaar PCM, 2016, NEUROIMAGE, V125, P791, DOI 10.1016/j.neuroimage.2015.10.088
Molenaar PCM, 2009, CURR DIR PSYCHOL SCI, V18, P112, DOI 10.1111/j.1467-8721.2009.01619.x
Muehlenkamp JJ, 2009, BEHAV RES THER, V47, P83, DOI 10.1016/j.brat.2008.10.011
Mumford JA, 2014, NEUROIMAGE, V86, P573, DOI 10.1016/j.neuroimage.2013.10.020
Myin-Germeys I, 2001, ARCH GEN PSYCHIAT, V58, P1137, DOI 10.1001/archpsyc.58.12.1137
Myin-Germeys I, 2009, PSYCHOL MED, V39, P1533, DOI 10.1017/S0033291708004947
Newman MEJ, 2004, PHYS REV E, V69, DOI 10.1103/PhysRevE.69.026113
Nichols TT, 2014, ADDICT BIOL, V19, P931, DOI 10.1111/adb.12060
Pe ML, 2015, CLIN PSYCHOL SCI, V3, P292, DOI 10.1177/2167702614540645
Pons P, 2005, LECT NOTES COMPUT SC, V3733, P284
Price RB, 2017, BIOL PSYCHIAT, V81, P347, DOI 10.1016/j.biopsych.2016.06.023
Ram N, 2005, PSYCHOL AGING, V20, P623, DOI 10.1037/0882-7974.20.4.623
Ram N, 2009, INT J BEHAV DEV, V33, P565, DOI 10.1177/0165025409343765
Ramsey JD, 2014, NEUROIMAGE, V84, P986, DOI 10.1016/j.neuroimage.2013.09.062
Ramsey JD, 2011, NEUROIMAGE, V58, P838, DOI 10.1016/j.neuroimage.2011.06.068
Sadikaj G, 2013, J ABNORM PSYCHOL, V122, P195, DOI 10.1037/a0030871
SEARLES JS, 1995, J STUD ALCOHOL, V56, P375, DOI 10.15288/jsa.1995.56.375
Shiffman S, 2002, J ABNORM PSYCHOL, V111, P531, DOI 10.1037//0021-843X.111.5.531
Shiffman S, 2008, ANNU REV CLIN PSYCHO, V4, P1, DOI 10.1146/annurev.clinpsy.3.022806.091415
Shimizu S, 2006, J MACH LEARN RES, V7, P2003
Silk JS, 2003, CHILD DEV, V74, P1869, DOI 10.1046/j.1467-8624.2003.00643.x
Smith SM, 2011, NEUROIMAGE, V54, P875, DOI 10.1016/j.neuroimage.2010.08.063
Smyth JM, 2007, J CONSULT CLIN PSYCH, V75, P629, DOI 10.1037/0022-006X.75.4.629
Steinley D, 2004, PSYCHOL METHODS, V9, P386, DOI 10.1037/1082-989X.9.3.386
Trull TJ, 2008, J ABNORM PSYCHOL, V117, P647, DOI 10.1037/a0012532
Trull TJ, 2013, ANNU REV CLIN PSYCHO, V9, P151, DOI 10.1146/annurev-clinpsy-050212-185510
WARD JH, 1963, J AM STAT ASSOC, V58, P236, DOI 10.2307/2282967
Wright AGC, 2016, J ABNORM PSYCHOL, V125, P641, DOI 10.1037/abn0000169
Wright AGC, 2015, FRONT PSYCHOL, V6, DOI 10.3389/fpsyg.2015.01914
Wright AGC, 2015, J PERS DISORD, V29, P503, DOI 10.1521/pedi.2015.29.4.503
Wright AGC, 2013, J PERS DISORD, V27, P125, DOI 10.1521/pedi.2013.27.2.125
Yang J, 2015, J NEUROLINGUIST, V33, P29, DOI 10.1016/j.jneuroling.2014.09.004
Zelle SL, 2017, NEUROIMAGE, V151, P24, DOI 10.1016/j.neuroimage.2016.03.015
ZEVON MA, 1982, J PERS SOC PSYCHOL, V43, P111, DOI 10.1037/0022-3514.43.1.111
Zimmermann J, PSYCHOLOGICAL ASSESS

NR 84
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Z9 1
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PU AMER PSYCHOLOGICAL ASSOC
PI WASHINGTON
PA 750 FIRST ST NE, WASHINGTON, DC 20002-4242 USA
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   Gaynor, M
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CR Adler-Milstein J, 2017, MILBANK Q, V95, P117, DOI 10.1111/1468-0009.12247
   Agency for Healthcare Research & Quality, 2015, CAHPS CLIN GROUP SUR
   Allen Arthur, 2018, POLITICO
   [Anonymous], 2018, ONC CERT HLTH IT PRO
   [Anonymous], 2016, FED REGISTER, V82
   [Anonymous], 2018, FED REGISTER, V83, p[20, 164]
   [Anonymous], MER BAS INC PAYM SYS
   [Anonymous], 2018, FED REGISTER, V83, p[41, 688]
   [Anonymous], 2018 PROM INT
   [Anonymous], 2018, FED REGISTER, V83, P144
   [Anonymous], 2016, SUBM SW VIRG HLTH AU
```

[Anonymous], 2017, SUPPL SUBM TENN DEP
[Anonymous], 2017, FED REG, V82, p[53, 570]
[Anonymous], 2016, ONC API TASK FORCE R
[Anonymous], 2017, FED REGISTER, V82, P53568
[Anonymous], 2015, FED REGISTER, V80, p[62, 675]
[Anonymous], 2018, FED REGISTER, V83, p[20, 550]
[Anonymous], 2014, EX HLTH CAR COMP
[Anonymous], 2018, FED REG, V83, p[41, 637]
[Anonymous], 2017, FED REG, V82, P30015
[Anonymous], 2019, FED REG
[Anonymous], 2017, FED REGISTER, V82
[Anonymous], 2018, FED REGISTER, V83, p[41, 635]
[Anonymous], 2016, COMMUNICATION
[Anonymous], 2017, FED REG, V82
[Anonymous], 1995, FED REG, V60
[Anonymous], 2016, ACC AL POP BAS PAYM
[Anonymous], 2016, BECKERS HOSP REV
[Anonymous], 2018, FED REGISTER, V83, P634
Baer Bill, 2015, COMMUNICATION
Baker LC, 2016, J HEALTH ECON, V50, P1, DOI 10.1016/j.jhealeco.2016.08.006
Becker's Hospital Review, 2015, BECKERS HOSP REV
Blue Cross Blue Shield of Mich, 2017, 2017 PGIP FACT SHEET
Boone Keith, 2017, WHATS MY DOCTORS DIR
Brennan Patti, 2017, IS EHR NEW BIG DATA
Centers for M Medicaid S Office of the National Coordinator for Health Information Technology HHS, 2014, FED REGISTER, V79, P52909
Centers for Medicare & Medicaid Services (CMS) HHS, 2017, Fed Regist, V82, P37990
Centers for Medicare & Medicaid Services (CMS) HHS, 2010, Fed Regist, V75, P44313
Chopra Ancesh, 2018, 2018 EHR NAT S STANF
CMS, PROM INT PI REQ
Cross DA, 2016, J AM MED INFORM ASSN, V23, P297, DOI 10.1093/jamia/ocv072
Ctrs. for Medicare & Medicaid Servs. Dept of Health & Human Services, INTR MED MEAN US PRO, V12
DEFICE or THE NAT'L COORDINATOR FOR HEALTH INFO. TECH. DEPT. 01' HEALTH & HUMAN SERVS., 2016, EHR CONTR UNT SEL WI, P9
ESAC INC. & SRS INC., 2017, HHSP233201600224A ES
Everson J, 2016, HEALTH AFFAIR, V35, P1286, DOI 10.1377/hlthaff.2015.1215
FamilicsUSA, 2014, MEAS HEALTHC QUAL OV
Farr Christina, 2017, FAST CO
Fed. Trade Comm'n, 2008, BRIEF OV FED TRAD CO
Governor of Ohio, 2015, OH MED REF
Grossman J. M., 2008, CREATING SUSTAINABLE
Harper Ellen M, 2013, Nurs Adm Q, V37, P105, DOI 10.1097/NAQ.0b013e318286db0d
Holmgren AJ, 2017, HEALTH AFFAIR, V36, P1820, DOI 10.1377/hlthaff.2017.0546
Joseph Conn Epic, 2014, MODERN HEALTHCARE
Kliff Sarah, 2018, VOX 0112
Koslov Tara Isa, 2014, PROMOTING HLTH COMPE
LEVINSON DANIEL R., 2017, MEDICARE PAID 100S M
LIN SC, 2018, J HLTH SERVS RES, V53, P3285, DOI DOI 10.1111/1475-6773.12838
Manjoo Farhad, 2017, NY TIMES
Mello MM, 2018, MILBANK Q, V96, P110, DOI 10.1111/1468-0009.12313
Miller AR, 2014, J HEALTH ECON, V33, P28, DOI 10.1016/j.jhealeco.2013.10.004
Morris Genevieve, 2017, PAN ANN M OFF NATL C
Mukherjee S, 2018, FORTUNE
Murphy Brooke, 2017, BECKERS HOSP REV
National Quality Forum, 2017, MEAS FRAM ASS NAT PR

```
   OECD, 2016, BIG DAT BRING COMP P
   OFFICE OF THE. NAT'l. COORDINATOR FOR HEALTH INFO. TECH. OFFICE OF THE SEC'Y
U.S. DEPT OF HEALTH & HUMAN SERVS., 2016, 2016 C HLTH IT PROGR, P5
   OFFICE OF THE NAT'L COORDINATOR FOR HEALTH INFO. TECH. U.S. DEP'T or HEALTH &
HUMAN SERvs., 2015, REP HLTH INF BLOCK
   Office of the National Coordinator for Health Information Technology, 2015,
FED REGISTER, V80, P62602
   Office of the National Coordinator for Health Information Technology (ONC)
Department of Health and Human Services (HHS), 2015, Fed Regist, V80, P62601
   ONC, 2019, NOT PROP RUL IMPR IN
   Powers BW, 2018, HEALTHCARE-J DEL SCI, V6, P79, DOI
10.1016/j.hjdsi.2017.06.003
   Roth Mandy, 2018, HLTH LEADERS ME 0928
   Ruoff Alex, 2015, CONNECTICUT DEBATE S
   Sahni NR, 2017, HARVARD BUS REV, V95, P129
   SALOP SC, 1983, AM ECON REV, V73, P267
   Savage Lucia, 2017, COMBAT INFORM BLOCKI, DOI DOI
10.1377/HBLOG20170824.061636/FULU
   Shah Angela Mitchell, 2015, ADV INTEROPERABILITY
   Slavitt Andy, 2016, A SLAVITT K DESALVO
   Solove Daniel J, 2013, J AHIMA, V84, P22
   Tahir Darius, 2015, POLITICO
   Terry Nick, 2014, INFORM BLOCKING INTE
   U.S. Ctrs. for Medicare & Medicaid Servs, 2012, EL HLTH REC
   U.S. DEP'T OF HEALTH & HUMAN SERVS, 2018, TOP 5 ISS INV
   Verma Seema, 2018, COMMUNICATION
NR 84
TC 1
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PA 321 N CLARK ST, CHICAGO, IL 60610 USA
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   Azzariti, DR
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   Goehringer, SR
   Ramos, EM
   Rodriguez, LL
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Knoppers, B
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CA Clinical Genome Resource Educ Work
TI Development of a consent resource for genomic data sharing in the clinical setting
SO GENETICS IN MEDICINE
LA English
DT Article
DE Broad consent; Data sharing; Genetic testing; Informed consent; ClinGen
ID CLINVAR PUBLIC ARCHIVE; SEQUENCE VARIATION; COMMON RULE; LABORATORIES

AB Purpose: Data sharing between clinicians, laboratories, and patients is essential for improvements in genomic medicine, but obtaining consent for individual-level data sharing is often hindered by a lack of time and resources. To address this issue, the Clinical Genome Resource (ClinGen) developed tools to facilitate consent, including a one-page consent form and online supplemental video with information on key topics, such as risks and benefits of data sharing.

Methods: To determine whether the consent form and video accurately conveyed key data sharing concepts, we surveyed 5,162 members of the general public. We measured comprehension at baseline, after reading the form and watching the video. Additionally, we assessed participants' attitudes toward genomic data sharing.

Results: Participants' performance on comprehension questions significantly improved over baseline after reading the form and continued to improve after watching the video.

Conclusion: Results suggest reading the form alone provided participants with important knowledge regarding broad data sharing, and watching the video allowed for broader comprehension. These materials are now available at http://www.clinicalgenome.org/share. These resources will provide patients a straightforward way to share their genetic and health information, and improve the scientific community's access to data generated through routine healthcare.

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   (Rehm), U41HG009649 (Bustamante), and U41HG009650 (Berg),
   HHSN261200800001E.
CR American Medical Association, 2013, GEN AN VAR ID
   Azzariti DR, 2018, CSH MOL CASE STUD, V4, DOI 10.1101/mcs.a002345
   Department of Health and Human Services, 2015, FED POL PROT HUM SUB
   Department of Health and Human Services, 2017, FED POL PROT HUM SUB
   Garber KB, 2016, AM J HUM GENET, V99, P1140, DOI 10.1016/j.ajhg.2016.09.015
   Global Alliance for Genomics and Health, CONS POL
   Harrison SM, 2017, GENET MED, V19, P1096, DOI 10.1038/gim.2017.14
   Hudson KL, 2015, NEW ENGL J MED, V373, P2293, DOI 10.1056/NEJMp1512205
   Jurgens J, 2015, HUM MUTAT, V36, P1004, DOI 10.1002/humu.22839
   Kirkpatrick BE, 2015, HUM MUTAT, V36, P974, DOI 10.1002/humu.22838
   Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
   Landrum MJ, 2016, NUCLEIC ACIDS RES, V44, pD862, DOI 10.1093/nar/gkv1222
   Landrum MJ, 2014, NUCLEIC ACIDS RES, V42, pD980, DOI 10.1093/nar/gkt1113
   Loucks CM, 2015, HUM MUTAT, V36, P1015, DOI 10.1002/humu.22843
   Menikoff J, 2017, NEW ENGL J MED, V376, P613, DOI 10.1056/NEJMp1700736
   National Institutes of Health, 2014, FED REG, V79
   National Society of Genetic Counselors, 2015, CLIN DAT SHAR
   Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
   Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
NR 19
TC 1
Z9 1
U1 0
U2 1
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
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AU Jones, KM
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AF Jones, Kathryn Maxson
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TI The Bermuda Triangle: The Pragmatics, Policies, and Principles for Data
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LA English
DT Article
DE Bayh-Dole Act; Bermuda Principles; Big science; Bioinformatics;
   Biotechnology; C. elegans; Celera Genomics; Co-production; Community
   resource projects; Data hoarding; Data release; Data sharing; Databases;
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   sequencing; Ethical Legal and Social Implications (ELSI); European
   Bioinformatics Institute (EBI); GenBank; Gene patenting; Genetics;
   Genetic mapping; Genome commons; Genomics; Human Genome Project (HGP);
   Intellectual property; Medical genetics; Model organisms; Molecular
   biology; Moral economy of science; National Center for Human Genome
   Research (NCHGR); National Human Genome Research Institute (NHGRI);
   National Institutes of Health (NIH); Nematode worm; Open science;
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   sequence; Science policy; Wellcome Trust
ID EXPRESSED SEQUENCE TAGS; BREAST-CANCER SUSCEPTIBILITY; COMPREHENSIVE
   GENETIC-MAP; PROTEOMICS DATA RELEASE; DNA-SEQUENCE; MOLECULAR-BIOLOGY;
   PHYSICAL MAP; BIG SCIENCE; MENDELIAN-INHERITANCE; INTERNATIONAL SUMMIT
AB The Bermuda Principles for DNA sequence data sharing are an enduring legacy
of the Human Genome Project (HGP). They were adopted by the HGP at a strategy
meeting in Bermuda in February of 1996 and implemented in formal policies by
early 1998, mandating daily release of HGP-funded DNA sequences into the public
domain. The idea of daily sharing, we argue, emanated directly from strategies
for large, goal-directed molecular biology projects first tested within the
community of C. elegans researchers, and were introduced and defended for the
HGP by the nematode biologists John Sulston and Robert Waterston. In the C.
elegans community, and subsequently in the HGP, daily sharing served the
pragmatic goals of quality control and project coordination. Yet in the HGP
human genome, we also argue, the Bermuda Principles addressed concerns about
gene patents impeding scientific advancement, and were aspirational and flexible
in implementation and justification. They endured as an archetype for how rapid
data sharing could be realized and rationalized, and permitted adaptation to the
needs of various scientific communities. Yet in addition to the support of
Sulston and Waterston, their adoption also depended on the clout of
administrators at the US National Institutes of Health (NIH) and the UK
nonprofit charity the Wellcome Trust, which together funded 90% of the HGP human
sequencing effort. The other nations wishing to remain in the HGP consortium had
to accommodate to the Bermuda Principles, requiring exceptions from incompatible
existing or pending data access policies for publicly funded research in Germany,
Japan, and France. We begin this story in 1963, with the biologist Sydney
Brenner's proposal for a nematode research program at the Laboratory of
Molecular Biology (LMB) at the University of Cambridge. We continue through 2003,
with the completion of the HGP human reference genome, and conclude with
observations about policy and the historiography of molecular biology.
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FX Kathryn Maxson Jones led the conduct of this research from 2010 to 2013, and the writing of the manuscript from 2013-2018. From 2010-2013, she worked as a Research Aide at the Center for Public Genomics at Duke University, a Center of Excellence in Ethical, Legal, and Social Implications (ELSI) Research co-funded by the US Department of Energy and the US National Human Genome Research Institute (NHGRI) under the NIH Grant Number P50-HG-003391. In September 2018, while maintaining her PhD candidacy at Princeton University, Kathryn Maxson Jones will begin her tenure as a McDonnell Foundation Scholar at the Marine Biological Laboratory in Woods Hole, MA, which will last through June 2019. From 2002-2016, Robert Cook-Deegan was a Research Professor of Public Policy, Internal Medicine, and Biology at Duke University, and from 2004-2016 he served as the director of the Center for Public Genomics. He is also a senior fellow at FasterCures, a center of the nonprofit Milken Institute. Other funding included grants from the NIH (R01-HG-008918), the United States Studies Centre (USSC) of the University of Sydney, Australia ("The Ethos and Effects of Data-Sharing Rules: Examining the History of the 'Bermuda Principles' and Their Impact on US 21st Century Science,'' Rachel A. Ankeny and Robert M. Cook-Deegan, 2011), and the Ewing Marion Kauffman Foundation. The contents of this publication are solely the responsibility of the authors, and do not reflect the views of their funders or employers. The charges associated with making this article open access were funded by an award from the Wellcome Library Open Access Fund.
CR Abbate Janet, 1999, INVENTING INTERNET
Abbott A, 1997, NATURE, V387, P536, DOI 10.1038/42311
Adams Mark, 2012, COMMUNICATION
ADAMS MD, 1993, NAT GENET, V4, P256, DOI 10.1038/ng0793-256
Adams MD, 2003, P NATL ACAD SCI USA, V100, P3025, DOI 10.1073/pnas.0637478100
ADAMS MD, 1993, NAT GENET, V4, P373, DOI 10.1038/ng0893-373
Adams MD, 2000, SCIENCE, V287, P2185, DOI 10.1126/science.287.5461.2185
ADAMS MD, 1992, NATURE, V355, P632, DOI 10.1038/355632a0
ADAMS MD, 1991, SCIENCE, V252, P1651, DOI 10.1126/science.2047873
Adams MD, 1996, SCIENCE, V274, P534, DOI 10.1126/science.274.5287.534
Aicardi C, 2016, STUD HIST PHI PART C, V55, P41, DOI 10.1016/j.shpsc.2015.09.009
Allen Garland E, 1978, TH MORGAN MAN HIS SC
ANDERSON A, 1992, SCIENCE, V256, P462
ANDERSON C, 1992, NATURE, V355, P4, DOI 10.1038/355004a0
ANDERSON C, 1991, NATURE, V353, P485
Angrist Misha, 2010, HERE IS HUMAN BEING
Ankeny RA, 2003, ENDEAVOUR, V27, P87, DOI 10.1016/S0160-9327(03)00061-9
Ankeny RA, 2001, PHILOS SCI, V68, pS251, DOI 10.1086/392913

Ankeny RA, 2001, NAT REV GENET, V2, P474, DOI 10.1038/35076538
Ankeny Rachel A, 2015, POSTGENOMICS PERSPEC, P126
Ankeny Rachel A., 2007, SCI LAWS MODEL SYSTE, P46
[Anonymous], 2014, NATURE, V507, P273
[Anonymous], 1997, HUM GENOME NEWS, V8, P8
[Anonymous], 1993, RES PORTF ONL REP TO
[Anonymous], 1996, COMMUNICATION
[Anonymous], 1998, 1998 BERM M PHOT PHO
[Anonymous], 1996, E COMMUNICATION
[Anonymous], 1998, 1998 BERMUDA OPTIMIS
[Anonymous], 2012, DAT REL ACC PRINC PO
[Anonymous], 1996, INT STRAT M HUM GEN
[Anonymous], 2017, CANC MOONSH
[Anonymous], 1997, 1997 M SUMM SU UNPUB, P7108
[Anonymous], 1999, MEMORANDUM PRESIDENT
[Anonymous], 2000, NHGRI POL REL DAT DE
[Anonymous], 1994, HUM GEN PROJ P UNPUB
[Anonymous], 1996, NHGRI POL REG INT PR
[Anonymous], 1999, NIH IN OBT CLON FULL
[Anonymous], 1984, OTABA218 US C OFF TE
[Anonymous], 1997, RES PORTF ONL REP TO
[Anonymous], 2009, AB JST
[Anonymous], 1996, E COMMUNICATION
[Anonymous], 1997, DOEER0713 OFF BIOL 1
[Anonymous], 2018, NHGRI HIST GEN PROGR
[Anonymous], 1988, MAPPING SEQUENCING H
[Anonymous], 1996, COMMUNICATION
[Anonymous], 2018, ETH LEG SOC IMPL ELS
[Anonymous], 2003, M ORG WELLC TRUST HE
[Anonymous], 2005, BRIEF HIST BIO UNPUB
[Anonymous], 2009, J SULSTON BIOGRAPHY
[Anonymous], PHRED PHRAP CONS
[Anonymous], 1990, DOEER0452P NAT I HLT
[Anonymous], 2009, INT HIST HUM GEN PRO
[Anonymous], 1998, 3 INT STRAT M UNPUB
[Anonymous], 2012, NAT BIOEC BLUEPR
[Anonymous], 2018, US
[Anonymous], 1987, MAPP OUR GEN TRANSCR
[Anonymous], 1998, HUM GENOME NEWS, V9, P1
[Anonymous], 1996, TYPEWRITTEN NOTES HU
Arias JJ, 2015, J LAW BIOSCI, V2, P56, DOI 10.1093/jlb/lsu032
Aronova E, 2010, HIST STUD NAT SCI, V40, P183, DOI 10.1525/hsns.2010.40.2.183
Ashburner Michael, 2011, COMMUNICATION
Baetu TM, 2012, STUD HIST PHI PART C, V43, P191, DOI 10.1016/j.shpsc.2011.10.022
Baldwin AL, 2013, GENOME MED, V5, DOI 10.1186/gm412
Balmer B, 1996, SOC STUD SCI, V26, P531, DOI 10.1177/030631296026003002
Balmer B., 1996, PERSPECTIVES SCI, V4, P249
Balmer B, 1998, SCI PUBL POLICY, V25, P185
Balmer Brian, 1998, GENETIC IMAGINATIONS, P7
Balter M, 1998, SCIENCE, V280, P30, DOI 10.1126/science.280.5360.30
Bartlett Andrew, 2008, THESIS
Bazerman Charles, 1988, SHAPING WRITTEN KNOW
Begley Sharon, 2017, STAT NEWS
BELLANNECHANTELOT C, 1992, CELL, V70, P1059, DOI 10.1016/0092-8674(92)90254-A
Bentley DR, 1996, SCIENCE, V274, P533, DOI 10.1126/science.274.5287.533
Bentley DR, 1998, TRENDS GENET, V14, P381, DOI 10.1016/S0168-9525(98)01591-1
Berenson Alex, 2000, NY TIMES

Berman Helen M., 2004, Current Proteomics, V1, P49, DOI 10.2174/1570164043488252
Bermuda Principles Foundation Fund, 2017, BERM PRINC FDN FUND
Berners-Lee T., 1999, WEAVING WEB ORIGINAL
Berol David Nathaniel, 2001, THESIS
Biagioli M, 2012, BRIT J HIST SCI, V45, P213, DOI 10.1017/S0007087412000088
Blattner FR, 1997, SCIENCE, V277, P1453, DOI 10.1126/science.277.5331.1453
Bostanci A, 2004, ROUTL ST HIST SCI TE, V20, P158, DOI 10.4324/9780203375334_chapter_8
Bowker GC, 1999, SORTING THINGS OUT C
Boyle James, 2010, PUBLIC DOMAIN ENCLOS
BRANDT KA, 1993, B MED LIBR ASSOC, V81, P285
Branscomb Elbert, 2011, COMMUNICATION
BRENNER S, 1974, NATURE, V248, P785, DOI 10.1038/248785a0
BRENNER S, 1974, GENETICS, V77, P71
BRENNER S, 1973, BRIT MED BULL, V29, P269, DOI 10.1093/oxfordjournals.bmb.a071019
Brenner S, 2009, GENETICS, V182, P413, DOI 10.1534/genetics.109.104976
Brown Andrew, 2003, BEGINNING WAS WORM F
Brownlee C, 2004, P NATL ACAD SCI USA, V101, P13991, DOI 10.1073/pnas.0406437101
Brownlee GG, 2014, FRED SANGER: DOUBLE NOBEL LAUREATE: A BIOGRAPHY, P1
BURKE DT, 1987, SCIENCE, V236, P806, DOI 10.1126/science.3033825
Burks Christian, 2003, THEORY ACTION HIGHLI, P95
Burks Christian, 1989, BIOMOLECULAR DATA RE, P327
Burris J, 1998, NAT GENET, V20, P333, DOI 10.1038/3803
Butler D, 1999, NATURE, V402, P569, DOI 10.1038/45039
C elegans Sequencing Consortium, 1998, SCIENCE, V282, P2012, DOI 10.1126/science.282.5396.2012
Calia Kurt Geoffrey, 1992, BIOTECHNOL LAW REP, V11, P540
Cameron Graham, 2012, COMMUNICATION
Campbell EG, 2002, JAMA-J AM MED ASSOC, V287, P473, DOI 10.1001/jama.287.4.473
CANTOR CR, 1990, SCIENCE, V248, P49, DOI 10.1126/science.2181666
CAPSHEW JH, 1992, OSIRIS, V7, P3, DOI 10.1086/368703
Carbon John, 1993, P375
Caskey C. Thomas, 2012, COMMUNICATION
CECI SJ, 1988, SCI TECHNOL HUM VAL, V13, P45
CHALK R, 1985, SCI TECHNOL HUM VAL, P28
Chow-White PA, 2012, SCI TECHNOL HUM VAL, V37, P124, DOI 10.1177/0162243910397969
CHUMAKOV I, 1992, NATURE, V359, P380, DOI 10.1038/359380a0
CHUMAKOV IM, 1995, NATURE, V377, P175
Church DM, 2009, GENOME BIOL, V10, DOI 10.1186/gb-2009-10-4-105
Cinkosky Michael J, 1992, LOS ALAMOS SCI, V20, P270
COHEN D, 1993, NATURE, V366, P698, DOI 10.1038/366698a0
Cohen Stanley N, 1980, US Patent, Patent No. [4,237,224, 4237224]
COLLINS F, 1993, SCIENCE, V262, P43, DOI 10.1126/science.8211127
Collins Francis, 2012, COMMUNICATION
Collins Francis S, 2007, LANGUAGE GOD SCI PRE
Collins FS, 2004, NATURE, V431, P931, DOI 10.1038/nature03001
Collins FS, 2003, NATURE, V422, P835, DOI 10.1038/nature01626
COLLINS FS, 1995, P NATL ACAD SCI USA, V92, P10821, DOI 10.1073/pnas.92.24.10821
Collins FS, 2003, SCIENCE, V300, P286, DOI 10.1126/science.1084564
Collins FS, 1998, SCIENCE, V282, P682, DOI 10.1126/science.282.5389.682
Collins S., 2000, J TECHNOLOGY TRANSFE, V25, P213, DOI DOI 10.1023/A:1007884925676

Colwell Rita R, 1989, BIOMOLECULAR DATA RE
Comfort Nathaniel, 2012, SCI HUMAN PERFECTION
Contreras J. L., 2011, MINN J L SCI TECH, V120, P61
Contreras Jorge, 2017, E COMMUNICATION
Contreras JL, 2016, GEORGETOWN LAW J, V105, P1
Contreras JL, 2015, TRENDS GENET, V31, P55, DOI 10.1016/j.tig.2014.12.006
Contreras JL, 2010, SCIENCE, V329, P393, DOI 10.1126/science.1189253
Contreras Jorge L, 2017, GOVERNING MED KNOWLE, P19
Contreras Jorge L, 2014, GOVERNING KNOWLEDGE, P99
Cook-Deegan R, 2007, J TECHNOL TRANSFER, V32, P133, DOI 10.1007/s10961-006-9016-9
Cook-Deegan R, 2006, INT SOC SCI J, V58, P299, DOI 10.1111/j.1468-2451.2006.00620.x
Cook-Deegan R, 2017, ANNU REV GENOM HUM G, V18, P389, DOI 10.1146/annurev-genom-083115-022515
Cook-Deegan R, 2010, ANNU REV GENOM HUM G, V11, P383, DOI 10.1146/annurev-genom-082509-141811
Cook-Deegan Robert, 1994, GENE WARS SCI POLITI
COOKDEEGAN RM, 1989, GENOMICS, V5, P661, DOI 10.1016/0888-7543(89)90042-6
CookDeegan RM, 1996, NATURE, V382, P17, DOI 10.1038/382017b0
COPELAND NG, 1993, SCIENCE, V262, P57, DOI 10.1126/science.8211130
Cottingham Katie, 2008, J Proteome Res, V7, P4612, DOI 10.1021/pr800781d
Coulson A, 1995, METHOD CELL BIOL, V48, P533
COULSON A, 1986, P NATL ACAD SCI USA, V83, P7821, DOI 10.1073/pnas.83.20.7821
COULSON A, 1988, NATURE, V335, P184, DOI 10.1038/335184a0
COULSON A, 1991, BIOESSAYS, V13, P413, DOI 10.1002/bies.950130809
Cox David, 2011, COMMUNICATION
Creager A. N. H., 2007, SCI LAWMODEL SYSTE
Creager ANH, 2010, J HIST BIOL, V43, P183, DOI 10.1007/s10739-010-9226-8
Creager ANH, 2009, STUD HIST PHI PART C, V40, P29, DOI 10.1016/j.shpsc.2008.12.005
Creager Angela N H, 2001, LIFE VIRUS TOBACCO M
Creager Angela N. H., 2013, LIFE ATOMIC HIST RAD
CULLITON BJ, 1982, SCIENCE, V216, P155, DOI 10.1126/science.11643731
Curnutte MA, 2014, NAT BIOTECHNOL, V32, P980, DOI 10.1038/nbt.3030
Curnutte MA, 2016, NAT BIOTECHNOL, V34, P466, DOI 10.1038/nbt.3545
DASTON L, 1995, OSIRIS, V10, P2, DOI 10.1086/368740
Davies G, 2013, BIOSOCIETIES, V8, P386, DOI 10.1057/biosoc.2013.26
Davies K, 1996, BREAKTHROUGH RACE FI
Davies Kevin, 2001, CRACKING GENOME INSI
Davies Kevin, 2016, HUMAN GENOME PROJECT
Davies Kevin, 2010, 1 000 GENOME REVOLUT
Dayhoff Margaret O, 1965, ATLAS PROTEIN SEQUEN
de Chadarevian S, 2004, ROUTL ST HIST SCI TE, V20, P95, DOI 10.4324/9780203375334_chapter_5
de Chadarevian Soraya, 1998, Studies in History and Philosophy of Biological and Biomedical Sciences, V29C, P81, DOI 10.1016/S1369-8486(98)00004-1
De Chadarevian Soraya, 2002, DESIGNS LIFE MOL BIO
Deichmann Ute, 1996, BIOL HITLER
DELISI C, 1988, AM SCI, V76, P488
Demaine LT, 2002, STANFORD LAW REV, V55, P303, DOI 10.2307/1229595
Deverka PA, 2017, GENOME MED, V9, DOI 10.1186/s13073-017-0476-3
Diaz ES, 2007, SCI CONTEXT, V20, P649, DOI 10.1017/S0269889707001482
Dib C, 1996, NATURE, V380, P152, DOI 10.1038/380152a0
DICKSON D, 1994, NATURE, V371, P365
Dickson D, 1998, NATURE, V393, P201, DOI 10.1038/30314
Dickson D, 1996, NATURE, V380, P279
Dietrich MR, 2014, GENETICS, V198, P787, DOI 10.1534/genetics.114.169714

Dietrich MR, 1998, J HIST BIOL, V31, P85, DOI 10.1023/A:1004257523100
DIETRICH WF, 1994, NAT GENET, V7, P220, DOI 10.1038/ng0694supp-220
Dietrich WF, 1996, NATURE, V380, P149, DOI 10.1038/380149a0
Doggett N. A., 1992, LOS ALMOS SCI, V20, P128
Dove ES, 2015, J LAW MED ETHICS, V43, P675, DOI 10.1111/jlme.12311
Durbin Richard, 2012, COMMUNICATION
Eddy Sean, 2012, COMMUNICATION
Edwards A, 2008, NAT STRUCT MOL BIOL, V15, P116, DOI 10.1038/nsmb0208-116
Eisenberg RS, 2006, IND CORP CHANGE, V15, P1013, DOI 10.1093/icc/dtl025
Eisenberg RS, 2000, NAT REV GENET, V1, P70, DOI 10.1038/35049590
Eisenberg RS, 2002, ACAD MED, V77, P1392, DOI 10.1097/00001888-200212001-00011
Eisenberg RS, 1996, TRENDS BIOTECHNOL, V14, P302, DOI 10.1016/0167-7799(96)10040-8
Enserink M, 2000, SCIENCE, V287, P1196, DOI 10.1126/science.287.5456.1196
Ewing B, 1998, GENOME RES, V8, P186, DOI 10.1101/gr.8.3.186
Ewing B, 1998, GENOME RES, V8, P175, DOI 10.1101/gr.8.3.175
Fasman KH, 1997, NUCLEIC ACIDS RES, V25, P72, DOI 10.1093/nar/25.1.72
FEDER T, 1995, NATURE, V375, P259
Feingold EA, 2004, SCIENCE, V306, P636, DOI 10.1126/science.1105136
Field D, 2009, SCIENCE, V326, P234, DOI 10.1126/science.1180598
FLEISCHMANN RD, 1995, SCIENCE, V269, P496, DOI 10.1126/science.7542800
Fortun Michael, 2008, PROMISING GENOMICS I
Fox Jeffrey L., 1992, NAT BIOTECHNOL, V10, P1410
Francis S.Collins, 2000, E COMMUNICATION
Galison P., 1992, BIG SCI GROWTH LARGE
GALLOWAY J, 1990, NEW SCI, V127, P41
Garcia-Sancho M., 2006, GENOMICS SOCIETY AND, V2, P15
Garcia-Sancho M, 2007, ENDEAVOUR, V31, P18, DOI 10.1016/j.endeavour.2007.01.006
Garcia-Sancho Miguel, 2015, BIOL COMPUTING HIST
Gaudilliere JP, 2009, STUD HIST PHI PART C, V40, P20, DOI 10.1016/j.shpsc.2008.12.004
Gaudilliere Jean-Paul, 2004, MOL GENETICS GENOMIC
GAUDILLIERE JP, 1993, J HIST BIOL, V26, P473, DOI 10.1007/BF01062058
Gibbs RA, 2003, NATURE, V426, P789, DOI 10.1038/nature02168
Gilbert G., 1984, OPENING PANDORAS BOX
Giles Chrissie, 2010, IT WAS DAGGERS DRAWN
Goffeau A, 1996, SCIENCE, V274, P546, DOI 10.1126/science.274.5287.546
Gold ER, 2010, GENET MED, V12, pS39, DOI 10.1097/GIM.0b013e3181d72661
Gordon D, 1998, GENOME RES, V8, P195, DOI 10.1101/gr.8.3.195
Gordon D, 2001, GENOME RES, V11, P614, DOI 10.1101/gr.171401
Gordon D, 2013, BIOINFORMATICS, V29, P2936, DOI 10.1093/bioinformatics/btt515
Green Eric, 2011, COMMUNICATION
Green ED, 2015, NATURE, V526, P29, DOI 10.1038/526029a
Green P, 1997, GENOME RES, V7, P410, DOI 10.1101/gr.7.5.410
Green Phil, 2018, E COMMUNICATION
Green Phil, 2012, COMMUNICATION
Grubb AM, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0023420
Guyer M, 1998, GENOME RES, V8, P413
Guyer Mark, 2011, COMMUNICATION
GYAPAY G, 1994, NAT GENET, V7, P246, DOI 10.1038/ng0694supp-246
Hackett Edward J, 2013, COLLABORATION NEW LI, pxvii
Hagstrom Warren, 1982, SCI CONTEXT READINGS, P21
Halliday L, 2010, COLLABORATION IN THE NEW LIFE SCIENCES, P219
Hamosh A, 2005, NUCLEIC ACIDS RES, V33, pD514
Hardin G, 1998, SCIENCE, V280, P682, DOI 10.1126/science.280.5364.682
Hattori M, 2000, NATURE, V405, P311

Hattori Masahira, 2012, E COMMUNICATION
Hayden EC, 2014, NATURE, V507, P294, DOI 10.1038/507294a
HEALY B, 1992, NEW ENGL J MED, V327, P664, DOI 10.1056/NEJM199208273270930
Heeney C, 2011, PUBLIC HEALTH GENOM, V14, P17, DOI 10.1159/000294150
HEILBRON JL, 1988, MINERVA, V26, P299, DOI 10.1007/BF01096399
Helmreich S, 2010, REPRESENTATIONS, P27, DOI 10.1525/rep.2010.112.1.27
Helmreich Stefan, 2000, SILICON 2 NATURE CUL
Hencke David, 1999, GUARDIAN
Hess C, 2007, UNDERSTANDING KNOWLE
HILGARTNER S, 1995, SCI COMMUN, V17, P240, DOI 10.1177/1075547095017002009
Hilgartner S, 2004, ROUTL ST HIST SCI TE, V20, P113, DOI 10.4324/9780203375334_chapter_6
HILGARTNER S, 1994, KNOWLEDGE, V15, P355, DOI 10.1177/107554709401500401
Hilgartner S, 2013, BIOSOCIETIES, V8, P397, DOI 10.1057/biosoc.2013.31
Hilgartner S, 2012, BIOSOCIETIES, V7, P188, DOI 10.1057/biosoc.2012.5
Hilgartner S, 2012, BRIT J HIST SCI, V45, P267, DOI 10.1017/S0007087412000106
Hilgartner Stephen, 2017, REORDERING LIFE KNOW
Hilgartner Stephen, 2000, SCI STAGE EXPERT ADV
Hilgartner Stephen, 1995, HDB SCI TECHNOLOGY S, P302
Hilgartner Stephen, 1998, PRIVATE SCI BIOTECHN, P202
Hilgartner Stephen, 2004, STATES KNOWLEDGE, P131
Hillier LaDeana, 2012, COMMUNICATION
Hirakawa Mika, 1997, GENOME INFORM, V8, P278
Holden AL, 2002, BIOTECHNIQUES, P22
Horvitz H Robert, 2000, PERSPECTIVES GENETIC, P176
Hubbard Tim, 2011, COMMUNICATION
HUDSON TJ, 1995, SCIENCE, V270, P1945, DOI 10.1126/science.270.5244.1945
Hughes S., 2011, GENENTECH BEGINNINGS
Hughes SS, 2001, ISIS, V92, P541, DOI 10.1086/385281
International Large-Scale Sequencing Meeting, 1996, HUMAN GENOME NEWS, V7, P19
Jaillon O, 2004, NATURE, V431, P946, DOI 10.1038/nature03025
Jasanoff S, 2011, BASIC BIOETH, P1
JASANOFF S, 1985, RES POLICY, V14, P23, DOI 10.1016/0048-7333(85)90022-8
Jasanoff S, 2004, STATES KNOWLEDGE COP
Jasanoff S, 2009, MINERVA, V47, P119, DOI 10.1007/s11024-009-9124-4
Jasanoff Sheila, 2015, DREAMSCAPES MODERNIT
Jasanoff Sheila, 2003, SOCIAL STUDIES SCI T, P155
Jasanoff Sheila, 2005, DESIGNS NATURE SCI D
Jasny BR, 2013, EPJ DATA SCI, V2, DOI 10.1140/epjds13
Joly PB, 1998, SOCIAL MANAGEMENT GE, P77
Judson Horace Freeland, 1996, 8 DAY CREATION MAKER
Judson Horace Freeland, 1992, CODE CODES SCI SOCIA, P37
Kahn P, 1996, SCIENCE, V271, P1798
KAHN P, 1995, SCIENCE, V268, P1556, DOI 10.1126/science.7777848
Kaufmann A, 2004, ROUTL ST HIST SCI TE, V20, P129, DOI 10.4324/9780203375334_chapter_7
Kaul S, 2000, NATURE, V408, P796, DOI 10.1038/35048692
Kay Lily, 2000, WHO WROTE BOOK LIFE
Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
KAYTON I, 1982, GEORGE WASH LAW REV, V50, P191
Kelty CM, 2012, BIOSOCIETIES, V7, P140, DOI 10.1057/biosoc.2012.8
Kelty CM, 2008, 2 BITS CULTURAL SIGN
Kent Jill, 1997, E COMMUNICATION, P7108
Kevles D, 1997, HIST STUD PHYS BIOL, V27, P269, DOI 10.2307/27757780
Kevles DJ, 2012, PALGRAVE STUD CULT, P147
Kevles Daniel J, 1992, CODE CODESCI SOCIA
Kevles Daniel J, 1995, PHYS HIST SCI COMMUN

KEVLES DJ, 1994, HIST STUD PHYS BIOL, V25, P111, DOI 10.2307/27757736
Kiley Thomas D, 1982, BANBURY REPORT 10 PA, P191
Kleinman Daniel Lee, 1995, POLITICS ENDLESS FRO
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Knoppers BM, 2011, GENOME MED, V3, DOI 10.1186/gm262
Knorr Cetina Karin D, 1998, EPISTEMIC CULTURES S
Kohler Robert, 1994, LORDS FLY DROSOPHILA
Kowalski TJ, 2000, NAT BIOTECHNOL, V18, P349, DOI 10.1038/73820
Lander Eric, 2012, COMMUNICATION
Lander ES, 2001, NATURE, V409, P860, DOI 10.1038/35057062
Latour Bruno, 1987, SCI ACTION
Lee Peter, 2017, GOVERNING MED KNOWLE, P46
Lehrach Hans, 2012, COMMUNICATION
Lemke Amy A, 2011, IRB, V33, P1
Lenoir T, 1999, ASIS MONOGR, P27
Leonelli S, 2012, STUD HIST PHI PART C, V43, P1, DOI 10.1016/j.shpsc.2011.10.001
Leonelli S, 2013, B SCI TECHNOL SOC, V33, P6, DOI DOI 10.1177/0270467613496768
Leonelli S., 2016, DATA CENTRIC BIOL PH
Leonelli S, 2007, HIST PHIL LIFE SCI, V29, P193
Leonelli S, 2013, BIOSOCIETIES, V8, P449, DOI 10.1057/biosoc.2013.23
Leonelli S, 2012, STUD HIST PHI PART C, V43, P29, DOI 10.1016/j.shpsc.2011.10.003
Leonelli Sabina, 2010, COMMODIFICATION ACAD, P132
Leonelli Sabina, 2011, WELL DO FACTS TRAVEL, P325
Letovsky SI, 1998, NUCLEIC ACIDS RES, V26, P94, DOI 10.1093/nar/26.1.94
Levin N, 2017, SCI TECHNOL HUM VAL, V42, P280, DOI 10.1177/0162243916672071
LEWIN R, 1990, NEW SCI, V127, P38
LEWIN R, 1986, SCIENCE, V232, P1599, DOI 10.1126/science.3715467
Lindee M Susan, 2005, MOMENTS TRUTH GENETI
LITT M, 1989, AM J HUM GENET, V44, P397
Loots Eli A, 2002, BERKELEY TECH LJ, V17, P117
Lowy DR, 2017, LANCET ONCOL, V18, pE622, DOI 10.1016/S1470-2045(17)30797-0
Macilwain C, 2000, NATURE, V405, P983, DOI 10.1038/35016696
MACILWAIN C, 1995, NATURE, V376, P541
MACILWAIN C, 1996, NATURE, V380, P471
MADDOX J, 1989, NATURE, V342, P855, DOI 10.1038/342855a0
MADDOX J, 1989, NATURE, V341, P277, DOI 10.1038/341277a0
MAIENSCHEIN J, 1993, J HIST BIOL, V26, P167, DOI 10.1007/BF01061964
Majumder MA, 2016, PLOS BIOL, V14, DOI 10.1371/journal.pbio.2000206
Mapping Our Genes : US Congress Office of Technology Assessment, 1988, OTABA373 US C
Mardis ER, 2008, ANNU REV GENOM HUM G, V9, P387, DOI 10.1146/annurev.genom.9.081307.164359
MARSHALL E, 1990, SCIENCE, V248, P954, DOI 10.1126/science.2140466
Marshall E, 2000, SCIENCE, V287, P1903
MARSHALL E, 1990, SCIENCE, V248, P952, DOI 10.1126/science.2343306
Marshall E, 2000, SCIENCE, V287, P2127
MARSHALL E, 1994, SCIENCE, V266, P208, DOI 10.1126/science.7939649
Marshall E, 1996, SCIENCE, V272, P188, DOI 10.1126/science.272.5259.188
Marshall E, 2001, SCIENCE, V291, P1192, DOI 10.1126/science.291.5507.1192
MARSHALL E, 1995, SCIENCE, V267, P783, DOI 10.1126/science.7846520
MARSHALL E, 1994, SCIENCE, V266, P25, DOI 10.1126/science.7939640
Marshall E, 1996, SCIENCE, V272, P477
Marshall Eliot, 2012, COMMUNICATION
Martinell James, 1992, BIOTECHNOL LAW REP, V11, P578
MATSUBARA K, 1992, GENOMICS, V12, P618, DOI 10.1016/0888-7543(92)90460-A

Matsumoto T, 2005, NATURE, V436, P793, DOI 10.1038/nature03895
Max Gitlin Jonathan, 2013, NEWS FEATURES OFFICE
MAXAM AM, 1977, P NATL ACAD SCI USA, V74, P560, DOI 10.1073/pnas.74.2.560
MCCAIN KW, 1995, SCI COMMUN, V16, P403, DOI 10.1177/1075547095016004003
MCCAIN KW, 1991, SCI TECHNOL HUM VAL, V16, P491, DOI 10.1177/016224399101600404
McCombie Richard, 2012, COMMUNICATION
McCray WP, 2000, SOC STUD SCI, V30, P685, DOI 10.1177/030631200030005002
McElheny Victor K, 2010, DRAWING MAP LIFE INS
MCGOURTY C, 1989, NATURE, V342, P724, DOI 10.1038/342724a0
McKusick V. A., 1987, GENOMICS, V1, P1, DOI DOI 10.1016/0888-7543(87)90098-X
McKusick VA, 2007, AM J HUM GENET, V80, P588, DOI 10.1086/514346
McKusick Victor A, 1966, MENDELIAN INHERITANC
Merges Robert P., 1995, AIPLA Q J, V23, P1
Merrill Stephen A., 2006, REAP BEN GEN PROT RE
Merton RK, 1942, SOCIOLOGY SCI THEORE, P267
MONACO AP, 1994, TRENDS BIOTECHNOL, V12, P280, DOI 10.1016/0167-7799(94)90140-6
Morange M, 1997, HIST PHIL LIFE SCI, V19, P369
Morange M, 2008, HIST PHIL LIFE SCI, V30, P31
Morange Michel, 2000, HIST MOL BIOL
Morgan Michael, 2012, COMMUNICATION
Myers EW, 2002, P NATL ACAD SCI USA, V99, P4145, DOI 10.1073/pnas.092136699
Myers Richard, 2011, COMMUNICATION
NCHGR becomes NIH institute, 1997, HUM GENOME NEWS, V3, P8
Nelson Nicole, 2017, MODEL BEHAV ANIMAL E
New Developments in Biotechnology: US Congress Office of Technology Assessment, 1989, OTABA370 US C
Nielsen Michael, 2011, REINVENTING DISCOVER
NIH, 1993, HUM GENOME NEWS, V4, P4
November Joseph, 2012, BIOMEDICAL COMPUTING
Nummedal Tara, 2000, THORNTON TULLYS SCI, P164
Nusbaum C, 1999, NAT GENET, V22, P388, DOI 10.1038/11967
Office of the White House Press Secretary, 2000, PRES CLINT ANN COMPL
OLSON M, 1989, SCIENCE, V245, P1434, DOI 10.1126/science.2781285
Olson Maynard, 2012, COMMUNICATION
OLSON MV, 1986, P NATL ACAD SCI USA, V83, P7826, DOI 10.1073/pnas.83.20.7826
Olson MV, 2002, J MOL BIOL, V319, P931, DOI 10.1016/S0022-2836(02)00333-9
OLSON MV, 1995, SCIENCE, V270, P394, DOI 10.1126/science.270.5235.394
Ostrom E, 1990, GOVERNING COMMONS EV
Ostrom E, 2010, CORNELL LAW REV, V95, P807
Ouellette BFF, 1997, GENOME RES, V7, P952, DOI 10.1101/gr.7.10.952
PALCA J, 1989, SCIENCE, V245, P131, DOI 10.1126/science.2749252
pallab Bosh, 2001, BBC NEWS WORLD 0212
Parker JN, 2010, COLLABORATION IN THE NEW LIFE SCIENCES, P85
Parthasarathy Shobita, 2007, BUILDING GENETIC MED
Parthasarathy Shobita, 2017, PATENT POLITICS LIFE
Patrinos Aristides, 2011, COMMUNICATION
Pauly P. J., 2000, BIOL PROMISE AM LIFE
Pennisi E, 1998, SCIENCE, V280, P814, DOI 10.1126/science.280.5365.814
Pennisi E, 1999, SCIENCE, V283, P1822, DOI 10.1126/science.283.5409.1822
Pickvance Richard, 2012, GUARDIAN
Pickvance Simon, 1976, RADICAL SCI J, V4, P11
Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
POOL R, 1993, SCIENCE, V261, P842, DOI 10.1126/science.261.5123.842
Popp Berman Elizabeth, 2012, CREATING MARKET U AC

Powell A, 2009, STUD HIST PHI PART C, V40, P54, DOI 10.1016/j.shpsc.2008.12.007
Powledge Tabitha M, 2003, GENOME BIOL, V4, P2
Price D. J. de Solla, 1963, LITTLE SCI BIG SCI
PTO examiner to the NIH, 1992, BIOTECHNOL LAW REP, V11, P558
Qiang BQ, 2004, J MOL MED, V82, P214, DOI 10.1007/s00109-003-0515-y
Rabeharisoa Vololona, 2004, STATES KNOWLEDGE COP, P142
Rabinow Paul, 1999, FRENCH DNA TROUBLE P
Rabinow Paul, 1996, MAKING PCR STORY BIO
Rachel AAnkeny, 1997, THESIS
Rader K., 2004, MAKING MICE STANDARD
Rai AK, 2016, NAT BIOTECHNOL, V34, P292, DOI 10.1038/nbt.3504
Rajan Kaushik Sunder, 2006, BIOCAPITAL CONSTITUT
Rasmussen N, 2014, GENE JOCKEYS: LIFE SCIENCE AND THE RISE OF BIOTECH ENTERPRISE, P1
Rasmussen N, 1997, HIST SCI, V35, P245, DOI 10.1177/007327539703500301
Reardon J, 2005, IN-FORMATION, P1
Reardon J, 2016, GIGASCIENCE, V5, DOI 10.1093/gigascience/giw003
Reardon Jenny, 2017, POSTGENOMIC CONDITIO
REES DA, 1991, NATURE, V354, P426, DOI 10.1038/354426a0
Rhee SY, 2003, NUCLEIC ACIDS RES, V31, P224, DOI 10.1093/nar/gkg076
Richardson Sarah S, 2015, POSTGENOMICS PERSPEC
ROBERTS L, 1991, SCIENCE, V252, P1618, DOI 10.1126/science.2047871
ROBERTS L, 1991, SCIENCE, V254, P184, DOI 10.1126/science.1925568
ROBERTS L, 1990, SCIENCE, V248, P1310, DOI 10.1126/science.2356467
Robertson D, 1999, NAT BIOTECHNOL, V17, P125, DOI 10.1038/6119
Rodriguez H, 2008, J PROTEOME RES, V7, P4609, DOI 10.1021/pr800779q
Rodriguez H, 2009, J PROTEOME RES, V8, P3689, DOI 10.1021/pr900023z
Roe Bruce, 2012, COMMUNICATION
Rogers Jane, 2012, COMMUNICATION
Roland A, 2002, HIST COMP, P13
Roosth Sophia, 2017, SYNTHETIC LIFE GOT M
Rosenthal Andre, 1997, E COMMUNICATION, P7108
Rosenthal Andre, 2011, COMMUNICATION
Royal Society, 2012, SCI OPEN ENTERPRISE
Saegusa A, 1998, NATURE, V392, P219, DOI 10.1038/32510
Saegusa A, 1998, NATURE, V391, P111, DOI 10.1038/34244
Sakaki Yoshiyuki, 2011, COMMUNICATION
Salzberg S, 2003, NATURE, V422, P801, DOI 10.1038/422801a
SANGER F, 1988, ANNU REV BIOCHEM, V57, P1, DOI 10.1146/annurev.bi.57.070188.000245
SANGER F, 1975, J MOL BIOL, V94, P441, DOI 10.1016/0022-2836(75)90213-2
SANGER F, 1977, P NATL ACAD SCI USA, V74, P5463, DOI 10.1073/pnas.74.12.5463
Schuler GD, 1996, SCIENCE, V274, P540, DOI 10.1126/science.274.5287.540
Shapin Steven, 1985, LEVIATHAN AIR PUMP H
Shaw J, 2016, STUD HIST PHI PART C, V55, P61, DOI 10.1016/j.shpsc.2015.08.005
Shendure J, 2008, NAT BIOTECHNOL, V26, P1135, DOI 10.1038/nbt1486
Sherkow JS, 2015, ANNU REV GENET, V49, P161, DOI 10.1146/annurev-genet-112414-054731
Shreeve James, 2004, GENOME WAR C VENTER
Simon Tripp, 2011, EC IMPACT HUMAN GENO
Slavov D, 2000, GENE, V247, P215, DOI 10.1016/S0378-1119(00)00089-5
SMITH LM, 1985, NUCLEIC ACIDS RES, V13, P2399, DOI 10.1093/nar/13.7.2399
SMITH LM, 1986, NATURE, V321, P674, DOI 10.1038/321674a0
SMITH TF, 1990, GENOMICS, V6, P701, DOI 10.1016/0888-7543(90)90509-S
STADEN R, 1979, NUCLEIC ACIDS RES, V6, P2601, DOI 10.1093/nar/6.7.2601
Star SL, 1996, INFORM SYST RES, V7, P111, DOI 10.1287/isre.7.1.111
STAR SL, 1989, SOC STUD SCI, V19, P387, DOI 10.1177/030631289019003001

Stein L, 2001, NUCLEIC ACIDS RES, V29, P82, DOI 10.1093/nar/29.1.82
Stemerding Dirk, 1998, GETTING NEW TECHNOLO, P39
Stephen Hilgartner, 1997, INTELLECTUAL PROPERT, P28
Stevens H, 2018, J HIST BIOL, V51, P657, DOI 10.1007/s10739-017-9490-y
Stevens H, 2015, TECHNOL CULT, V56, P839, DOI 10.1353/tech.2015.0119
Stevens H, 2015, INFORM CULT, V50, P465, DOI 10.7560/IC50402
Stevens Hallam, 2011, Perspectives on Science, V19, P263
Stevens Hallam, 2015, POSTGENOMICS PERSPEC, P103
Stevens Hallam, 2013, LIFE OUT SEQUENCE DA
Stokes Donald E., 1997, PASTEURS QUADRANT BA
Stokstad E, 2002, SCIENCE, V295, P599
Strandburg Katherine J, 2017, GOVERNING MED KNOWLE
Strasser B, 2003, EMBO REP, V4, P540, DOI 10.1038/sj.embor.embor879
Strasser BJ, 2008, SCIENCE, V322, P537, DOI 10.1126/science.1163399
Strasser BJ, 2012, STUD HIST PHI PART C, V43, P85, DOI 10.1016/j.shpsc.2011.10.009
Strasser BJ, 2011, ISIS, V102, P60, DOI 10.1086/658657
Strasser BJ, 2010, J HIST BIOL, V43, P623, DOI 10.1007/s10739-009-9221-0
Strasser Bruno J, 2005, HIST EPISTEMOLOGY MO, P105
Strasser Bruno J, 2006, FABRIQUE NOUVELLE SC
STRATTON MR, 1994, NAT GENET, V7, P103, DOI 10.1038/ng0594-103
Suarez-Diaz E, 2008, STUD HIST PHI PART C, V39, P451, DOI 10.1016/j.shpsc.2008.09.002
Sulston, 1996, INT STRAT M HUM GEN
SULSTON J, 1992, NATURE, V356, P37, DOI 10.1038/356037a0
Sulston J, 2001, BIOCHEM SOC T, V29, P27, DOI 10.1042/BST0290027
SULSTON JE, 1976, PHILOS T ROY SOC B, V275, P287, DOI 10.1098/rstb.1976.0084
SULSTON JE, 1977, DEV BIOL, V56, P110, DOI 10.1016/0012-1606(77)90158-0
SULSTON JE, 1983, DEV BIOL, V100, P64, DOI 10.1016/0012-1606(83)90201-4
SULSTON JE, 1974, GENETICS, V77, P95
Sulston John, 2002, COMMON THREAD STORY
SUMMERS WC, 1993, J HIST BIOL, V26, P255, DOI 10.1007/BF01061969
SWINBANKS D, 1991, NATURE, V351, P593
SWINBANKS D, 1990, NATURE, V343, P195
Technologies for Detecting Heritable Mutations in Human Beings : US Congress Office of Technology Assessment, 1986, OTAH298 US C
Teegarden Henry D, 2015, PATENTS WORLD
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
The C. elegans Genome Consortium Genome Sequencing Center Washington University School of Medicine St. Louis Missouri USA and Sanger Centre Hinxton Hall Cambridge UK, 1994, WORM BREEDERS G 0201, V13, P14
THOMPSON L, 1993, SCIENCE, V259, P22
Thorisson GA, 2005, GENOME RES, V15, P1592, DOI 10.1101/gr.4413105
Thorisson GA, 2003, NUCLEIC ACIDS RES, V31, P124, DOI 10.1093/nar/gkg052
Toronto Int Data Release Workshop, 2009, NATURE, V461, P168, DOI 10.1038/461168a
Tozzi Christopher J, 2017, FUN PROFIT HIST FREE
Unterhuber R, 1997, NATURE, V387, P111, DOI 10.1038/387111a0
UNTERHUBER R, 1995, NATURE, V378, P6, DOI 10.1038/378006a0
van Ommen Gert-Jan, 2012, COMMUNICATION
Vayena E, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001937
Venter J. C., 2007, LIFE DECODED MY GENO
Venter J. Craig, 2012, COMMUNICATION
Venter JC, 1998, SCIENCE, V280, P1540, DOI 10.1126/science.280.5369.1540
Venter JC, 2001, SCIENCE, V291, P1304, DOI 10.1126/science.1058040
Vermeulen N, 2010, COLLABORATION IN THE NEW LIFE SCIENCES, P3
Vermeulen Niki, 2009, SUPERSIZING SCI BUIL
Von Borstel Robert C, 1993, EARLY DAYS YEAST GEN, P453

Wade Nicholas, 1998, NY TIMES
Wade Nicholas, 2014, TROUBLESOME INHERITA
Wadman M, 1998, NATURE, V393, P399, DOI 10.1038/30790
Wailoo Keith, 2006, TROUBLED DREAM GENET
Waterston R, 1998, SCIENCE, V282, P53, DOI 10.1126/science.282.5386.53
Waterston RH, 2002, NATURE, V420, P520, DOI 10.1038/nature01262
Waterston RH, 2002, P NATL ACAD SCI USA, V99, P3712, DOI 10.1073/pnas.042692499
Waterston Robert, 2011, COMMUNICATION
Waterston Robert, 2017, E COMMUNICATION
Waterston Robert, 2018, COMMUNICATION
Waterston Robert, 2017, COMMUNICATION
Waterston Robert, 1997, E COMMUNICATION, P7108
Watson James D, 2017, DNA STORY GENETIC RE
WATSON JD, 1990, SCIENCE, V248, P44, DOI 10.1126/science.2181665
Weber JL, 1997, GENOME RES, V7, P401, DOI 10.1101/gr.7.5.401
WEBER JL, 1989, AM J HUM GENET, V44, P388
Weinberg A., 1967, REFLECTIONS BIG SCI
Weinberg Robert A, 1993, RESPONSIBLE SCI ENSU, VII, P66
WEISSENBACH J, 1992, NATURE, V359, P794, DOI 10.1038/359794a0
Weissenbach Jean, 2012, COMMUNICATION
Weissenbach Jean, 2017, E COMMUNICATION
Weller Andreas, 2013, COMMUNICATION   1107
Wiechers IR, 2013, GENOME MED, V5, DOI 10.1186/gm487
Williams HL, 2013, J POLIT ECON, V121, P1, DOI 10.1086/669706
Williamson AR, 1999, DRUG DISCOV TODAY, V4, P115, DOI 10.1016/S1359-6446(99)01303-3
Wilson RK, 1999, TRENDS GENET, V15, P51, DOI 10.1016/S0168-9525(98)01666-7
WOOD WB, 1988, NEMATODE CAENORHABDI
WOOSTER R, 1995, TRENDS GENET, V11, P3, DOI 10.1016/S0168-9525(00)88974-X
WOOSTER R, 1994, SCIENCE, V265, P2088, DOI 10.1126/science.8091231
WOOSTER R, 1995, NATURE, V378, P789, DOI 10.1038/378789a0
Yi D, 2008, J HIST BIOL, V41, P589, DOI 10.1007/s10739-008-9149-9
Yi Doogab, 2015, RECOMBINANT U GENETI
Young ND, 2011, NATURE, V480, P520, DOI 10.1038/nature10625
Zarate OA, 2016, HASTINGS CENT REP, V46, P36, DOI 10.1002/hast.523
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PA VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS
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TI Rethinking Data Sharing at the Dawn of a Health Data Economy: A
   Viewpoint
SO JOURNAL OF MEDICAL INTERNET RESEARCH
LA English
DT Article
DE economics; hospital; machine learning; models; economic; precision
   medicine
AB A health data economy has begun to form, but its rise has been tempered by
the profound lack of sharing of both data and data products such as models,
intermediate results, and annotated training corpora, and this severely limits
the potential for triggering economic cluster effects. Economic cluster effects
represent a means to elicit benefit from economies of scale from internal data
innovations and are beneficial because they may mitigate challenges from
external sources. Within institutions, data product sharing is needed to spark
data entrepreneurship and data innovation, and cross-institutional sharing is
also critical, especially for rare conditions.
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CR [Anonymous], 2018, ECONOMIST
   Deng J, 2009, 2009 PROC IEEE CVF C, P807
   Hawksworth John, 2017, LONG VIEW WILL GLOBA
   Hodson R, 2016, NATURE, V537, pS49, DOI 10.1038/537S49a
   Johnson AEW, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.35
   Lotterman E., 2018, E LOTTERMAN INFORM H
   Olsen LA, 2007, LEARNING HEALTHCARE
   Tang C., 2016, DATA IND BUSINESS EC, P216
   The European Commission, 2017, BUILD EUR DAT EC
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   Hanboonkunupakarn, Borimas
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   Jittamala, Podjanee
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   Day, Nicholas P. J.
   Parker, Michael
   Bull, Susan
TI Challenges arising when seeking broad consent for health research data
   sharing: a qualitative study of perspectives in Thailand
SO BMC MEDICAL ETHICS
LA English
DT Article
DE Data sharing; Secondary use; Broad consent; Thailand; Research ethics;
   Research
ID PLASMODIUM-FALCIPARUM MALARIA; COMMUNITY ADVISORY BOARDS;
   INFORMED-CONSENT; RESEARCH STAKEHOLDERS; DYNAMIC CONSENT;
   CLINICAL-TRIALS; VIEWS; PARTICIPANTS; EXPERIENCES; ENGAGEMENT
AB BackgroundResearch funders, regulatory agencies, and journals are
increasingly expecting that individual-level data from health research will be
shared. Broad consent to such sharing is considered appropriate, feasible and
acceptable in low- and middle-income settings, but to date limited empirical
research has been conducted to inform the design of such processes. We examined
stakeholder perspectives about how best to seek broad consent to sharing data
from the Mahidol Oxford Tropical Medicine Research Unit, which implemented a
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data sharing policy and broad consent to data sharing in January 2016.MethodsBetween February and August 2017 qualitative data were collected at two sites, Bangkok and the Thai-Myanmar border town of Mae Sot. We conducted eighteen semi-structured interviews. We also conducted four focus group discussions with a total of nineteen people. Descriptive and thematic coding informed analysis of aspects of data sharing that are considered most important to inform participants about, and the best ways to explain complex and abstract topics relating to data sharing.ResultsThe findings demonstrated that clinical trial participants prioritise information about the potential benefits and harms of data sharing. Stakeholders made multiple suggestions for clarifying information provided about data sharing on such topics. There was significant variation amongst stakeholders' perspectives about how much information should be provided about data sharing, and it was clear that effective information provision should be responsive to the study, the study population, the individual research participant and the research context.ConclusionsEffectively communicating about data sharing with research participants is challenging in practice, highlighting the importance of robust and effective data sharing governance in this context. Broad consent should incorporate effective and efficient explanations of data sharing to promote informed decision-making, without impeding research participants' understandings of key aspects of the research from which data will be shared. Further work is required to refine both the development of core information about data sharing to be provided to all research participants, and appropriate solutions for context specific-challenges arising when explaining data sharing.

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CR Afolabi MO, 2014, TROP MED INT HEALTH, V19, P625, DOI 10.1111/tmi.12288
Afolabi Muhammed Olanrewaju, 2014, J Clin Res Bioeth, V5, P178
[Anonymous], 2017, POL DAT SOFTW MAT MA
[Anonymous], 2016, MORU TROP NETW DAT S

Ashley EA, 2014, NEW ENGL J MED, V371, P411, DOI 10.1056/NEJMoa1314981
Bill & Melinda Gates Foundation, OP ACC POL 2015
Budin-Ljosne I, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-016-0162-9
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Bull S, 2012, J EMPIR RES HUM RES, V7, P37, DOI 10.1525/jer.2012.7.1.37
Castelnuovo Barbara, 2014, J Clin Res Bioeth, V5, P165
Cheah Phaik Yeong, 2017, Asian Bioeth Rev, V9, P393, DOI 10.1007/s41649-017-0029-5
Cheah PY, 2017, LANCET, V390, P1642, DOI 10.1016/S0140-6736(17)31951-7
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Council for International Organisations of Medical Sciences, INT ETH GUID HLTH RE
Das D, 2014, MALARIA J, V13, DOI 10.1186/1475-2875-13-217
de Vries J, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-62
Denny SG, 2015, J EMPIR RES HUM RES, V10, P290, DOI 10.1177/1556264615592386
European Medicines Agency, 2014, EMA2408102013
Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Hofmann B, 2009, J MED ETHICS, V35, P125, DOI 10.1136/jme.2008.024851
Jao I, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135545
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Lwin KM, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-12
Lwin KM, 2012, ANTIMICROB AGENTS CH, V56, P1571, DOI 10.1128/AAC.05877-11
Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
Tam NT, 2015, B WORLD HEALTH ORGAN, V93, P186, DOI 10.2471/BLT.14.141390
Ohmann C, 2017, BMJ OPEN, V7, DOI 10.1136/bmjopen-2017-018647
Onyamboko MA, 2014, ANTIMICROB AGENTS CH, V58, P5528, DOI 10.1128/AAC.02682-14
Participants in the Community Engagement and Consent Workshop Kilifi Kenya March 2011, 2013, J Empir Res Hum Res Ethics, V8, P1, DOI 10.1525/jer.2013.8.4.1
Pisani E, 2016, BMJ-BRIT MED J, V355, DOI 10.1136/bmj.i5295
Ploug T, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2146
Pratt B, 2015, DEV WORLD BIOETH, V15, P18, DOI 10.1111/dewb.12031
Ritchie J., 2002, QUALITATIVE RES COMP
Sheehan M, 2011, PUBLIC HEALTH ETH-UK, V4, P226, DOI 10.1093/phe/phr020
Steinsbekk KS, 2013, EUR J HUM GENET, V21, P897, DOI 10.1038/ejhg.2012.282
Synnot A, 2014, COCHRANE DB SYST REV, V5
Taichman DB, 2017, B WORLD HEALTH ORGAN, V95, P482, DOI 10.2471/BLT.17.196733
Tindana P, 2016, ANNU REV GENOM HUM G, V22, P22
Tindana P, 2012, BMC MED ETHICS, V13, DOI 10.1186/1472-6939-13-15
Traore K, 2015, BMC MED ETHICS, V16, DOI 10.1186/s12910-015-0035-7
NR 42
TC 1
Z9 1
U1 0
U2 3
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1472-6939
J9 BMC MED ETHICS
JI BMC Med. Ethics
PD NOV 7
PY 2018
VL 19
AR 86
DI 10.1186/s12910-018-0326-x

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PG 11
WC Ethics; Medical Ethics; Social Sciences, Biomedical
SC Social Sciences - Other Topics; Medical Ethics; Biomedical Social
   Sciences
GA GZ8IT
UT WOS:000449734000001
PM 30404642
OA DOAJ Gold, Green Published
DA 2019-08-06
ER

PT J
AU Selby, K
   Michel, M
   Gildengorin, G
   Karliner, L
   Pramanik, R
   Fontil, V
   Potter, MB
AF Selby, Kevin
   Michel, Martha
   Gildengorin, Ginny
   Karliner, Leah
   Pramanik, Rajiv
   Fontil, Valy
   Potter, Michael B.
TI Disparities in Hypertension Control Across and Within Three Health
   Systems Participating in a Data-Sharing Collaborative
SO JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE
LA English
DT Article; Proceedings Paper
CT Annual Meeting of the North-American-Primary-Care-Research-Group
CY NOV 17-21, 2017
CL Montreal, CANADA
SP N Amer Primary Care Res Grp
DE Blood Pressure; Hypertension; Multivariate Analysis; Primary Health
   Care; Retrospective Studies Quality Improvement
ID NUTRITION EXAMINATION SURVEY; BLOOD-PRESSURE CONTROL; NATIONAL-HEALTH;
   ADULTS; DISEASE
AB Introduction: We aimed to standardize data collection from 3 health systems
(HS1, HS2, HS3) participating in the San Francisco Bay Collaborative Research
Network, and compare rates and predictors of uncontrolled blood pressure among
hypertensive adults to identify opportunities for regional collaboration in
quality improvement.
   Methods: Retrospective cohort study using deidentified electronic health
record data from all primary care patients with at least 1 visit in a 2-year
period, using standard data definitions in a common data repository. Primary
outcome was uncontrolled blood pressure at the most recent primary care visit.
   Results: Of 169,793 adults aged 18 to 85 years, 53,133 (31.3%) had a
diagnosis of hypertension. Of these, 18,751 (35%) had uncontrolled blood
pressure at their last visit, with the proportion varying by system (29%, HS1;
31%, HS2; and 44%, HS3) and by clinical site within each system. In multivariate
analyses, differences between health systems persisted, with HS2 and HS3
patients having a 1.15 times (95% CI, 1.11 to 1.19) and 1.46 times (95% CI, 1.42
to 1.50) greater relative risk of uncontrolled blood pressure compared with HS1.
Across health systems, hypertensive patients were more likely to have
uncontrolled blood pressure if they were uninsured, African Americans, current
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smokers, obese, or had fewer than 2 primary care visits during the 2-year measurement period.

Conclusions: After controlling for standard individual predictors of hypertension control, significant and substantial differences in hypertension control persisted between health systems, possibly due to local quality improvement programs among other factors. There may be opportunities to share best practices and address common disparities across health systems.

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FX This research was supported by the National Center for Advancing Translational Sciences, National Institutes of Health (UL1 TR001872). Dr. Selby was supported by the Swiss Cancer Research Foundation (BIL KFS-3720-08-2015).

CR AAFP, AAFP DEC NOT END AHA
[ACC/AHA/AAPA/ABC/ACPM/AGS/APhA/ASH/ASPC/NMA/PCNA 12], 2018, J AM COLL CARDIOL
Cipparone CW, 2015, J AM BOARD FAM MED, V28, P678, DOI 10.3122/jabfm.2015.05.140136
Cohen JB, 2018, ANN INTERN MED, V168, P287, DOI 10.7326/M17-3103
Egan BM, 2014, HYPERTENSION, V64, P997, DOI 10.1161/HYPERTENSIONAHA.114.04276
Gliklich RE, 2014, PATIENT REGISTRIES
Gu QP, 2012, CIRCULATION, V126, P2105, DOI 10.1161/CIRCULATIONAHA.112.096156
Hyman DJ, 2001, NEW ENGL J MED, V345, P479, DOI 10.1056/NEJMoa010273
Jaffe MG, 2013, JAMA-J AM MED ASSOC, V310, P699, DOI 10.1001/jama.2013.108769
James PA, 2014, JAMA-J AM MED ASSOC, V311, P507, DOI [10.1001/jama.2013.284427, DOI 10.1001/JAMA.2013.284427]
Knol MJ, 2012, CAN MED ASSOC J, V184, P895, DOI 10.1503/cmaj.101715
Mozaffarian D, 2016, CIRCULATION, V133, pE38, DOI 10.1161/CIR.0000000000000350
Qaseem A, 2017, ANN INTERN MED, V166, P430, DOI 10.7326/M16-1785

NR 13
TC 1
Z9 1
U1 1
U2 3
PU AMER BOARD FAMILY MEDICINE
PI LEXINGTON
PA 2228 YOUNG DR, LEXINGTON, KY 40505 USA
SN 1557-2625
EI 1558-7118
J9 J AM BOARD FAM MED
JI J. Am. Board Fam. Med.
PD NOV-DEC
PY 2018

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VL 31
IS 6
BP 897
EP 904
DI 10.3122/jabfm.2018.06.180166
PG 8
WC Primary Health Care; Medicine, General & Internal
SC General & Internal Medicine
GA HA0FK
UT WOS:000449883000008
PM 30413545
OA Green Accepted, Bronze
DA 2019-08-06
ER

PT J
AU Savatt, JM
   Azzariti, DR
   Faucett, WA
   Harrison, S
   Hart, J
   Kattman, B
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   Ledbetter, DH
   Miller, VR
   Palen, E
   Rehm, HL
   Rhode, J
   Turner, S
   Vidal, JA
   Wain, KE
   Riggs, ER
   Martin, CL
AF Savatt, Juliann M.
   Azzariti, Danielle R.
   Faucett, W. Andrew
   Harrison, Steven
   Hart, Jennifer
   Kattman, Brandi
   Landrum, Melissa J.
   Ledbetter, David H.
   Miller, Vanessa Rangel
   Palen, Emily
   Rehm, Heidi L.
   Rhode, Jud
   Turner, Stefanie
   Vidal, Jo Anne
   Wain, Karen E.
   Riggs, Erin Rooney
   Martin, Christa Lese
TI ClinGen's GenomeConnect registry enables patient-centered data sharing
SO HUMAN MUTATION
LA English
DT Article
DE ClinGen; ClinVar; genomic data sharing; matchmaking; patient registry;
   variant interpretation
ID HUMAN PHENOTYPE ONTOLOGY; CLINVAR PUBLIC ARCHIVE; VARIANT
   INTERPRETATIONS; CLINICAL LABORATORIES; MEDICAL GENETICS;
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AMERICAN-COLLEGE; STANDARDS; GENOMICS; CARE

AB GenomeConnect, the NIH-funded Clinical Genome Resource (ClinGen) patient registry, engages patients in data sharing to support the goal of creating a genomic knowledge base to inform clinical care and research. Participant self-reported health information and genomic variants from genetic testing reports are curated and shared with public databases, such as ClinVar. There are four primary benefits of GenomeConnect: (1) sharing novel genomic data-47.9% of variants were new to ClinVar, highlighting patients as a genomic data source; (2) contributing additional phenotypic information-of the 52.1% of variants already in ClinVar, GenomeConnect provided enhanced case-level data; (3) providing a way for patients to receive variant classification updates if the reporting laboratory submits to ClinVar-97.3% of responding participants opted to receive such information and 13 updates have been identified; and (4) supporting connections with others, including other participants, clinicians, and researchers to enable the exchange of information and support-60.4% of participants have opted to partake in participant matching. Moving forward, ClinGen plans to increase patient-centric data sharing by partnering with other existing patient groups. By engaging patients, more information is contributed to the public knowledge base, benefiting both patients and the genomics community.

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FU National Human Genome Research Institute [U41HG006834]; U.S. National Library of Medicine
FX National Human Genome Research Institute, Grant/Award Number: U41HG006834; U.S. National Library of Medicine; Intramural Research Funding

CR American Medical Association, 2013, GEN AN VAR ID POL D
Barsh GS, 2015, PLOS GENET, V11, DOI 10.1371/journal.pgen.1005716
Harrison SM, 2017, GENET MED, V19, P1096, DOI 10.1038/gim.2017.14
Kirkpatrick BE, 2015, HUM MUTAT, V36, P974, DOI 10.1002/humu.22838
Kohler S, 2017, NUCLEIC ACIDS RES, V45, pD865, DOI 10.1093/nar/gkw1039
Landrum MJ, 2018, NUCLEIC ACIDS RES, V46, pD1062, DOI 10.1093/nar/gkx1153
Landrum MJ, 2016, NUCLEIC ACIDS RES, V44, pD862, DOI 10.1093/nar/gkv1222
Landrum MJ, 2014, NUCLEIC ACIDS RES, V42, pD980, DOI 10.1093/nar/gkt1113
National Institutes of Health, 2014, FR

```
   National Society of Genetic Counselors, 2015, CLIN DAT SHAR
   Philippakis AA, 2015, HUM MUTAT, V36, P915, DOI 10.1002/humu.22858
   Rehm HL, 2017, GENET MED, V19, P1092, DOI 10.1038/gim.2017.90
   Rehm HL, 2015, NEW ENGL J MED, V372, P2235, DOI 10.1056/NEJMsr1406261
   Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
   Riggs ER, 2012, HUM MUTAT, V33, P787, DOI 10.1002/humu.22052
   Robinson PN, 2010, CLIN GENET, V77, P525, DOI 10.1111/j.1399-
0004.2010.01436.x
   Sobreira Nara, 2015, Hum Mutat, V36, P928, DOI 10.1002/humu.22844
   Sobreira Nara L M, 2017, Curr Protoc Hum Genet, V95, DOI 10.1002/cphg.50
   Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
   Zurynski Y, 2008, ARCH DIS CHILD, V93, P1071, DOI 10.1136/adc.2007.134940
NR 20
TC 1
Z9 1
U1 0
U2 1
PU WILEY
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1059-7794
EI 1098-1004
J9 HUM MUTAT
JI Hum. Mutat.
PD NOV
PY 2018
VL 39
IS 11
SI SI
BP 1668
EP 1676
DI 10.1002/humu.23633
PG 9
WC Genetics & Heredity
SC Genetics & Heredity
GA GW7HX
UT WOS:000447138900020
PM 30311371
DA 2019-08-06
ER

PT J
AU Grant, AR
   Hemphill, SE
   Vincent, LM
   Rehm, HL
AF Grant, Andrew R.
   Hemphill, Sarah E.
   Vincent, Lisa M.
   Rehm, Heidi L.
TI Reclassification of the BRAF p.Ile208Val variant by case-level data
   sharing
SO COLD SPRING HARBOR MOLECULAR CASE STUDIES
LA English
DT Article
ID NOONAN-SYNDROME; MUTATIONS; SPECTRUM; MELANOMA
AB The ClinVar database is a useful tool for patients and physicians to view
variant interpretations submitted by clinical and nonclinical labs. However,
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variants of uncertain significance (VUS) in ClinVar can pose a significant burden on patients. If possible, it is important to resolve discrepancies and uncertainties surrounding interpreted variants. Here we highlight a case of a family who received a report of a variant (c.622A>G, p.Ile208Val) in BRAF following prenatal RASopathy testing. The variant had been previously classified by our laboratory as a VUS, so the mother contacted our laboratory via ClinVar for further information, which prompted reevaluation of the variant. Multiple sources of case-level data as well as the presence of the variant in the general population yielded sufficient evidence to reclassify the variant as likely benign. This reclassification alleviated significant concern for the family, and the child was born healthy with no clinical manifestations of Noonan syndrome or a RASopathy.

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FU National Human Genome Research Institute (NHGRI); Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) [U41HG006834]
FX This study was supported in part by the National Human Genome Research Institute (NHGRI) in conjunction with funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) under award U41HG006834. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

CR Azzariti DR, 2017, COLD SPRING HARB MOL, V4
Duzkale H, 2013, CLIN GENET, V84, P453, DOI 10.1111/cge.12257
Garber KB, 2016, AM J HUM GENET, V99, P1140, DOI 10.1016/j.ajhg.2016.09.015
Gelb BD, 2018, GENET MED, V20, P1334, DOI 10.1038/gim.2018.3
Halaban R, 2016, J INVEST DERMATOL, V136, P1755, DOI 10.1016/j.jid.2016.05.095
Holderfield M, 2014, NAT REV CANCER, V14, P455, DOI 10.1038/nrc3760
Ikediobi ON, 2006, MOL CANCER THER, V5, P2606, DOI 10.1158/1535-7163.MCT-06-0433
Lee BH, 2011, J PEDIATR-US, V159, P1029, DOI 10.1016/j.jpeds.2011.05.024
Nisbet DL, 1999, PRENATAL DIAG, V19, P642, DOI 10.1002/(SICI)1097-0223(199907)19:7<642::AID-PD610>3.0.CO;2-1
Razzaque MA, 2007, NAT GENET, V39, P1013, DOI 10.1038/ng2078
Richards S, 2015, GENET MED, V17, P405, DOI 10.1038/gim.2015.30
Sarkozy A, 2009, HUM MUTAT, V30, P695, DOI 10.1002/humu.20955
van Trier DC, 2016, OPHTHALMOLOGY, V123, P2137, DOI 10.1016/j.ophtha.2016.06.061
Zenker M, 2004, J PEDIATR-US, V144, P368, DOI 10.1016/j.jpeds.2003.11.032

NR 14
TC 1
Z9 1
U1 0
U2 0
PU COLD SPRING HARBOR LAB PRESS, PUBLICATIONS DEPT
PI COLD SPRING HARBOR
PA 1 BUNGTOWN RD, COLD SPRING HARBOR, NY 11724 USA
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J9 CSH MOL CASE STUD
JI Cold Spring Harb. Mol. Case Stud.
PD OCT
PY 2018
VL 4
IS 5
AR a002675
DI 10.1101/mcs.a002675
PG 4
WC Medicine, Research & Experimental
SC Research & Experimental Medicine
GA HB3NJ
UT WOS:000450957900001
PM 29945942
OA Other Gold, Green Published
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ER

PT J
AU Alshagathrh, F
   Khan, SA
   Alothmany, N
   Al-Rawashdeh, N
   Househ, M
AF Alshagathrh, Fahad
   Khan, Samina A.
   Alothmany, Nazeeh
   Al-Rawashdeh, Nedal
   Househ, Mowafa
TI Building a cloud-based data sharing model for the Saudi national
   registry for implantable medical devices: Results of a readiness
   assessment
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Implantable devices; Medical registries; Readiness assessment; Data
   sharing; Saudi Food and Drug Authority (SFDA); Saudi Arabia
ID AMERICAN-HEART-ASSOCIATION; DISEASE; STENTS; UPDATE
AB Background: Implantable medical device registries are used as a medium to
conduct post-marketing surveillance. Little information is available on the
development and implementation of implantable biomedical device registries in
general and specifically in Saudi Arabia and the Middle East.
   Objectives: This study presents the experiences of building an implantable
medical device registry in the Kingdom of Saudi Arabia. The work specifically
addresses the early experiences of the Saudi Food and Drug Authority in the
planning and development of a data sharing model for the implementation of a
medical device registry at different hospital sites within the country.
   Methods: A two-year case study in which 60 health professionals from 5
hospitals in Saudi Arabia participated in a readiness assessment survey. The
readiness assessment examined system-level capacity, hospital workflow and
operations, clinical staff-level engagement, and technological assessment as
they relate to the implementation of the Implantable Medical Device Registry
(IMDR). Both subjective and objective data were collected as part of the
readiness assessment survey at each hospital site. Data was collected from
participants either individually or as part of a group at each hospital site.
Using Microsoft Excel, Microsoft Word, flip charts, and back-and-forth
discussion, the data was descriptively summarized and synthesized to provide an
overview of hospital readiness for IMDR implementation.
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Results: Results show that there are large differences among Saudi hospitals in terms of their readiness for IMDR implementation due to a variety of factors relating to differences in hospital-wide organizational systems, clinical practice, technological infrastructure, and data sharing capabilities. Each of the hospitals surveyed in this study had differences in how clinical biomedical implantation policies and procedures were utilized. Manual entry into the cloud-based IMDR was recommended as the most optimal data sharing model that would mitigate the differences between hospital readiness for IMDR implementation.

Conclusion: Registries play a major role in monitoring the effectiveness of implantable biomedical devices. National standardized policies, enforced regulations, and information technology infrastructure are needed to achieve this goal. Furthermore, due to differences in hospital readiness, building a cloud-based registry system through manual data entry into the IMDR was found to be the most appropriate data sharing model that can be implemented at the national level.

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CR Agency for Healthcare Research and Quality (US), 2014, REG EV PAT OUTC US I
Al-Surimi K, 2015, STUD HEALTH TECHNOL, V213, P23, DOI 10.3233/978-1-61499-538-8-23
Alings M, 2009, EUROPACE, V11, P370, DOI 10.1093/europace/eup013
Aloufi B, 2017, STUD HEALTH TECHNOL, V238, P173, DOI 10.3233/978-1-61499-781-8-173
[Anonymous], 2018, S AFR MED
Athappan G, 2010, J CARDIOVASC MED, V11, P103, DOI 10.2459/JCM.0b013e32832ffc85
Benjamin EJ, 2017, CIRCULATION, V135, pE146, DOI 10.1161/CIR.0000000000000485
Carter J., 2008, ELECT HLTH RECORDS
Daemen J, 2007, LANCET, V369, P667, DOI 10.1016/S0140-6736(07)60314-6
E.C.D.G.f.H.a. CONSUMERS, 2012, GUID MED DEV POST MA
Ginebra MP, 2006, J CONTROL RELEASE, V113, P102, DOI 10.1016/j.jconrel.2006.04.007
Howard JJ, 2014, MED DEVICES-EVID RES, V7, P385, DOI 10.2147/MDER.S73079
Ishii L, 2016, FACIAL PLAST SURG, V32, P636, DOI 10.1055/s-0036-1596047
Khan W., 2014, FOCAL CONTROLLED DRU, P33, DOI DOI 10.1007/978-1-4614-9434-8_2
Leavy R.E., 2014, REGISTRIES EVALUATIN
McNeil J.J., 2012, PHARM MED, V24, P281, DOI 10.1007/bf03256826
Polisena J, 2015, SYST REV, V4, DOI 10.1186/s13643-015-0028-0
Roger VL, 2012, CIRCULATION, V125, pE2, DOI 10.1161/CIR.0b013e31823ac046
Sedrakyan A, 2010, MED CARE, V48, pS121, DOI 10.1097/MLR.0b013e3181d991c4
Stefanini GG, 2013, NEW ENGL J MED, V368, P254, DOI 10.1056/NEJMra1210816
Wizemann T., 2011, MEASURING POSTMARKET
Wizemann T, 2010, PUBLIC HLTH EFFECTIV

Zainal Z, 2007, J KEMANUSIAAN, V9, P1, DOI [DOI 10.1177/1522302004003007, 10.1177/ 1522302004003007]
Zhou D., 2010, GREENBAUM, DOI [10.1007/978-0-387-98120-8I, DOI 10.1007/978-0-387-98120-8I]
NR 24
TC 1
Z9 1
U1 2
U2 5
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
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EI 1872-8243
J9 INT J MED INFORM
JI Int. J. Med. Inform.
PD OCT
PY 2018
VL 118
BP 113
EP 119
DI 10.1016/j.ijmedinf.2018.08.005
PG 7
WC Computer Science, Information Systems; Health Care Sciences & Services;
Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA GR4UL
UT WOS:000442614500014
PM 30153916
DA 2019-08-06
ER

PT J
AU Holmgren, AJ
Ford, EW
AF Holmgren, A. Jay
Ford, Eric W.
TI Assessing the impact of health system organizational structure on
hospital electronic data sharing
SO JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION
LA English
DT Article
DE electronic health records; hospitals; health information exchange
ID INFORMATION EXCHANGE; US HOSPITALS; INTEROPERABILITY; CONSOLIDATION;
ENGAGEMENT; NETWORKS; TAXONOMY; ADOPTION

AB Objective: Horizontal consolidation in the hospital industry has gained momentum in the United States despite concerns over rising costs and lower quality. Hospital systems frequently point to potential gains in interoperability and electronic exchange of patient information as consolidation benefits. We sought to assess whether hospitals in different health system structures varied in their interoperable data sharing.

Materials and methods: We created a cross-sectional national hospital sample from the 2014 AHA Annual Survey and 2015 IT Supplement. We combined the existing taxonomy of health system organizational forms and the ONC's functionality-based, technology-agnostic definition of interoperability. We used logistic regression models to assess the relationship between health systems' organizational forms and interoperability engagement, controlling for hospital characteristics.

Results: We found that interoperability engagement varied greatly across hospitals in different health system structures, with facilities in more centralized health systems more likely to be interoperable. Hospitals in one system type, featuring centralized insurance product development but diverse service offerings across member organizations, had significantly higher odds of being engaged in interoperable data sharing in our multivariate regression results.

Discussion: The heterogeneity in health system interoperability engagement indicates that incentives to share data vary greatly across organizational strategies and structures. Our results suggest that horizontal consolidation in the hospital industry may not bring significant gains in interoperability progress unless that consolidation takes a specific business alignment form.

Conclusion: Policymakers should be wary of claims that horizontal consolidation will lead to interoperability gains. Future research should explore the specific mechanisms that lead to greater interoperability in certain health system organizational structures.

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CR Adler-Milstein J, 2008, HEALTH AFFAIR, V27, pW60, DOI 10.1377/hlthaff.27.1.w60
Adler-Milstein J, 2017, J AM MED INFORM ASSN, V24, P1142, DOI 10.1093/jamia/ocx080
Adler-Milstein J, 2011, AM J MANAG CARE, V17, P761
Association AH, 2014, AHA ANN SURV DAT
Avdic D, 2016, J HEALTH ECON, V48, P44, DOI 10.1016/j.jhealeco.2016.02.002
Bazzoli GJ, 1999, HEALTH SERV RES, V33, P1683
Charles D, 2014, INTEROPERABILITY US
Cooper Z, 2011, ECON J, V121, pF228, DOI 10.1111/j.1468-0297.2011.02449.x
Dafny L, 2016, NATL BUREAU EC RES W, V22106, DOI [10.3386/w22106, DOI 10.3386/W22106]
Dafny L, 2014, NEW ENGL J MED, V370, P198, DOI 10.1056/NEJMp1313948
Delbanco SF, 2011, PROMISING PAYMENT RE
Dubbs NL, 2004, HEALTH SERV RES, V39, P207, DOI 10.1111/j.1475-6773.2004.00222.x
Everson J, 2014, J AM MED INFORM ASSN, V21, pE257, DOI 10.1136/amiajnl-2013-002449
Holmgren AJ, 2017, HEALTH AFFAIR, V36, P1820, DOI 10.1377/hlthaff.2017.0546
Holmgren AJ, 2017, J HOSP MED, V12, P193, DOI 10.12788/jhm.2704
Holmgren AJ, 2016, AM J MANAG CARE, V22, pE395
Jaffe S, 2015, LANCET, V385, P2137, DOI 10.1016/S0140-6736(15)61008-X
Jha AK, 2009, NEW ENGL J MED, V360, P1628, DOI 10.1056/NEJMsa0900592
Noether Monica, 2017, HOSP MERGER BENEFITS
Opoku-Agyeman W, 2016, HEALTH CARE MANAGE R, V41, P325, DOI 10.1097/HMR.0000000000000081
Rudin RS, 2014, ANN INTERN MED, V161, P803, DOI 10.7326/M14-0877
Thorn SA, 2014, ANN EMERG MED, V63, P329, DOI 10.1016/j.annemergmed.2013.09.024
Vest JR, 2016, MILBANK Q, V94, P77, DOI 10.1111/1468-0009.12180
Walker Jan, 2005, Health Aff (Millwood), VSuppl Web Exclusives, pW5

NR 24
TC 1
Z9 1
U1 3

```
U2 6
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1067-5027
EI 1527-974X
J9 J AM MED INFORM ASSN
JI J. Am. Med. Inf. Assoc.
PD SEP
PY 2018
VL 25
IS 9
BP 1147
EP 1152
DI 10.1093/jamia/ocy084
PG 6
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services;
   Information Science & Library Science; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Information Science &
   Library Science; Medical Informatics
GA GS5TO
UT WOS:000443733900001
PM 29982687
DA 2019-08-06
ER

PT J
AU Chen, YX
   Song, LQ
AF Chen, Yongxi
   Song, Lingqiao
TI China: concurring regulation of cross-border genomic data sharing for
   statist control and individual protection
SO HUMAN GENETICS
LA English
DT Review
AB This paper reviews the major legal instruments and self-regulations that bear
heavily on the cross-border sharing of genomic data in China. It first maps out
three overlapping frameworks on genomic data and analyzes their underpinning
policy goals. Subsequent sections examine the regulatory approaches with respect
to five aspects of responsible use and sharing of genomic data, namely, consent,
privacy, security, compatible processing, and oversight. It argues that
substantial centralised control exerted by the state is, and would probably
remain, the dominant feature of genomic data governance in China, though
concerns of individual protection are gaining momentum. Rather than revolving
around a simplistic antinomy between privacy preservation and open science, the
regulatory landscape is mainly shaped by the tension between government desires
for national security, state competitiveness, and public health benefits.
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CR [Anonymous], 2012, DRAFT REG HUM GEN RE
   [Anonymous], 2017, NOT STREAML APPR PRO
   [Anonymous], 2003, M ORG WELLC TRUST 14
   [Anonymous], 2015, ACT OUTL PROM BIG DA
```

[Anonymous], 2018, PROTEIN CELL, DOI DOI 10.1007/S13238-018-05392
[Anonymous], 1998, INT MEAS HUM GEN RES
[Anonymous], 2018, CHINA SCI NEWS 0619
[Anonymous], 2017, GEN PRINC CIV LAW
[Anonymous], 2018, APPR RES
[Anonymous], 2015, SERV GUID ADM LIC CO
[Anonymous], 2014, DAT ACC SAMPL PRES P
[Anonymous], 2017, SEC RUL SHENZH NAT G
[Anonymous], 2017, INF SEC TECHN GUID S
[Anonymous], 1998, MED PRACT LAW
[Anonymous], 2018, GUANGMING DAILY
[Anonymous], 2016, MEAS ETH REV BIOM RE
[Anonymous], 2018, LEGALTECH NEWS
[Anonymous], 2010, BAS NORMS EL MED REC
[Anonymous], 2009, TORT LIAB LAW
[Anonymous], 2016, PRECISION MED CHINA
[Anonymous], 2017, SEC ASS MEAS ECP PER
[Anonymous], 2003, ADM LIC LAW
[Anonymous], 2017, MOST OFFICIALS ANALY
[Anonymous], 2016, DRAFT REG HUM UNPUB
[Anonymous], 2014, MEAS POP INF TRIAL I
[Anonymous], 2018, SCI DAT MEAS
[Anonymous], 2018, DRAFT ETH GUID MAN M
[Anonymous], 2015, BIOBANKING 21 CENTUR
[Anonymous], 2016, EXPL DRAFT REG UNPUB
[Anonymous], 2017, REG SEC CRIT INF INF
[Anonymous], GUID OP PROM REG APP
[Anonymous], 2017, INF TECHN SEC PERS I
[Anonymous], 2016, CYB LAW
[Anonymous], 2017, PROV SUPR PEOPL COUR
[Anonymous], 2018, DEC REV 2 ADM LIC
[Anonymous], 2013, PROV MED REC ADM HLT
Chen HD, 2015, J LAW MED ETHICS, V43, P726, DOI 10.1111/jlme.12315
Chen Y, 2015, EUR DATA PROT LAW RE, V1, P265, DOI [10.21552/EDPL/2015/4/5, DOI 10.21552/EDPL/2015/4/5]
Global Alliance for Genomics & Health, 2014, FRAM RESP SHAR GEN H
Human Genome Organization (HUGO), 1996, PRINC AGR 1 INT STRA
Joly Y, 2017, TRENDS GENET, V33, P299, DOI 10.1016/j.tig.2017.02.002
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Lawler A, 2002, SCIENCE, V296, P28
Livingston S, 2017, PRIV LAWS BUS INT RE, V147, P9
Parasol M, 2018, COMPUT LAW SECUR REV, V34, P67, DOI 10.1016/j.clsr.2017.05.022
Regulatory and Ethics Working Group Global Alliance for Genomics & Health, 2014, Hugo J, V8, P1, DOI 10.1186/1877-6566-8-1
Wang H, 2011, PROTECTING PRIVACY IN CHINA: A RESEARCH ON CHINAS PRIVACY STANDARDS AND THE POSSIBILITY OF ESTABLISHING THE RIGHT TO PRIVACY AND THE INFORMATION PRIVACY PROTECTION LEGISLATION IN MODERN CHINA, P1, DOI 10.1007/978-3-642-21750-0
Wang ZC, 2014, BMC MED ETHICS, V15, DOI 10.1186/1472-6939-15-79
Yu X, 2014, BIOTECHNOL LAW REP, V33, P155, DOI 10.1089/blr.2014.9979
Zhang L, 2017, J SICHUAN NORMAL U, V44, P29
NR 51
TC 1
Z9 1
U1 1
U2 5

PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
EI 1432-1203
J9 HUM GENET
JI Hum. Genet.
PD AUG
PY 2018
VL 137
IS 8
SI SI
BP 605
EP 615
DI 10.1007/s00439-018-1903-2
PG 11
WC Genetics & Heredity
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OA Other Gold, Green Published
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PT J
AU Townend, D
AF Townend, David
TI Conclusion: harmonisation in genomic and health data sharing for
   research: an impossible dream?
SO HUMAN GENETICS
LA English
DT Review
ID PRIVACY
AB There are clear benefits from genomics and health data sharing in research
and in therapy for individuals across societies. At the same time, citizens have
different expectations and fears about that data sharing. International
legislation in relation with research ethics and practice and, particularly,
data protection create a particular environment that, as is seen in the articles
in part two of this special issue, are crying out for harmonisation both at a
procedural but at fundamental conceptual levels. The law of data sharing is
pulling in different directions. This paper poses the question, harmonisation,
an impossible dream?' and the answer is a qualified no'. The paper reflects on
what can be seen in the papers in part two of the special issue. It then
identifies three major areas of conceptual uncertainty in the new EU General
Data Protection Regulation (not because it has superiority over other
jurisdictions, but because it is a recent revision of data protection law that
leaves universal conceptual questions unclear). Thereafter, the potential for
Artificial Intelligence to meet some of the shortcomings is discussed. The paper
ends with a consideration of the conditions under which data sharing
harmonisation might be achieved: an understanding of a human rights approach and
citizen sensitivities in considering the public interest'; social liberalism as
a basis of solidarity; and the profession of researcher'.
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FU Wyng Foundation of Hong Kong
FX The project was made possible by a grant from the Wyng Foundation of
   Hong Kong.
CR Beale H, 2012, LAW SECURITY TITLE B
   Damiani A, 2018, J E-LEARN KNOWL SOC, V14, P71, DOI 10.20368/1971-8829/1454
   Deist TM, 2017, CLIN TRANSL RAD ONCO, V4, P24, DOI 10.1016/j.ctro.2016.12.004
   Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
   Knoppers BM, 2018, HUM GENET
   Litton JE, 2017, NATURE, V541, P437, DOI 10.1038/541437a
   Phillips M, 2018, HUM GENET
   Roelofs E, 2014, RADIOTHER ONCOL, V110, P370, DOI
10.1016/j.radonc.2013.11.001
   Taylor MJ, 2018, HUM GENET
   Townend D, 2017, ETHICAL RATIONALISM AND THE LAW, P171
   Townend D, 2016, J LAW MED ETHICS, V44, P128, DOI 10.1177/1073110516644204
   van Soest Johan, 2018, Stud Health Technol Inform, V247, P581
   Voshmgir S, 2017, BLOCKCHAINHUB
   Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
   World Med Assoc, 2013, JAMA-J AM MED ASSOC, V310, P2191, DOI
10.1001/jama.2013.281053
NR 15
TC 1
Z9 1
U1 5
U2 7
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
EI 1432-1203
J9 HUM GENET
JI Hum. Genet.
PD AUG
PY 2018
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DI 10.1007/s00439-018-1924-x
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WC Genetics & Heredity
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PT J
AU DuGoff, EH
   Fernandes-Taylor, S
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Weissman, GE
Huntley, JH
Pollack, CE
AF DuGoff, Eva H.
Fernandes-Taylor, Sara
Weissman, Gary E.
Huntley, Joseph H.
Pollack, Craig Evan
TI A scoping review of patient-sharing network studies using administrative data
SO TRANSLATIONAL BEHAVIORAL MEDICINE
LA English
DT Review
DE Social networks; Patient-sharing; Care coordination; Social contagion; Diffusion of innovation; Scoping review
ID PHYSICIAN SOCIAL NETWORKS; QUALITY-OF-CARE; COLLABORATION NETWORK; CANCER-TREATMENT; PUBLIC-HEALTH; CLAIMS-DATA; OUTCOMES; COORDINATION; COMMUNITIES; CONSISTENCY

AB There is a robust literature examining social networks and health, which draws on the network traditions in sociology and statistics. However, the application of social network approaches to understand the organization of health care is less well understood. The objective of this work was to examine approaches to conceptualizing, measuring, and analyzing provider patient-sharing networks. These networks are constructed using administrative data in which pairs of physicians are considered connected if they both deliver care to the same patient. A scoping review of English language peer-reviewed articles in PubMed and Embase was conducted from inception to June 2017. Two reviewers evaluated article eligibility based upon inclusion criteria and abstracted relevant data into a database. The literature search identified 10,855 titles, of which 63 full-text articles were examined. Nine additional papers identified by reviewing article references and authors were examined. Of the 49 papers that met criteria for study inclusion, 39 used a cross-sectional study design, 6 used a cohort design, and 4 were longitudinal. We found that studies most commonly theorized that networks reflected aspects of collaboration or coordination. Less commonly, studies drew on the strength of weak ties or diffusion of innovation frameworks. A total of 180 social network measures were used to describe the networks of individual providers, provider pairs and triads, the network as a whole, and patients. The literature on patient-sharing relationships between providers is marked by a diversity of measures and approaches. We highlight key considerations in network identification including the definition of network ties, setting geographic boundaries, and identifying clusters of providers, and discuss gaps for future study.

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Institute [T32HL098054]; Center for Demography and Ecology [P2CHD047873]; Center for Demography of Health and Aging [P30AG017266]; AHRQ [R21HS023395]; Commonwealth Fund and National Institutes of Aging [R01AG050504]

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CR Anderson CJ, 1999, SOC NETWORKS, V21, P37, DOI 10.1016/S0378-8733(98)00012-4
Bae SH, 2015, NURS OUTLOOK, V63, P566, DOI 10.1016/j.outlook.2015.05.006
Barnett ML, 2012, MED CARE, V50, P152, DOI 10.1097/MLR.0b013e31822dcef7
Barnett ML, 2011, HEALTH SERV RES, V46, P1592, DOI 10.1111/j.1475-6773.2011.01262.x
Carson MB, 2016, CIRC-CARDIOVASC QUAL, V9, P670, DOI 10.1161/CIRCOUTCOMES.116.003041
Carson MB, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0163861
Casalino LP, 2015, MED CARE, V53, P534, DOI 10.1097/MLR.0000000000000365
Chambers D, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0041911
Committee on Geographic Variation in Health Care Spending and Promotion of High-Value Care; Board on Health Care Services; Institute of Medicine, 2013, VARIATION HLTH CARE
Cunningham FC, 2012, BMJ QUAL SAF, V21, P239, DOI 10.1136/bmjqs-2011-000187
Donker T, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0035002
Donker T, 2010, PLOS COMPUT BIOL, V6, DOI 10.1371/journal.pcbi.1000715
DuGoff EH, 2018, MED CARE RES REV, V75, P586, DOI 10.1177/1077558717697016
Fernandez-Gracia J, 2017, SCI REP-UK, V7, DOI 10.1038/s41598-017-02245-7
FREEMAN LC, 1977, SOCIOMETRY, V40, P35, DOI 10.2307/3033543
Gelman A., SELECTION BIAS REPOR
GRANOVETTER MS, 1973, AM J SOCIOL, V78, P1360, DOI 10.1086/225469
Hollingsworth JM, 2016, CIRC-CARDIOVASC QUAL, V9, P641, DOI 10.1161/CIRCOUTCOMES.116.002714
Hollingsworth JM, 2015, MED CARE, V53, P160, DOI 10.1097/MLR.0000000000000291
Hsu J, 2016, HEALTH AFFAIR, V35, P422, DOI 10.1377/hlthaff.2015.0805
Hussain T, 2015, J ONCOL PRACT, V11, pE388, DOI 10.1200/JOP.2014.003293
Iwashyna TJ, 2009, CHEST, V135, P827, DOI 10.1378/chest.08-1052
Kim DA, 2015, LANCET, V386, P145, DOI 10.1016/S0140-6736(15)60095-2
Kunz SN, 2017, J PERINATOL, V37, P702, DOI 10.1038/jp.2017.20
Landon BE, 2013, MED CARE, V51, P715, DOI 10.1097/MLR.0b013e3182977991
Landon BE, 2012, JAMA-J AM MED ASSOC, V308, P265, DOI 10.1001/jama.2012.7615
Latapy M, 2008, SOC NETWORKS, V30, P31, DOI 10.1016/j.socnet.2007.04.006
Laumann E. O., 1989, RES METHODS SOC NETW, V61, P87
Lee BY, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0029342
Lee BY, 2011, AM J PUBLIC HEALTH, V101, P707, DOI 10.2105/AJPH.2010.202754
Lomi A, 2014, MED CARE, V52, P407, DOI 10.1097/MLR.0000000000000107
Luke DA, 2007, ANNU REV PUBL HEALTH, V28, P69, DOI 10.1146/annurev.publhealth.28.021406.144132
Luke DA, 2012, ANNU REV PUBL HEALTH, V33, P357, DOI 10.1146/annurev-publhealth-031210-101222
Mandl KD, 2014, J GEN INTERN MED, V29, P1499, DOI 10.1007/s11606-014-2964-0
Mascia D, 2015, SOC SCI MED, V132, P113, DOI 10.1016/j.socscimed.2015.03.029

Merrill JA, 2015, APPL CLIN INFORM, V6, P548, DOI 10.4338/ACI-2015-02-RA-0021
Moen EL, 2016, HEALTH SERV OUTCOME, V16, P132, DOI 10.1007/s10742-016-0152-x
O'Malley AJ, 2013, STAT MED, V32, P539, DOI 10.1002/sim.5630
Ong MS, 2017, DRUG SAFETY, V40, P263, DOI 10.1007/s40264-016-0490-1
Ong MS, 2016, J GEN INTERN MED, V31, P7
Paul S, 2014, SOC SCI MED, V117, P67, DOI 10.1016/j.socscimed.2014.07.014
Pham MT, 2014, RES SYNTH METHODS, V5, P371, DOI 10.1002/jrsm.1123
Pollack CE, 2017, JNCI-J NATL CANCER I, V109, P1
Pollack CE, 2015, MED CARE, V53, P317, DOI 10.1097/MLR.0000000000000319
Pollack CE, 2015, CANCER-AM CANCER SOC, V121, P2799, DOI 10.1002/cncr.29409
Pollack CE, 2014, VALUE HEALTH, V17, P611, DOI 10.1016/j.jval.2014.04.011
Pollack CE, 2014, J CANCER SURVIV, V8, P156, DOI 10.1007/s11764-014-0349-3
Pollack CE, 2013, J GEN INTERN MED, V28, P459, DOI 10.1007/s11606-012-2104-7
Pollack CE, 2012, HEALTH SERV RES, V47, P380, DOI 10.1111/j.1475-6773.2011.01331.x
Ray MJ, 2016, CLIN INFECT DIS, V63, P889, DOI 10.1093/cid/ciw461
Rogers E. M., 1983, DIFFUSION INNOVATION
Simmering JE, 2015, INFECT CONT HOSP EP, V36, P1031, DOI 10.1017/ice.2015.130
Southwell B. G., 2013, SOCIAL NETWORKS POPU
Southwell BG, 2010, SOC SCI MED, V71, P1627, DOI 10.1016/j.socscimed.2010.08.009
Stein BD, 2017, J ADDICT DIS, V36, P14, DOI 10.1080/10550887.2016.1211784
Tankard ME, 2016, SOC ISS POLICY REV, V10, P181, DOI 10.1111/sipr.12022
Tasselli S, 2014, MED CARE RES REV, V71, P619, DOI 10.1177/1077558714557079
Tranmer M, 2016, SOC NETWORKS, V44, P269, DOI 10.1016/j.socnet.2015.06.005
Uddin S, 2015, DRIVING REFORM DIGIT
Uddin S, 2016, AUST HEALTH REV, V40, P500, DOI 10.1071/AH15058
Uddin S, 2016, SCI REP-UK, V6, DOI 10.1038/srep20222
Uddin S, 2013, STAT MED, V32, P3539, DOI 10.1002/sim.5770
Uddin S, 2013, BMC INFECT DIS, V13, DOI 10.1186/1472-6963-13-234
Uddin S, 2012, EUR J PUBLIC HEALTH, V22, P629, DOI 10.1093/eurpub/ckr153
van Kleef E, 2013, BMC INFECT DIS, V13, DOI 10.1186/1471-2334-13-294
von Luxburg U, 2008, ANN STAT, V36, P555, DOI 10.1214/009053607000000640
Yaraghi N, 2014, J AM MED INFORM ASSN, V21, P671, DOI 10.1136/amiajnl-2012-001293
Zand MS, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0175876
NR 68
TC 1
Z9 1
U1 4
U2 5
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1869-6716
EI 1613-9860
J9 TRANSL BEHAV MED
JI Transl. Behav. Med.
PD AUG
PY 2018
VL 8
IS 4
SI SI
BP 598
EP 625
DI 10.1093/tbm/ibx015
PG 28
WC Public, Environmental & Occupational Health

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SC Public, Environmental & Occupational Health
GA GZ0LO
UT WOS:000449054400009
PM 30016521
OA Bronze
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ER

PT J
AU Kim, H
   Kim, SY
   Joly, Y
AF Kim, Hannah
   Kim, So Yoon
   Joly, Yann
TI South Korea: in the midst of a privacy reform centered on data sharing
SO HUMAN GENETICS
LA English
DT Review
ID BROAD CONSENT; CHILDREN; POLICY
AB With rapid developments in genomic and digital technologies, genomic data
sharing has become a key issue for the achievement of precision medicine in
South Korea. The legal and administrative framework for data sharing and
protection in this country is currently under intense scrutiny from national and
international stakeholders. Policymakers are assessing the relevance of specific
restrictions in national laws and guidelines for better alignment with
international approaches. This manuscript will consider key issues in
international genome data sharing in South Korea, including consent, privacy,
security measures, compatible adequacy and oversight, and map out an approach to
genomic data sharing that recognizes the importance of patient engagement and
responsible use of data in South Korea.
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CR Allen Claudia, 2014, EGEMS (Wash DC), V2, P1057, DOI 10.13063/2327-9214.1057
   [Anonymous], 2017, NEWSIS
   [Anonymous], 2016, POSS MAN STOR EL MED
   [Anonymous], 2017, ALL US RES PROGRAM
   [Anonymous], 2007, MUNHWA ILBO
   [Anonymous], 2016, STUDY PROMOTING LEGA
   [Anonymous], 2018, REG OP MAN NAT BIOB
   [Anonymous], 2017, 2016 REP PREM FEAS S
   [Anonymous], 2007, OECD PRINCIPLES GUID
   [Anonymous], 2017, KOR BIOB PROJ
   [Anonymous], 2011, PREC MED BUILD KNOWL
   [Anonymous], 2016, HLTH SOCIAL WELFARE
   [Anonymous], 2016, GUID DEID PERS DAT
   [Anonymous], 2015, PAT REC LEAK
   [Anonymous], 2018, 2 WORKSH PREC MED PR
   [Anonymous], 2015, HLTH SOCIAL WELFARE
   [Anonymous], 2017, KOREA BIOMEDICAL REV
   [Anonymous], 2017, SHSYESIBC24173REV2 U
   Arora S, 2014, ALCOHOL RES-CURR REV, V36, P143
   Borry P, 2018, J COMMUNITY GENET
   Bovenberg JA, 2016, BIOPRESERV BIOBANK, V14, P217, DOI 10.1089/bio.2016.0007
```

de Montjoye YA, 2013, SCI REP-UK, V3, DOI 10.1038/srep01376
Dummer TJB, 2018, CAN MED ASSOC J, V190, pE710, DOI 10.1503/cmaj.170292
Global Alliance for Genomics and Health, 2014, FRAM RESP SHAR GEN H
Grady C, 2015, AM J BIOETHICS, V15, P34, DOI 10.1080/15265161.2015.1062162
Grossman RL, 2016, NEW ENGL J MED, V375, P1109, DOI 10.1056/NEJMp1607591
Jeong G, 2017, PUBLIC HEALTH GENOM, V20, P166, DOI 10.1159/000479290
Johnson KJ, 2014, J Cancer Policy, V2, P75, DOI 10.1016/j.jcpo.2014.05.001
Joly Y, 2012, PLOS COMPUT BIOL, V8, DOI 10.1371/journal.pcbi.1002549
Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71
Kim H, 2017, ASIAN BIOETH REV, V9, P367
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Knoppers Bartha Maria, 2014, Hugo J, V8, P3, DOI 10.1186/s11568-014-0003-1
Maier RM, 2018, NAT COMMUN, V9, DOI 10.1038/s41467-017-02769-6
McMahon AW, 2018, NEW ENGL J MED, V378, P2155, DOI 10.1056/NEJMp1802197
Parker SM, 2018, BMJ OPEN, V8, DOI 10.1136/bmjopen-2018-023239
Perkins BA, 2018, P NATL ACAD SCI USA, V115, P3686, DOI 10.1073/pnas.1706096114
Phillips M, 2017, J BIOETHIC INQ, V14, P527, DOI 10.1007/s11673-017-9806-9
Phillips M, 2016, NAT BIOTECHNOL, V34, P1102, DOI 10.1038/nbt.3696
Ploug T, 2016, BIOETHICS, V30, P721, DOI 10.1111/bioe.12286
Rathbone AL, 2017, J MED INTERNET RES, V19, DOI 10.2196/jmir.7740
Robinson JO, 2015, J LAW BIOSCI, V2, P697, DOI 10.1093/jlb/lsv030
Rothstein MA, 2017, J LAW MED ETHICS, V45, P274, DOI 10.1177/1073110517720655
Shin SY, 2018, J KOREAN MED SCI, V33, DOI 10.3346/jkms.2018.33.e41
Shin Y, 2015, STUD HEALTH TECHNOL, V216, P924, DOI 10.3233/978-1-61499-564-7-924
Steinsbekk KS, 2013, EUR J HUM GENET, V21, P897, DOI 10.1038/ejhg.2012.282
Sudlow C, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001779
UNESCO, 2003, INT DECL HUM GEN DAT
Wade CH, 2013, ANNU REV GENOM HUM G, V14, P535, DOI 10.1146/annurev-genom-091212-153425
Willink A, 2018, NEW ENGL J MED, V378, P2153, DOI 10.1056/NEJMp1803292
Ïú†ÌòÑÏ¢Ö, 2015, [Korean Journal of Medicine and Law, ÌïúÍµ≠ÏùòÎ£åÎ≤ïÌïôÌöåÏßÄ], V23, P21, DOI 10.17215/kaml.2015.06.23.1.21
NR 51
TC 1
Z9 1
U1 0
U2 0
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0340-6717
EI 1432-1203
J9 HUM GENET
JI Hum. Genet.
PD AUG
PY 2018
VL 137
IS 8
SI SI
BP 627
EP 635
DI 10.1007/s00439-018-1920-1
PG 9
WC Genetics & Heredity
SC Genetics & Heredity
GA GS8YV

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UT WOS:000444002500010
PM 30121900
OA Green Published, Other Gold
DA 2019-08-06
ER

PT J
AU Kostkova, P
AF Kostkova, Patty
TI Disease surveillance data sharing for public health: the next ethical
   frontiers
SO LIFE SCIENCES SOCIETY AND POLICY
LA English
DT Article
AB In the recent years, we have been witnessing a digital revolution in public
and global health creating unprecedented opportunities for epidemic intelligence
and public health emergencies. However, these opportunities created a double
edge sword as access to data, quality monitoring and assurance, as well as
governance and regulation frameworks for data privacy are lagging behind
technological achievements.
   In this paper we identify three ethical challenges: sharing data across
various early warning tools to support risk assessment. Secondly, define the
challenges to be addressed by the legal frameworks for public health data
sharing to unlock the potential of population-level datasets for research with
no impact on citizens privacy. The third challenge lies with stricter regulation
of the IT industry with regards to manipulating user data - such an initiative,
GDPR, comes to force in the EU in May 2018.
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CR Albinati J, 2017, P DH 17 P 2017 INT C, P109
   Barboza P, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0057252
   Beltran JD, 2018, DH '18: PROCEEDINGS OF THE 2018 INTERNATIONAL CONFERENCE ON
DIGITAL HEALTH, P90, DOI 10.1145/3194658.3194683
   Cook S, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0023610
   de Quincey E, 2010, L N INST COMP SCI SO, V27, P21
   Edelstein M, 2015, OVERCOMING BARRIERS
   Guerrisi C, 2016, J INFECT DIS, V214, pS386, DOI 10.1093/infdis/jiw280
   Hafen E, 2014, METHOD INFORM MED, V53, P82, DOI 10.3414/ME13-02-0051
   Kostkova P, 2010, INT J INFECT DIS, V14, pE384, DOI
10.1016/j.ijid.2010.02.475
   Kostkova P, 2017, P 2017 INT C DIG HLT, P48, DOI [10.1145/3079452.3079505,
DOI 10.1145/3079452.3079505]
   Kostkova P., 2015, TWITTER DIGITAL SOCI, P111, DOI 10.3389/fpubh.2015.00134
   Kostkova P., 2013, P 22 INT C WORLD WID, P687
   Kostkova P, 2014, WWW'14 COMPANION: PROCEEDINGS OF THE 23RD INTERNATIONAL
CONFERENCE ON WORLD WIDE WEB, P657, DOI 10.1145/2567948.2579276
   Kostkova P, 2016, DH'16: PROCEEDINGS OF THE 2016 DIGITAL HEALTH CONFERENCE,
P163, DOI 10.1145/2896338.2896370
   Kostkova P, 2014, ACM TRANS MANAG INF, V5, DOI 10.1145/2597892
   Kostkova P, 2016, FRONT PUBLIC HEALTH, V4, DOI 10.3389/fpubh.2016.00007
   Kostkova Patty, 2015, Front Public Health, V3, P134, DOI
10.3389/fpubh.2015.00134
   Kostkova P, 2013, J MED INTERNET RES, V15, P167, DOI 10.2196/jmir.2146
   Lampos V, 2012, ACM T INTEL SYST TEC, V3, DOI 10.1145/2337542.2337557
   Lupton D, 2015, HEALTH PROMOT INT, V30, P174, DOI 10.1093/heapro/dau091
```

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   Madle Gemma, 2006, Health Informatics J, V12, P137, DOI
10.1177/1460458206063809
   Maier P., 2014, CRISIS MAPPING HAITI
   McGough SF, 2017, PLOS NEGLECT TROP D, V11, DOI 10.1371/journal.pntd.0005295
   Moon S, 2015, LANCET, V386, P2204, DOI 10.1016/S0140-6736(15)00946-0
   Roush S, 1999, JAMA-J AM MED ASSOC, V282, P164, DOI 10.1001/jama.282.2.164
   Salathe M, 2011, PLOS COMPUT BIOL, V7, DOI 10.1371/journal.pcbi.1002199
   St Louis C, 2012, BRIT MED J, V344, DOI 10.1136/bmj.e2353
   Szomszor M., 2011, 2011 IEEE/WIC/ACM International Joint Conferences on Web
Intelligence (WI) and Intelligent Agent Technologies, P320, DOI 10.1109/WI-
IAT.2011.311
   Szomszor M, 2010, LECT NOTES I COMPUTE, P18, DOI [10.1007/978-3-642-23635-8_3,
DOI 10.1007/978-3-642-23635-8_3]
   Valente TW, 2010, SOCIAL NETWORKS HLTH
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Vayena E, 2018, J LAW MED ETHICS, V46, P119, DOI 10.1177/1073110518766026
   von Gratz PG, 2016, MOVE FREEDOM DIGITAL
   Vorovchenko T, 2017, BIG DATA HEALTHCARE
   WHO, 2014, EP INT SYST EV DET
NR 35
TC 1
Z9 1
U1 0
U2 2
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
EI 2195-7819
J9 LIFE SCI SOC POLICY
JI Life Sci. Soc. Policy
PD JUL 4
PY 2018
VL 14
AR UNSP 16
DI 10.1186/s40504-018-0078-x
PG 5
WC Ethics; History & Philosophy Of Science; Social Sciences, Biomedical
SC Social Sciences - Other Topics; History & Philosophy of Science;
   Biomedical Social Sciences
GA HZ4NW
UT WOS:000468826100001
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PT J
AU Portellano-Ortiz, C
   Garre-Olmo, J
   Calvo-Perxas, L
   Conde-Sala, JL
AF Portellano-Ortiz, C.
   Garre-Olmo, J.
   Calvo-Perxas, L.
   Conde-Sala, J. L.
TI Depression and variables associated with quality of life in people over
   65 in Spain and Europe. Data from SHARE 2013
SO EUROPEAN JOURNAL OF PSYCHIATRY
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LA English
DT Article
DE Aging; Quality of life; SHARE; CASP-12; EURO-D
ID EARLY OLD-AGE; WELFARE-STATE REGIMES; PSYCHOMETRIC PROPERTIES;
SOCIOECONOMIC-STATUS; MULTILEVEL ANALYSIS; D SCALE; ADULTS; HEALTH;
SATISFACTION; SYMPTOMS

AB Background and objectives: The perception of quality of life (QoL) in people over 65 years of age can be affected by individual clinical and sociodemographic characteristics, and also by the nature of the welfare models in place in particular countries. The objective of this study was to compare the association between clinical/sociodemographic variables and QoL in people >= 65 in samples from Spain and from Central-Northern European countries, using data from the SHARE (Survey of Health, Ageing and Retirement in Europe) study.

Methods: Data from 22,189 participants in Wave 5 (2013) of the SHARE study were obtained. Instruments: CASP-12 (quality of life) and EURO-D (depression). Statistical analysis: Bivariate and multiple linear regression and correlations.

Results: In the regression analysis, the variables most closely associated with a lower QoL (CASP-12) in both groups (Spain, r(2) = 0.586 and Central-Northern Europe, (r(2) = 0.453) were high depression (beta = 0.444 vs. 0.361), poor physical health, economic difficulties, and deficits in activities of daily living (ADL); low level of education was relevant only in the Spanish sample. The mean QoL score in Spain was lower than in the other countries (34.8 +/- 6.8 vs. 38.5 +/- 5.8, p < 0.001; d = 0.58) and depression was more frequent (34.9% vs 27.4%, p < 0.001; V = 0.06).

Conclusions: In all countries, low QoL was associated with high rates of depression and poor physical health. The Spanish sample had lower QoL than their Central-Northern European counterparts. A high rate of depression was the most relevant differential variable. (c) 2017 Asociacion Universitaria de Zaragoza para el Progreso de la Psiquiatria y la Salud Mental. Published by Elsevier Espana, S. L. U. All rights reserved.

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FU 7th Framework Program of the European Commission (SHAREM4) [261982];
Project: SHARE (Survey of Health, Ageing and Retirement in Europe)
FX 7th Framework Program of the European Commission (SHAREM4, No. 261982).
Project: SHARE (Survey of Health, Ageing and Retirement in Europe).

CR Aragones E, 2016, ACTAS ESP PSIQUIATRI, V44, P79
Barcelos-Ferreira R, 2013, J AFFECT DISORDERS, V150, P616, DOI 10.1016/j.jad.2013.02.024
Bielderman A, 2015, QUAL LIFE RES, V24, P1697, DOI 10.1007/s11136-014-0898-y
Bilgili N, 2014, ARCH GERONTOL GERIAT, V59, P415, DOI 10.1016/j.archger.2014.07.005
Borsch-Supan A, 2013, INT J EPIDEMIOL, V42, P992, DOI 10.1093/ije/dyt088
Borsch-Supan A, 2005, HLTH AGEING RETIREME
Bourassa KJ, 2016, PSYCHOL SCI, V27, P270, DOI 10.1177/0956797615618968
Bray I, 2006, SOC PSYCH PSYCH EPID, V41, P333, DOI 10.1007/s00127-006-0049-z
Calha A, 2016, REV ROL ENFERM, V39, P8

Castro-Costa E, 2007, BRIT J PSYCHIAT, V191, P393, DOI 10.1192/bjp.bp.107.036772
Cherepanov D, 2010, QUAL LIFE RES, V19, P1115, DOI 10.1007/s11136-010-9673-x
Choi Y, 2017, GERIATR GERONTOL INT, V17, P132, DOI 10.1111/ggi.12685
Chung H, 2013, INT J ENV RES PUB HE, V10, P1324, DOI 10.3390/ijerph10041324
COHEN J, 1973, EDUC PSYCHOL MEAS, V33, P107, DOI 10.1177/001316447303300111
Cohen J., 1988, STAT POWER ANAL BEHA
Conde-Sala JL, 2017, QUAL LIFE RES, V26, P1059, DOI 10.1007/s11136-016-1436-x
de Araujo AA, 2016, PSYCHIAT QUART, V87, P281, DOI 10.1007/s11126-015-9386-y
de la Camara C, 2008, EUR J PSYCHIAT, V22, P131, DOI 10.4321/s0213-61632008000300002
Delhey J, 2016, INT J PSYCHOL, V51, P163, DOI 10.1002/ijop.12149
Dragomirecka E, 2008, CLIN PSYCHOL PSYCHOT, V15, P193, DOI 10.1002/cpp.571
Eikemo TA, 2008, SOC SCI MED, V66, P2281, DOI 10.1016/j.socscimed.2008.01.022
Elavsky S, 2005, ANN BEHAV MED, V30, P138, DOI 10.1207/s15324796abm3002_6
Elosua P, 2011, SOC INDIC RES, V104, P427, DOI 10.1007/s11205-010-9752-y
European Commission, 2013, QUAL LIF EUR SUBJ WE
Fusco O, 2012, AGING CLIN EXP RES, V24, P68, DOI 10.1007/BF03325356
Gallagher D, 2013, J AFFECT DISORDERS, V147, P192, DOI 10.1016/j.jad.2012.10.037
Guerra M, 2015, BMC PSYCHIATRY, V15, DOI 10.1186/s12888-015-0390-4
Guilford JP, 1973, FUNDAMENTAL STAT PSY
Guyatt GH, 1999, J CLIN EPIDEMIOL, V52, P187, DOI 10.1016/S0895-4356(98)00157-7
Hinz A, 2014, ACTA ONCOL, V53, P958, DOI 10.3109/0284186X.2013.879998
Hyde M, 2003, AGING MENT HEALTH, V7, P186, DOI 10.1080/1360786031000101157
Inouye K, 2007, REV LAT-AM ENFERM, V15, P742, DOI 10.1590/S0104-11692007000700005
Juul T, 2014, QUAL LIFE RES, V23, P2183, DOI 10.1007/s11136-014-0675-y
Kalpakjian CZ, 2011, ARCH PHYS MED REHAB, V92, P433, DOI 10.1016/j.apmr.2010.07.239
Kim GR, 2015, AGING MENT HEALTH, V19, P595, DOI 10.1080/13607863.2014.938605
Ladin K, 2010, GERONTOLOGIST, V50, P48, DOI 10.1093/geront/gnp065
Langlois F, 2013, J GERONTOL B-PSYCHOL, V68, P400, DOI 10.1093/geronb/gbs069
Larraga L, 2006, INT J GERIATR PSYCH, V21, P1199, DOI 10.1002/gps.1642
Layte R, 2013, J AM GERIATR SOC, V61, pS299, DOI 10.1111/jgs.12198
Lee JH, 2014, OCCUP THER INT, V21, P124, DOI 10.1002/oti.1371
Levecque K, 2011, J HEALTH SOC BEHAV, V52, P262, DOI 10.1177/0022146510394861
Low G, 2007, RES NURS HEALTH, V30, P141, DOI 10.1002/nur.20178
Low G, 2013, HEALTH QUAL LIFE OUT, V11, DOI 10.1186/1477-7525-11-146
Lundberg O, 2008, LANCET, V372, P1633, DOI 10.1016/S0140-6736(08)61686-4
Marmot M, 2005, LANCET, V365, P1099, DOI 10.1016/S0140-6736(05)71146-6
Matter F, 2015, SHARE WAVE 5 INNOVAT
Mielck A, 2014, HEALTH QUAL LIFE OUT, V12, DOI 10.1186/1477-7525-12-58
Murray CJL, 1997, LANCET, V349, P1436, DOI 10.1016/S0140-6736(96)07495-8
Netuveli G, 2006, J EPIDEMIOL COMMUN H, V60, P357, DOI 10.1136/jech.2005.040071
Niedzwiedz CL, 2014, AGE AGEING, V43, P431, DOI 10.1093/ageing/afu004
Palgi Y, 2015, QUAL LIFE RES, V24, P1835, DOI 10.1007/s11136-015-0918-6
Pinkas J, 2016, MED SCI MONITOR, V22, P3095, DOI 10.12659/MSM.900572
Pinquart M, 2000, PSYCHOL AGING, V15, P187, DOI 10.1037//0882-7974.15.2.187
Ponte C, 2014, SPAN J PSYCHOL, V17, DOI 10.1017/sjp.2014.15
Portellano-Ortiz C, 2016, INT J GERIATR PSYCH, V31, P1250, DOI 10.1002/gps.4467
Prince MJ, 1999, BRIT J PSYCHIAT, V174, P330, DOI 10.1192/bjp.174.4.330
Hernandez CR, 2009, ACTAS ESP PSIQUIATRI, V37, P61
Sparks Martha, 2004, J Gerontol Nurs, V30, P47
Unalan D, 2015, EUR GERIATR MED, V6, P319, DOI 10.1016/j.eurger.2015.02.009

van Tilburg T.G., 2008, AGEING INTERGENERATI, P141
Vassilev I, 2014, CHRONIC ILLN, V10, P273, DOI 10.1177/1742395314521641
Von dem Knesebeck O., 2005, HLTH AGEING RETIREME, P199
Von dem Knesebeck O, 2007, AGEING SOC, V27, P769
West C, 2015, ONCOL NURS FORUM, V42, P507, DOI 10.1188/15.ONF.507-516
WHO, 2014, PREV SUIC GLOB IMP
Wu J, 2014, EUR J AGEING, V11, P131, DOI 10.1007/s10433-013-0297-1
Ziolkowski A, 2015, ANN AGR ENV MED, V22, P147, DOI 10.5604/12321966.1141385

NR 67
TC 1
Z9 1
U1 4
U2 6
PU EUROPEAN JOURNAL OF PSYCHIATRY
PI ZARAGOZA
PA FAC MED, DEPT PSYCHIATRY PROF A LOBO, DOMINGO MIRAL S-N, 50009 ZARAGOZA, SPAIN
SN 0213-6163
J9 EUR J PSYCHIAT
JI Eur. J. Psychiat.
PD JUL-SEP
PY 2018
VL 32
IS 3
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DI 10.1016/j.ejpsy.2017.11.002
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WC Psychiatry
SC Psychiatry
GA HA8TG
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PT J
AU Freundlich, RE
Pandharipande, P
Ehrenfeld, JM
AF Freundlich, Robert E.
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Ehrenfeld, Jesse M.
TI A Call for Electronic Health Record-based Data Sharing for Clinical Trials in Critical Care
SO JOURNAL OF MEDICAL SYSTEMS
LA English
DT Editorial Material
ID BALANCED CRYSTALLOIDS; ILL ADULTS; SALINE
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CR Activity ALHS, 2013, OBS STUD LEARN HLTH
   Berman MF, 2017, ANESTH ANALG, V125, P1203, DOI 10.1213/ANE.0000000000002305
   Ford I, 2016, NEW ENGL J MED, V375, P454, DOI 10.1056/NEJMra1510059
   Freundlich RE, 2011, BEST PRACT RES-CLIN, V25, P489, DOI
10.1016/j.bpa.2011.08.008
   Lauer MS, 2017, NAT REV CARDIOL, V14, P493, DOI 10.1038/nrcardio.2017.60
   Lipman PD, 2017, TRIALS, V18, DOI 10.1186/s13063-017-2267-y
   Pandharipande PP, 2013, NEW ENGL J MED, V369, P1306, DOI
10.1056/NEJMoa1301372
   Pandharipande PP, 2007, JAMA-J AM MED ASSOC, V298, P2644, DOI
10.1001/jama.298.22.2644
   Pencina MJ, 2016, AM HEART J, V172, P64, DOI 10.1016/j.ahj.2015.11.002
   Rosenthal Gary E, 2014, Trans Am Clin Climatol Assoc, V125, P204
   Rosenthal GE, 2014, T AM CLIN CLIMAT ASS, V125, P217
   Sakr Y, 2005, CHEST, V128, P3098, DOI 10.1378/chest.128.5.3098
   SCHWARTZ D, 1967, J CHRON DIS, V20, P637, DOI 10.1016/0021-9681(67)90041-0
   Self WH, 2018, NEW ENGL J MED, V378, P819, DOI 10.1056/NEJMoa1711586
   Semler MW, 2018, NEW ENGL J MED, V378, P829, DOI 10.1056/NEJMoa1711584
   Thorpe KE, 2009, J CLIN EPIDEMIOL, V62, P464, DOI
10.1016/j.jclinepi.2008.12.011
NR 16
TC 1
Z9 1
U1 0
U2 3
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0148-5598
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J9 J MED SYST
JI J. Med. Syst.
PD JUL
PY 2018
VL 42
IS 7
AR 115
DI 10.1007/s10916-018-0984-8
PG 2
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA GH2UT
UT WOS:000433258200001
PM 29802451
OA Bronze
DA 2019-08-06
ER

PT J
AU Lu, W
   Scott, DM
   Dalumpines, R
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AF Lu, Wei
Scott, Darren M.
Dalumpines, Ron

TI Understanding bike share cyclist route choice using GPS data: Comparing dominant routes and shortest paths

SO JOURNAL OF TRANSPORT GEOGRAPHY
LA English
DT Article
DE Active travel; Bike share; Cycling; Dominant; Route choice; Shortest path
ID STATED PREFERENCE SURVEY; PHYSICAL-ACTIVITY; ACTIVE TRAVEL; HEALTH; COMMUTER; WORK; TRANSPORTATION; ADULTS; MODEL

AB This paper investigates cyclist route choices using global positioning system (GPS) data collected from 750 bicycles in Hamilton, Ontario's bike share system - SoBi (Social Bicycles) Hamilton. A dataset containing 161,426 GPS trajectories describing observed routes of cyclists using SoBi bikes over a 12-month period (April 1, 2015 to March 31, 2016) is used for analysis. This study groups trips by origin-destination hub pairs and uses a GIS (geographic information system)-based map-matching algorithm to generate routes along with attributes such as length, number of intersections, number of turns, and unique road segments. Unique routes and their use frequencies are extracted from all the hub-to-hub trips using a GIS-based link signature extraction tool developed for this research. The most popular routes between hubs taken by cyclists are then identified as dominant routes and their attributes are compared to those of corresponding shortest path routes derived by minimizing distance traveled. The comparison finds significant differences in multiple attributes, and demonstrates that dominant routes are significantly longer than their shortest distance counterparts, suggesting that cyclists are willing to detour for routes characterized by positive features such as bicycle facilities and low traffic volumes. Detouring does, however, come at a cost increases in number of turns and number of intersections. This research not only enhances our understanding of cyclist route preferences within a bike share system, it also presents a GIS-based approach for identifying potential locations for future bike facilities based on such preferences.

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CR Abraham J. E, 2002, 81 ANN M TRANSP RES
Andersen LB, 2000, ARCH INTERN MED, V160, P1621, DOI 10.1001/archinte.160.11.1621
Antonakos C.L., 1994, TRANSPORT RES REC, V1438, P25
Badland H., 2012, URBANIZATION GLOBAL, P51
Baetz B., 1997, TRANSPORT RES REC, V1578, P102, DOI DOI 10.3141/1578-13
Broach J, 2012, TRANSPORT RES A-POL, V46, P1730, DOI 10.1016/j.tra.2012.07.005
Dalumpines R, 2018, TRAVEL BEHAV SOC, V11, P121, DOI 10.1016/j.tbs.2017.04.001
Dalumpines R, 2011, LECT NOTES GEOINF CA, V1, P101, DOI 10.1007/978-3-642-19789-5_6
Dill J, 2009, J PUBLIC HEALTH POL, V30, pS95, DOI 10.1057/jphp.2008.56
DMTI Spatial, 2015, CANMAP CONT SUIT

Fishman E, 2016, TRANSPORT REV, V36, P1, DOI 10.1080/01441647.2015.1114271
Guttenplan M., 1995, TRANSPORT RES NEWS, V178, P7
Hood J, 2011, TRANSP LETT, V3, P63, DOI 10.3328/TL.2011.03.01.63-75
Howard C, 2001, TRANSPORT RES REC, P39, DOI 10.3141/1773-05
Hunt JD, 2007, TRANSPORTATION, V34, P453, DOI 10.1007/s11116-006-9109-1
Khatri R, 2016, TRANSPORT RES REC, P141, DOI 10.3141/2587-17
Lima A, 2016, J R SOC INTERFACE, V13, DOI 10.1098/rsif.2016.0021
Lott D.F, 1978, TRANSPORT RES REC, V683, P40
Menghini G, 2010, TRANSPORT RES A-POL, V44, P754, DOI 10.1016/j.tra.2010.07.008
Merom D, 2010, AM J PREV MED, V39, P113, DOI 10.1016/j.amepre.2010.04.007
Oja P, 2011, SCAND J MED SCI SPOR, V21, P496, DOI 10.1111/j.1600-0838.2011.01299.x
Papinski D, 2013, ENVIRON PLANN A, V45, P263, DOI 10.1068/a44545
Prato CG, 2009, J CHOICE MODEL, V2, P65, DOI [10.1016/S1755-5345(13)70005-8, DOI 10.1016/S1755-5345(13)70005-8]
Pucher J, 2010, AM J PUBLIC HEALTH, V100, P1986, DOI 10.2105/AJPH.2009.189324
Sahlqvist S, 2012, PREV MED, V55, P206, DOI 10.1016/j.ypmed.2012.06.028
Sallis JE, 2006, ANNU REV PUBL HEALTH, V27, P297, DOI 10.1146/annurev.publhealth.27.021405.102100
Saunders LE, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0069912
Sener IN, 2009, TRANSPORTATION, V36, P511, DOI 10.1007/s11116-009-9201-4
Shafizadeh K., 1997, TRANSPORT RES REC, V1578, P84, DOI DOI 10.3141/1578-11
St-Louis E, 2014, TRANSPORT RES F-TRAF, V26, P160, DOI 10.1016/j.trf.2014.07.004
Statistics Canada, 2016, CENS PROF 2016 CENS
Stinson MA, 2003, TRANSPORT RES REC, P107, DOI 10.3141/1828-13
Su JG, 2010, TRANSPORT RES A-POL, V44, P495, DOI 10.1016/j.tra.2010.03.015
Tilahun NY, 2007, TRANSPORT RES A-POL, V41, P287, DOI 10.1016/j.tra.2006.09.007
Transport Canada, 2010, BIC END OF TRIP FAC
Wergin J, 2017, TRANSPORT RES REC, P12, DOI 10.3141/2662-02
Winters M, 2010, TRANSP RES RECORD, P1, DOI 10.3141/2190-01
Winters M, 2010, J URBAN HEALTH, V87, P969, DOI 10.1007/s11524-010-9509-6
Winters M, 2010, AM J HEALTH PROMOT, V25, P40, DOI 10.4278/ajhp.081006-QUAN-236
Woodcock J, 2009, LANCET, V374, P1930, DOI 10.1016/S0140-6736(09)61714-1
NR 40
TC 1
Z9 1
U1 7
U2 15
PU ELSEVIER SCI LTD
PI OXFORD
PA THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, OXON, ENGLAND
SN 0966-6923
EI 1873-1236
J9 J TRANSP GEOGR
JI J. Transp. Geogr.
PD JUL
PY 2018
VL 71
BP 172
EP 181
DI 10.1016/j.jtrangeo.2018.07.012
PG 10
WC Economics; Geography; Transportation
SC Business & Economics; Geography; Transportation

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UT WOS:000447112400014
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ER

PT J
AU Kawahara, T
   Fukuda, M
   Oba, K
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   Buyse, M
AF Kawahara, Takuya
   Fukuda, Musashi
   Oba, Koji
   Sakamoto, Junichi
   Buyse, Marc
TI Meta-analysis of randomized clinical trials in the era of individual
   patient data sharing
SO INTERNATIONAL JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Article
DE Data sharing; Individual patient data; Meta-analysis
ID GASTRIC-CANCER; INTERNATIONAL COMMITTEE; ADJUVANT THERAPY; PARTICIPANT
   DATA; OPEN ACCESS; LEVEL DATA; CHEMOTHERAPY; EFFICACY
AB Individual patient data (IPD) meta-analysis is considered to be a gold
standard when the results of several randomized trials are combined. Recent
initiatives on sharing IPD from clinical trials offer unprecedented
opportunities for using such data in IPD meta-analyses.
   First, we discuss the evidence generated and the benefits obtained by a long-
established prospective IPD meta-analysis in early breast cancer. Next, we
discuss a data-sharing system that has been adopted by several pharmaceutical
sponsors. We review a number of retrospective IPD meta-analyses that have
already been proposed using this data-sharing system. Finally, we discuss the
role of data sharing in IPD meta-analysis in the future.
   Treatment effects can be more reliably estimated in both types of IPD meta-
analyses than with summary statistics extracted from published papers.
Specifically, with rich covariate information available on each patient,
prognostic and predictive factors can be identified or confirmed. Also, when
several endpoints are available, surrogate endpoints can be assessed
statistically.
   Although there are difficulties in conducting, analyzing, and interpreting
retrospective IPD meta-analysis utilizing the currently available data-sharing
systems, data sharing will play an important role in IPD meta-analysis in the
future.
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FU JSPS KAKENHI [15617613]; non-profit organization ECRIN ("Epidemiological
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and Clinical Research Information Network")
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CR Agnelli G, 2012, NEW ENGL J MED, V366, P601, DOI 10.1056/NEJMoa1108898
Albain K, 2012, LANCET, V379, P432, DOI 10.1016/S0140-6736(11)61625-5
[Anonymous], 1998, J Hypertens, V16, P127
Bauchner H, 2016, JAMA-J AM MED ASSOC, V315, P1237, DOI 10.1001/jama.2016.2420
Bierer BE, 2016, NEW ENGL J MED, V374, P2411, DOI 10.1056/NEJMp1605348
Bonini S, 2014, NEW ENGL J MED, V371, P2452, DOI 10.1056/NEJMp1409464
BUYSE M, 1988, JAMA-J AM MED ASSOC, V259, P3571
Buyse M, 2009, INT J CLIN ONCOL, V14, P95, DOI 10.1007/s10147-009-0879-2
Committee on Strategies for Responsible Sharing of Clinical Trial Data Board on Health Sciences Policy Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Darby S, 2005, CELEBRATING STAT
DOWNS JR, 1995, AM J CARDIOL, V75, P1130
Drazen JM, 2015, NEW ENGL J MED, V372, P201, DOI 10.1056/NEJMp1415160
European Federation of Pharmaceutical Industries and Associations, 2013, PRINC RESP CLIN TRIA
European Medicines Agency (EMA), 2014, EUR MED AG POL PUBL
Geifman N, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0525-y
Hamada C, 2009, INT J CLIN ONCOL, V14, P90, DOI 10.1007/s10147-008-0876-x
Higgins JPT, 2011, COCHRANE HDB SYSTEMA, DOI DOI 10.1002/9780470712184
Koenig F, 2015, BIOMETRICAL J, V57, P8, DOI 10.1002/bimj.201300283
Krumholz HM, 2014, JAMA-J AM MED ASSOC, V312, P1002, DOI 10.1001/jama.2014.9647
Lo B, 2016, NEW ENGL J MED, V375, P1112, DOI 10.1056/NEJMp1608351
Longo DL, 2016, NEW ENGL J MED, V374, P276, DOI 10.1056/NEJMe1516564
Meta Anal Grp Japanese Soc Canc, 2004, J CLIN ONCOL, V22, P484, DOI 10.1200/JCO.2004.04.065
Ministry of Education Culture Sports Science and Technology and the Ministry of Health Labour and Welfare, 2015, ETH GUID MED HLTH RE
Navar AM, 2016, JAMA-J AM MED ASSOC, V315, P1283, DOI 10.1001/jama.2016.2374
Nevitt SJ, 2017, BMJ-BRIT MED J, V357, DOI 10.1136/bmj.j1390
Nisen P, 2013, NEW ENGL J MED, V369, P475, DOI 10.1056/NEJMsr1302541
Oba K, 2013, EUR J CANCER, V49, P1565, DOI 10.1016/j.ejca.2012.12.016
Oba K, 2009, INT J CLIN ONCOL, V14, P85, DOI 10.1007/s10147-009-0877-4
Oba MS, 2016, GASTRIC CANCER, V19, P616, DOI 10.1007/s10120-015-0489-9
Paoletti X, 2010, JAMA-J AM MED ASSOC, V303, P1729, DOI 10.1001/jama.2010.534
PETO R, 1995, J CLIN EPIDEMIOL, V48, P23, DOI 10.1016/0895-4356(94)00150-O
Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
Sakamoto J, 2005, JPN J CLIN ONCOL, V35, P536, DOI 10.1093/jjco/hyi147
Schunemann HJ, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2015-010569
Shi Q, 2009, INT J CLIN ONCOL, V14, P102, DOI 10.1007/s10147-009-0885-4
Stewart LA, 2015, JAMA-J AM MED ASSOC, V313, P1657, DOI 10.1001/jama.2015.3656
Strom BL, 2016, NEW ENGL J MED, V375, P1608, DOI 10.1056/NEJMp1610336
Strom BL, 2014, NEW ENGL J MED, V371, P2052, DOI 10.1056/NEJMp1411794
Taichman DB, 2017, JAMA-J AM MED ASSOC, V317, P2491, DOI 10.1001/jama.2017.6514
Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMe1515172
Tucker ME, 2013, BMJ-BRIT MED J, V347, DOI 10.1136/bmj.f4465
van Doormaal FF, 2011, J CLIN ONCOL, V29, P2071, DOI 10.1200/JCO.2010.31.9293
Voysey M, 2017, VACCINE, V35, P5850, DOI 10.1016/j.vaccine.2017.09.002
Voysey M, 2017, JAMA PEDIATR, V171, P637, DOI 10.1001/jamapediatrics.2017.0638
Voysey M, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2016-011680

```
   Zarin DA, 2013, NEW ENGL J MED, V369, P468, DOI 10.1056/NEJMe1307268
NR 46
TC 1
Z9 1
U1 0
U2 0
PU SPRINGER JAPAN KK
PI TOKYO
PA CHIYODA FIRST BLDG EAST, 3-8-1 NISHI-KANDA, CHIYODA-KU, TOKYO, 101-0065,
   JAPAN
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J9 INT J CLIN ONCOL
JI Int. J. Clin. Oncol.
PD JUN
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IS 3
BP 403
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WC Oncology
SC Oncology
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PT J
AU Ribeiro, CD
   van Roode, MY
   Haringhuizen, GB
   Koopmans, MP
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   van de Burgwal, LHM
AF Ribeiro, Carolina dos S.
   van Roode, Martine Y.
   Haringhuizen, George B.
   Koopmans, Marion P.
   Claassen, Eric
   van de Burgwal, Linda H. M.
TI How ownership rights over microorganisms affect infectious disease
   control and innovation: A root-cause analysis of barriers to data
   sharing as experienced by key stakeholders
SO PLOS ONE
LA English
DT Article
ID OPINION-LEADER ANALYSIS; PROPERTY-RIGHTS; CHALLENGES; OUTBREAK; HEALTH
AB Background
   Genetic information of pathogens is an essential input for infectious disease
control, public health and for research. Efficiency in preventing and responding
to global outbreaks relies on timely access to such information. Still,
ownership barriers stand in the way of timely sharing of genetic data from
pathogens, frustrating efficient public health responses and ultimately the
potential use of such resources in innovations. Under a One Health approach,
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stakeholders, their interests and ownership issues are manifold and need to be investigated. We interviewed key actors from governmental and non-governmental bodies to identify overlapping and conflicting interests, and the overall challenges for sharing pathogen data, to provide essential inputs to the further development of political and practical strategies for improved data sharing practices.

Methods & findings

To identify and prioritize barriers, 52 Key Opinion Leaders were interviewed. A root-cause analysis was performed to identify causal relations between barriers. Finally, barriers were mapped to the innovation cycle reflecting how they affect the range of surveillance, innovation, and sharing activities. Four main barrier categories were found: compliance to regulations, negative consequences, self-interest, and insufficient incentives for compliance. When grouped in sectors (research institutes, public health organizations, supra-national organizations and industry) stakeholders appear to have similar interests, more than when grouped in domains (human, veterinary and food). Considering the innovation process, most of barriers could be mapped to the initial stages of the innovation cycle as sampling and sequencing phases. These are stages of primary importance to outbreak control and public health response. A minority of barriers applied to later stages in the innovation cycle, which are of more importance to product development.

Conclusion

Overall, barriers are complex and entangled, due to the diversity of causal factors and their crosscutting features. Therefore, barriers must be addressed in a comprehensive and integrated manner. Stakeholders have different interests highlighting the diversity in motivations for sharing pathogen data: prioritization of public health, basic research, economic welfare and/or innovative capacity. Broad inter-sectorial discussions should start with the alignment of these interests within sectors. The improved sharing of pathogen data, especially in upstream phases of the innovation process, will generate substantial public health benefits through increased availability of data to inform surveillance systems, as well as to allow the (re-) use of data for the development of medical countermeasures to control infectious diseases.

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   and supporting the performance of this study. We also acknowledge the
   European Commission for providing financial support to this study in the
   COMPARE project (http://www.compare-europe.eu) under the EU research
   program Horizon 2020.
CR Aarestrup FM, 2016, TRENDS MICROBIOL, V24, P241, DOI
10.1016/j.tim.2016.01.009
   Aarestrup Frank M, 2012, Emerg Infect Dis, V18, pe1, DOI
10.3201/eid/1811.120453
   [Anonymous], 2018, BBC NEWS
   Arzberger P, 2004, DATA SCI J, V3, P135, DOI DOI 10.2481/DSJ.3.135
   Bierer BE, 2017, DATA AUTHORSHIP INCE
   Burgwal LH, 2017, ZOONOSES PUBLIC HLTH
   Carroll MW, 2015, PLOS BIOL, V13, DOI 10.1371/journal.pbio.1002235
   Convention on Biological Diversity, 2011, NAG PROT ACC GEN RES
   Dedeurwaerdere T, 2006, INT SOC SCI J, V58, P351, DOI 10.1111/j.1468-
2451.2006.00623.x
   Dedeurwaerdere T, 2016, ENVIRON SCI POLICY, V55, P1, DOI
10.1016/j.envsci.2015.08.006
   Dedeurwaerdere T, 2010, RES MICROBIOL, V161, P414, DOI
10.1016/j.resmic.2010.04.012
   Dudas G, 2016, BIORXIV
   Fennell LA, 2011, INT J COMMONS, V5, P9, DOI 10.18352/ijc.252
   Gibbs EPJ, 2014, VET REC, V174, P85, DOI 10.1136/vr.g143
   Gostin LO, 2013, JAMA-J AM MED ASSOC, V310, P791, DOI
10.1001/jama.2013.177833
   Halewood M., 2010, INT J COMMONS, V4
   Hope J, 2009, BIOBAZAAR OPEN SOURC
   Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
   Millar M, 2012, PUBLIC HEALTH ETH-UK, V5, P314, DOI 10.1093/phe/phs025
   Moret M, 2007, FIELD METHOD, V19, P24, DOI 10.1177/1525822X06295630
   Noy C, 2008, INT J SOC RES METHOD, V11, P327, DOI 10.1080/13645570701401305
   Overheid Nederlandse., 1998, WET MED WET OND MENS
   Palaiologou I, 2015, DOING RES ED THEORY
   Palsson G, 2011, INT J COMMONS, V5, P259
   Reichman JH, 2016, GOVERNING DIGITALLY
   Ritchie J, 2002, QUALITATIVE RES COMP, P305, DOI DOI 10.4135/9781412986274
   Rosen L. E., 2005, OPEN SOURCE LICENSIN
   Rump B, 2017, EPIDEMIOL INFECT, V145, P1431, DOI 10.1017/S0950268817000127
   Sane J., 2015, OVERCOMING BARRIERS
   Simpson CL, 2014, INT J ENV RES PUB HE, V11, P8383, DOI
10.3390/ijerph110808383
   Swanson T, 2000, ECOL ECON, V32, P75, DOI 10.1016/S0921-8009(99)00072-5
   The Convention on Biological Diversity, 1992, UN C ENV DEV RIO DE
   Tietze F, 2015, TECHNOVATION, V38, P50, DOI
10.1016/j.technovation.2014.11.001
   van den Nieuwboer M., 2016, PharmaNutrition, V4, P9, DOI
10.1016/j.phanu.2015.09.003
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Weenen T. C., 2013, PharmaNutrition, V1, P79, DOI 10.1016/j.phanu.2013.04.001
   WHO, 2011, PAND INFL PREP FRAM
   Yozwiak NL, 2015, NATURE, V518, P477, DOI 10.1038/518477a
   Zhang J, 2011, J GENET GENOMICS, V38, P95, DOI 10.1016/j.jgg.2011.02.003
NR 39
TC 1
Z9 1
U1 0
U2 3
PU PUBLIC LIBRARY SCIENCE
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PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
SN 1932-6203
J9 PLOS ONE
JI PLoS One
PD MAY 2
PY 2018
VL 13
IS 5
AR e0195885
DI 10.1371/journal.pone.0195885
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WC Multidisciplinary Sciences
SC Science & Technology - Other Topics
GA GE5SH
UT WOS:000431281900037
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OA DOAJ Gold, Green Published
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PT J
AU Evans, BJ
   Jarvik, GP
AF Evans, Barbara J.
   Jarvik, Gail P.
TI Impact of HIPAA's minimum necessary standard on genomic data sharing
SO GENETICS IN MEDICINE
LA English
DT Article
DE genomic data sharing; HIPAA Privacy Rule; minimum necessary standard;
   research; treatment uses
AB This article provides a brief introduction to the Health Insurance
Portability and Accountability Act of 1996 (HIPAA) Privacy Rule's minimum
necessary standard, which applies to sharing of genomic data, particularly
clinical data, following 2013 Privacy Rule revisions. This research used the
Thomson Reuters Westlaw database and law library resources in its legal analysis
of the HIPAA privacy tiers and the impact of the minimum necessary standard on
genomic data sharing. We considered relevant example cases of genomic data-
sharing needs. In a climate of stepped-up HIPAA enforcement, this standard is of
concern to laboratories that generate, use, and share genomic information. How
data-sharing activities are characterized-whether for research, public health,
or clinical interpretation and medical practice support-affects how data access
and use. There is no clear regulatory guidance on how to apply HIPAA's minimum
necessary standard when considering the sharing of information in the data-rich
environment of genomic testing. Laboratories that perform genomic testing should
engage with policy makers to foster sound, well-informed policies and
appropriate characterization of data-sharing activities to minimize adverse
impacts on day-to-day workflows.
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FX This work received support from NIH/NHGRI/NCI, UO1HG008657, UO1HG006507,
   and U01HG007307. B.E. has served on the National Committee for Vital and
   Health Statistics, but the views expressed here are her own and do not
   reflect views of the Committee.
CR Donelson Baker, 2011, HIPAA POL AR COM REA
   National Committee on Vital and Health Statistics, 2016, REC HIPAA MIN NEC ST,
P22
   U.S. Department of Health and Human Services. Office for Civil Rights, 2013,
FED REGISTER, V78, P5566
   US Department of Health and Human Services, 2017, TOP 5 ISS INV CAS CL
   US Department of Health and Human Services, 2013, FAQ GUID
NR 5
TC 1
Z9 1
U1 2
U2 5
PU NATURE PUBLISHING GROUP
PI NEW YORK
PA 75 VARICK ST, 9TH FLR, NEW YORK, NY 10013-1917 USA
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J9 GENET MED
JI Genet. Med.
PD MAY
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IS 5
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WC Genetics & Heredity
SC Genetics & Heredity
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OA Green Accepted
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PT J
AU Howe, N
   Giles, E
   Newbury-Birch, D
   McColl, E
AF Howe, Nicola
   Giles, Emma
   Newbury-Birch, Dorothy
   McColl, Elaine
TI Systematic review of participants' attitudes towards data sharing: a
   thematic synthesis
SO JOURNAL OF HEALTH SERVICES RESEARCH & POLICY
LA English
DT Review
DE attitude; data sharing; research participant
ID HEALTH INFORMATION; INFORMED-CONSENT; VIEWS; TRUST; EXPERIENCES;
   OPINIONS; PRIVACY; LINKAGE
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AB Objectives Data sharing is well established in biological research, but evidence on sharing of clinical trial or public health research study data remains limited, in particular studies of research participants' perspectives of data sharing. This study systematically reviewed international evidence of research participants' attitudes towards the sharing of data for secondary research use.

Methods Systematic search of seven databases, and author-, citation- and bibliography-follow up to identify studies examining research participants' attitudes towards data sharing. Studies were thematically analysed using NVivo v10 to identify recurring themes.

Results Nine studies were eligible for inclusion. Thematic analysis identified four key themes: (1) benefits of data sharing, including benefit to participants or immediate community, benefits to the public and benefits to science or research; (2) fears and harms, such as fear of exploitation, stigmatization or repercussions, alongside concerns about confidentiality and misuse of data; (3) data sharing processes, in particular the role of consent in the process; and (4) the relationship between participants and research such as trust in different types of research or organization and the relationship with the original research team.

Conclusions The available literature on attitudes towards sharing data from clinical trials or public health interventions remains scant. This study has identified four themes regarding research participants' attitudes and preferences, which should be considered by policy makers, and explored with further research.

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CR Aitken M, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0153-x
Asai A, 2002, BMC MED ETHICS, V3, P10
BestBETs, 2012, BETS CA WORKSH
CASP, 2013, CRIT APPR SKILLS FRA
Chan TW, 2012, INT J EVID-BASED HEA, V10, P9, DOI 10.1111/j.1744-1609.2011.00251.x
Cheah PY, 2015, J EMPIR RES HUM RES, V10, P278, DOI 10.1177/1556264615592388
Grande D, 2013, JAMA INTERN MED, V173, P1798, DOI 10.1001/jamainternmed.2013.9166
Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383
Hill EM, 2013, BMC MED RES METHODOL, V13, DOI 10.1186/1471-2288-13-72
Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Jao I, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135545
Jao I, 2015, J EMPIR RES HUM RES, V10, P264, DOI 10.1177/1556264615592385
Kass NE, 2003, J LAW MED ETHICS, V31, P429, DOI 10.1111/j.1748-720X.2003.tb00105.x
King T, 2012, INT J MED INFORM, V81, P279, DOI 10.1016/j.ijmedinf.2012.01.005
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
Loder E, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2373
Ludman EJ, 2010, J EMPIR RES HUM RES, V5, P9, DOI 10.1525/jer.2010.5.3.9
Manhas KP, 2015, J EMPIR RES HUM RES, V10, P88, DOI 10.1177/1556264614564970

```
   Manhas Kiran Pohar, 2016, Life Sci Soc Policy, V12, P1, DOI 10.1186/s40504-
016-0034-6
   da Silva MEM, 2012, J MED ETHICS, V38, P639, DOI 10.1136/medethics-2011-
100208
   Merson L, 2015, J EMPIR RES HUM RES, V10, P251, DOI 10.1177/1556264615592387
   Moher D, 2015, SYST REV, V4, DOI 10.1186/2046-4053-4-1
   Nair Kalpana, 2004, J Health Serv Res Policy, V9, P22, DOI
10.1258/135581904322716076
   Pampel H, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0078080
   Platt J, 2015, J PERS MED, V5, P3, DOI 10.3390/jpm5010003
   PLOS, 2014, DAT AV
   PROSPERO, 2017, INT PROSP REG SYST R
   Robling MR, 2004, J MED ETHICS, V30, P104, DOI 10.1136/jme.2003.005157
   Rowhani-Farid A, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2016-011784
   Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI
10.1586/14737159.2014.961917
   Stone MA, 2005, BRIT J GEN PRACT, V55, P783
   Taichman DB, 2016, JAMA-J AM MED ASSOC, V315, P467, DOI
10.1001/jama.2015.18164
   Taylor Mark J, 2014, Life Sci Soc Policy, V10, P15, DOI 10.1186/s40504-014-
0015-6
   Thomas J, 2008, BMC MED RES METHODOL, V8, DOI 10.1186/1471-2288-8-45
   Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
   UK Data Archive, 2015, UKS LARG COLL DIG RE
   UK Data Service, 2016, MAN DAT PLAN SHAR
   UK Data Service, 2012, CONS DAT SHAR
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Whyte A, 2015, KEEP RES DATA DCC CH
NR 40
TC 1
Z9 1
U1 2
U2 17
PU SAGE PUBLICATIONS INC
PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
SN 1355-8196
EI 1758-1060
J9 J HEALTH SERV RES PO
JI J. Health Serv. Res. Policy
PD APR
PY 2018
VL 23
IS 2
BP 123
EP 133
DI 10.1177/1355819617751555
PG 11
WC Health Policy & Services
SC Health Care Sciences & Services
GA GC9JQ
UT WOS:000430113700008
PM 29653503
DA 2019-08-06
ER

PT J
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   Plutchak, TS
   Akers, KG
AF Read, Kevin B.
   Amos, Liz
   Federer, Lisa M.
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   Plutchak, T. Scott
   Akers, Katherine G.
TI Practicing what we preach: developing a data sharing policy for the
   Journal of the Medical Library Association
SO JOURNAL OF THE MEDICAL LIBRARY ASSOCIATION
LA English
DT Editorial Material
AB Providing access to the data underlying research results in published
literature allows others to reproduce those results or analyze the data in new
ways. Health sciences librarians and information professionals have long been
advocates of data sharing. It is time for us to practice what we preach and
share the data associated with our published research. This editorial describes
the activity of a working group charged with developing a research data sharing
policy for the Journal of the Medical Library Association.
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   Read, Kevin/0000-0002-7511-9036; Akers, Katherine/0000-0002-4578-6575;
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FU National Library of Medicine (NLM), National Institutes of Health
FX We thank the authors of JMLA articles who shared their data or concerns
   about data sharing with our data sharing policy working group. The
   contributions to this work by Liz Amos were provided with the support of
   the National Library of Medicine (NLM), National Institutes of Health.
CR [Anonymous], 2014, PLOS ONE
   [Anonymous], 2017, NATURE, V546, P327
   [Anonymous], 2015, SCIENCE
   [Anonymous], 2016, GIGASCIENCE
   Borgman CL, 2007, INT J DIGIT LIBRARIE, V7, P17, DOI 10.1007/s00799-007-0022-
9
   Cox AM, 2014, J LIBR INF SCI, V46, P299, DOI 10.1177/0961000613492542
   Higman R, 2015, PROGRAM-ELECTRON LIB, V49, P364, DOI 10.1108/PROG-01-2015-
0005
   Marcus A, 2017, STAT NEWS       0606
   Research Data Alliance, 2017, DAT POL STAND IMPL
   Taichman DB, 2017, NEW ENGL J MED, V376, P2277, DOI 10.1056/NEJMe1705439
   Wallis JC, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067332
   Warren E, 2016, NEW ENGL J MED, V375, P401, DOI 10.1056/NEJMp1607282
```

```
NR 12
TC 1
Z9 1
U1 1
U2 7
PU MEDICAL LIBRARY ASSOC
PI CHICAGO
PA 65 EAST WACKER PLACE, STE 1900, CHICAGO, IL 60601-7298 USA
SN 1536-5050
J9 J MED LIBR ASSOC
JI J. Med. Libr. Assoc.
PD APR
PY 2018
VL 106
IS 2
BP 155
EP 158
DI 10.5195/jmla.2018.431
PG 4
WC Information Science & Library Science
SC Information Science & Library Science
GA GC1SM
UT WOS:000429562100001
PM 29632437
OA DOAJ Gold, Green Published
DA 2019-08-06
ER

PT J
AU Wise, J
AF Wise, Jacqui
TI Sharing of patient data didn't breach rules, says public health agency
SO BMJ-BRITISH MEDICAL JOURNAL
LA English
DT News Item
CR [Anonymous], 2018, TELEGRAPH
   Caldicott F., 2016, REV DATA SECURITY CO
   Culnane C, 2017, HLTH DATA OPEN WORLD
   Department of Health, YOUR DAT BETT SEC BE
   Selbie D., 2018, TELEGRAPH, P17
NR 5
TC 1
Z9 1
U1 0
U2 1
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1756-1833
J9 BMJ-BRIT MED J
JI BMJ-British Medical Journal
PD JAN 22
PY 2018
VL 360
AR k293
DI 10.1136/bmj.k293
PG 2
WC Medicine, General & Internal
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SC General & Internal Medicine
GA FU2WL
UT WOS:000423710600003
PM 29358484
DA 2019-08-06
ER

PT B
AU Thwin, TT
   Vasupongayya, S
AF Thwin, Thein Than
   Vasupongayya, Sangsuree
GP IEEE
TI Blockchain Based Secret-Data Sharing Model for Personal Health Record
   System
SO 2018 5TH INTERNATIONAL CONFERENCE ON ADVANCED INFORMATICS: CONCEPTS,
   THEORY AND APPLICATIONS (ICAICTA 2018)
LA English
DT Proceedings Paper
CT 5th International Conference on Advanced Informatics - Concepts, Theory
   and Applications (ICAICTA)
CY AUG 14-17, 2018
CL Krabi, THAILAND
SP IEEE, IEEE Thailand Sect, IEEE Xplore Digital Lib, Toyohashi Univ Technol,
Inst Teknologi Bandung, Univ Sains Malaysia, Sirindhorn Int Inst Technol,
Burapha Univ, Fac Informat
DE PHRs; proxy re-encryption; cryptography; hyperledger; data sharing
AB The blockchain systems are analyzed under the context of the personal health
record system (PHRs) requirements. The transparent property of blockchain may
cause the privacy and confidentiality concerns for PHRs. The append-only storage
of blockchain can be a barrier for implementing the revocability of consent in
PHRs. Moreover, the health care data can be very large exceeding the practical
storage capabilities of the current blockchain usages. The most important issues
of blockchain include the limited storage, privacy, consent revocation,
performance, energy consumption and scalability. A blockchain based secret-data
sharing model is proposed by using a proxy re-encryption technique to support
the PHRs in this work. Some potential attacks which can attempt on the proposed
model and how the model can handle such attempts is also discussed.
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FU Higher Education Research Promotion and the Thailand's Education Hub for
   Southern Region of ASEAN Countries Project Office of the Higher
   Education Commission
FX The Higher Education Research Promotion and the Thailand's Education Hub
   for Southern Region of ASEAN Countries Project Office of the Higher
   Education Commission supported our work.
CR Aguilera MK, 1999, SIAM J COMPUT, V28, P890
   [Anonymous], 2018, CONS HLTH INF TECHN
   Ateniese G., 2006, ACM Transactions on Information and Systems Security, V9,
P1, DOI 10.1145/1127345.1127346
   Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG
DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11
```

Baird A., 2011, P 2011 ICONFERENCE 2, P281, DOI [10.1145/1940761.1940800, DOI 10.1145/1940761.1940800]
Blough D. M., 2011, TECHNICAL REPORT
Cachin Christian, 2016, ARCHITECTURE HYPERLE
Cahill JE, 2014, J NEURO-ONCOL, V117, P1, DOI 10.1007/s11060-013-1333-x
Christidis K, 2016, IEEE ACCESS, V4, P2292, DOI 10.1109/ACCESS.2016.2566339
Croman K, 2016, LECT NOTES COMPUT SC, V9604, P106, DOI 10.1007/978-3-662-53357-4_8
Gunn PP, 2004, MED CARE, V42, P321, DOI 10.1097/01.mlr.0000119578.94846.f2
Hintzman Z., 2017, 2017 FALL TECHN FOR
Kosba A, 2016, P IEEE S SECUR PRIV, P839, DOI 10.1109/SP.2016.55
Markus B., DOGECOIN
MILLER M, 2016, PROCEEDINGS OF THE 2, P31
Nakamoto S., 2008, BITCOIN PEER TO PEER
Nass S. J., 2009, VALUE IMPORTANCE HLT
P. Labs, IPFS IS DISTR WEB
Pfitzmann A., 2001, Designing Privacy Enhancing Technologies. International Workshop on Design Issues in Anonymity and Unobservability. Proceedings (Lecture Notes in Computer Science Vol.2009), P1
Roehrs A, 2017, J BIOMED INFORM, V71, P70, DOI 10.1016/j.jbi.2017.05.012
Swan M., 2015, BLOCKCHAIN BLUEPRINT
Tang PC, 2006, J AM MED INFORM ASSN, V13, P121, DOI 10.1197/jamia.M2025
Tapscott D., 2016, BLOCKCHAIN REVOLUTIO
Dinh TTA, 2017, SIGMOD'17: PROCEEDINGS OF THE 2017 ACM INTERNATIONAL CONFERENCE ON MANAGEMENT OF DATA, P1085, DOI 10.1145/3035918.3064033
Valve, STEEM BLOCKCH BAS SO
Vukolic M., 2015, INT WORKSH OP PROBL, P112, DOI DOI 10.1007/978-3-319-39028-4-9
Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843
Xia Q, 2017, INFORMATION, V8, DOI 10.3390/info8020044
Yermack D, 2017, REV FINANC, V21, P7, DOI 10.1093/rof/rfw074
Zhao HW, 2017, 2017 IEEE 13TH INTERNATIONAL SYMPOSIUM ON AUTONOMOUS DECENTRALIZED SYSTEMS (ISADS 2017), P229, DOI 10.1109/ISADS.2017.22
NR 30
TC 1
Z9 1
U1 1
U2 1
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-5386-4804-9
PY 2018
BP 196
EP 201
PG 6
WC Computer Science, Information Systems; Computer Science, Theory & Methods
SC Computer Science
GA BM5IX
UT WOS:000465085600035
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ER

PT J
AU Guo, BY
Deng, XF
Guan, QS

Tian, J
Zheng, XW
AF Guo, Bingyi
Deng, Xiaofang
Guan, Quansheng
Tian, Jie
Zheng, Xiangwei
TI An Incentive Mechanism for Cross-Organization Data Sharing Based on Data Competitiveness
SO IEEE ACCESS
LA English
DT Article
DE Incentive mechanism; data sharing; data competitiveness; Stackelberg game
ID HEALTH-CARE DATA; NETWORKS; PRIVACY

AB In the era of big data and artificial intelligence, data sharing is desirable for vigorous development of data-driven services, which improves our daily life. Although data sharing is supported to a certain extent by current mechanisms and technologies, organizations especially with potential competitive relationships might refuse to share their data due to the worry that data sharing improves competitors' competitiveness. To address this problem, this paper focuses on the competitiveness-driven target of win-win, and provides incentives to encourage potentially competing organizations to share their data. By introducing the concept of data competitiveness as a data transaction driving force, an incentive mechanism based on data competitiveness is established, which is formulated as a Stackelberg game. A gradient-based iteration algorithm is proposed to obtain the Stackelberg equilibrium solution to the data sharing incentive problem. Simulation results substantiate that performance of data sharing can be improved significantly by the proposed scheme.

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FU National Science Natural Fund of China [61801278, 61373149]; Guangxi Provincial Education Department Foundation [2017KY0202]; Guangxi Cognitive Radio and Information Processing Key Laboratory [CRKL150110]; 2017 Open Foundation [CRKL170203]; Guangxi Broadband Wireless Communication and Signal Processing Key Laboratory Foundation [GXKL06160114]; National Infrastructure Project [NSFC61571143]; Shandong Provincial Natural Science Foundation for Young Scholars of China [ZR2017QF008]; Shandong Provincial Scientific Research Programs in Colleges and Universities [J18KA310]; Shandong Provincial Key Laboratory of Computer Network [SDKLCN-2016-02]
FX This work was supported in part by the National Science Natural Fund of China under Grant 61801278 and Grant 61373149, in part by the Guangxi Provincial Education Department Foundation under Grant 2017KY0202, in part by the Guangxi Cognitive Radio and Information Processing Key Laboratory Authorized by China's Ministry of Education Foundation under Grant CRKL150110, in part by the 2017 Open Foundation under Grant

CRKL170203, in part by the Guangxi Broadband Wireless Communication and Signal Processing Key Laboratory Foundation under Grant GXKL06160114, in part by the National Infrastructure Project under Grant NSFC61571143, in part by the Shandong Provincial Natural Science Foundation for Young Scholars of China under Grant ZR2017QF008, in part by the Shandong Provincial Scientific Research Programs in Colleges and Universities under Grant J18KA310, and in part by the Open Research Fund from the Shandong Provincial Key Laboratory of Computer Network under Grant SDKLCN-2016-02.

CR Alharbi KN, 2017, IEEE INTERNET THINGS, V4, P555, DOI 10.1109/JIOT.2016.2561908
Bu SR, 2013, IEEE INFOCOM SER, P980
Duan LJ, 2014, IEEE T MOBILE COMPUT, V13, P2320, DOI 10.1109/TMC.2014.2307327
Fabian B, 2015, INFORM SYST, V48, P132, DOI 10.1016/j.is.2014.05.004
Gao H, 2015, IEEE COMMUN SURV TUT, V17, P918, DOI 10.1109/COMST.2014.2387836
Groves P., 2016, MCKINSEY CO, V2, P13
Guo BY, 2014, IEEE T WIREL COMMUN, V13, P6484, DOI 10.1109/TWC.2014.2325864
Hassan MM, 2017, FUTURE GENER COMP SY, V66, P48, DOI 10.1016/j.future.2015.12.016
Hou SJ, 2017, PATTERN RECOGN, V68, P66, DOI 10.1016/j.patcog.2017.03.003
Jin AL, 2016, IEEE T SERV COMPUT, V9, P895, DOI 10.1109/TSC.2015.2430315
Juong-Sik Lee, 2010, 2010 IEEE International Conference on Pervasive Computing and Communications (PerCom 2010), P60, DOI 10.1109/PERCOM.2010.5466993
Kreinovich V, 2013, COMPUTATIONAL COMPLE, V10
Kwak D, 2016, IEEE ACCESS, V4, P3617, DOI 10.1109/ACCESS.2016.2569585
Li R, 2017, IEEE INTERNET THINGS, V4, P791, DOI 10.1109/JIOT.2017.2666799
Ma Q., 2016, P IEEE WIOPT MAY, P1
Poldrack RA, 2014, NAT NEUROSCI, V17, P1510, DOI 10.1038/nn.3818
Skopik F, 2016, COMPUT SECUR, V60, P154, DOI 10.1016/j.cose.2016.04.003
Stoica I., 2017, BERKELEY VIEW SYSTEM
Tian J, 2018, IEEE T COMMUN, V66, P1064, DOI 10.1109/TCOMM.2017.2775239
Wang X, 2017, IEEE T VEH TECHNOL, V66, P2902, DOI 10.1109/TVT.2016.2592685
Will MA, 2017, IEEE TRUST BIG, P1024, DOI 10.1109/Trustcom/BigDataSE/ICESS.2017.347
Xu L, 2015, IEEE J-STSP, V9, P1256, DOI 10.1109/JSTSP.2015.2425798
Zhang T, 2018, IEEE ACCESS, V6, P2760, DOI 10.1109/ACCESS.2017.2785265
Zheng ZZ, 2017, IEEE T MOBILE COMPUT, V16, P2392, DOI 10.1109/TMC.2016.2632721

NR 24
TC 1
Z9 1
U1 7
U2 7
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
PI PISCATAWAY
PA 445 HOES LANE, PISCATAWAY, NJ 08855-4141 USA
SN 2169-3536
J9 IEEE ACCESS
JI IEEE Access
PY 2018
VL 6
BP 72836
EP 72844
DI 10.1109/ACCESS.2018.2882233
PG 9
WC Computer Science, Information Systems; Engineering, Electrical & Electronic; Telecommunications
SC Computer Science; Engineering; Telecommunications

GA HE8SM
UT WOS:000453717700001
OA DOAJ Gold
DA 2019-08-06
ER

PT J
AU Huang, QL
Yue, W
He, Y
Yang, YX
AF Huang, Qinlong
Yue, Wei
He, Yue
Yang, Yixian
TI Secure Identity-Based Data Sharing and Profile Matching for Mobile Healthcare Social Networks in Cloud Computing
SO IEEE ACCESS
LA English
DT Article
DE Conditional proxy re-encryption; data security; encryption; health information management; profile matching
ID PROXY RE-ENCRYPTION; PUBLIC-KEY ENCRYPTION; EQUALITY TEST; EFFICIENT

AB Cloud computing and social networks are changing the way of healthcare by providing real-time data sharing in a cost-effective manner. However, data security issue is one of the main obstacles to the wide application of mobile healthcare social networks (MHSNs), since health information is considered to be highly sensitive. In this paper, we introduce a secure data sharing and profile matching scheme for the MHSN in cloud computing. The patients can outsource their encrypted health records to cloud storage with an identity-based broadcast encryption technique, and share them with a group of doctors in a secure and efficient manner. We then present an attribute-based conditional data re-encryption construction which permits the doctors who satisfy the pre-defined conditions in the ciphertext to authorize the cloud platform to convert a ciphertext into a new ciphertext of an identity-based encryption scheme for specialist without leaking any sensitive information. Furthermore, we provide a profile matching mechanism in the MHSN based on identity-based encryption with an equality test, which helps patients to find friends in a privacy-preserving way and achieves flexible authorization on the encrypted health records with resisting the keywords guessing attack. Moreover, this mechanism reduces the computation cost on the patient side. The security analysis and experimental evaluation show that our scheme is practical for protecting the data security and privacy in the MHSN.

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FU National Key Research and Development Program of China [2016YFB0800605]; National Natural Science Foundation of China [61572080]; Key Program of Joint Funds of the National Natural Science Foundation of China [U1736212]; China Scholarship Council [201806475007]
FX This work was supported in part by the National Key Research and Development Program of China under Grant 2016YFB0800605, in part by the National Natural Science Foundation of China under Grant 61572080, in part by the Key Program of Joint Funds of the National Natural Science Foundation of China under Grant U1736212, and in part by the China Scholarship Council under Grant 201806475007.

CR Abbas A, 2014, IEEE J BIOMED HEALTH, V18, P1431, DOI 10.1109/JBHI.2014.2300846
Barua Mrinmoy, 2011, International Journal of Security and Networks, V6, P67, DOI 10.1504/IJSN.2011.043666
Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
Blaze M, 1998, LECT NOTES COMPUT SC, V1403, P127
Delerablee C, 2007, LECT NOTES COMPUT SC, V4833, P200
Green M, 2007, LECT NOTES COMPUT SC, V4521, P288
Guo LK, 2012, INT CON DISTR COMP S, P224, DOI 10.1109/ICDCS.2012.45
Huang Q., 2018, SENSORS, V18, pE666
Huang Q., IEEE T SERV COMPUT, DOI [10.1109/TSC.2018.2850344, DOI 10.1109/TSC.2018.2850344.]
Huang QL, 2018, FUTURE GENER COMP SY, V86, P1523, DOI 10.1016/j.future.2017.05.026
Jian Weng R. H.-K., 2009, ASIACCS 2009, P322
Li GC, 2018, CONCURR COMP-PRACT E, V30, DOI 10.1002/cpe.4236
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Li M, 2011, IEEE INFOCOM SER, P2435, DOI 10.1109/INFCOM.2011.5935065
Liang KT, 2015, FUTURE GENER COMP SY, V52, P95, DOI 10.1016/j.future.2014.11.016
Liu Y, 2018, FUTURE GENER COMP SY, V78, P1020, DOI 10.1016/j.future.2016.12.027
Ma S, 2016, INFORM SCIENCES, V328, P389, DOI 10.1016/j.ins.2015.08.053
Ma S, 2015, IEEE T INF FOREN SEC, V10, P458, DOI 10.1109/TIFS.2014.2378592
Matsuo T, 2007, LECT NOTES COMPUT SC, V4575, P247
Qiu S., IEEE T CLOUD COMPUT, DOI [10.1109/TCC.2015.2511723, DOI 10.1109/TCC.2015.2511723.]
Shucheng Y, 2010, P IEEE INFOCOM, P1, DOI DOI 10.1109/INFCOM.2010.5462174
Tan CC, 2009, IEEE T INF TECHNOL B, V13, P926, DOI 10.1109/TITB.2009.2033055
Wang XA, 2017, FUTURE GENER COMP SY, V67, P242, DOI 10.1016/j.future.2016.08.008
Wu L., 2018, IEEE T SUSTAIN COMPU, V3, P44, DOI DOI 10.1109/TSUSC.2017.2734110
Wu LB, 2017, FUTURE GENER COMP SY, V73, P22, DOI 10.1016/j.future.2017.03.007
Xu P, 2016, IEEE T COMPUT, V65, P66, DOI 10.1109/TC.2015.2417544
Yang GM, 2010, LECT NOTES COMPUT SC, V5985, P119
Yang Y., IEEE T DEPEND SECURE, DOI [10.1109/TDSC.2017.2729556, DOI 10.1109/TDSC.2017.2729556.]
Yang Y., IEEE T IND INFORM, DOI [10.1109/TII.2017.2751640, DOI 10.1109/TII.2017.2751640.]
Yang YJ, 2016, PERVASIVE MOB COMPUT, V28, P122, DOI 10.1016/j.pmcj.2015.06.017
Zhang L, 2015, IEEE T MOBILE COMPUT, V14, P1888, DOI 10.1109/TMC.2014.2366773
Zhang R, 2013, IEEE J SEL AREA COMM, V31, P656, DOI 10.1109/JSAC.2013.SUP.0513057
Zhou YY, 2016, FUTURE GENER COMP SY, V62, P128, DOI 10.1016/j.future.2015.09.027
NR 33
TC 1
Z9 1
U1 2
U2 5
PU IEEE-INST ELECTRICAL ELECTRONICS ENGINEERS INC
PI PISCATAWAY
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JI IEEE Access

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BP 36584
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DI 10.1109/ACCESS.2018.2852784
PG 11
WC Computer Science, Information Systems; Engineering, Electrical &
   Electronic; Telecommunications
SC Computer Science; Engineering; Telecommunications
GA GO1GT
UT WOS:000439698700011
OA DOAJ Gold
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ER

PT J
AU Wang, HQ
AF Wang, Huaqun
TI Anonymous Data Sharing Scheme in Public Cloud and Its Application in
   E-Health Record
SO IEEE ACCESS
LA English
DT Article
DE Attribute-based encryption; cloud computing; data sharing; searchable
   encryption
ID ATTRIBUTE-BASED ENCRYPTION; PRIVACY; SECURITY
AB In the past few years, cloud computing develops very quickly. A large amount
of data are uploaded and stored in remote public cloud servers which cannot
fully be trusted by users. Especially, more and more enterprises would like to
manage their data by the aid of the cloud servers. However, when the data
outsourced in the cloud are sensitive, the challenges of security and privacy
becomes urgent for wide deployment of the cloud systems. This paper proposes a
secure data sharing scheme to ensure the privacy of data owner and the security
of the outsourced cloud data. The proposed scheme provides flexible utility of
data while solving the privacy and security challenges for data sharing. The
security and efficiency analysis demonstrate that the designed scheme is
feasible and efficient. At last, we discuss its application in electronic health
record.
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FX This work was supported in part by the Qing Lan Project of Jiangsu
   Province, in part by the 1311 Talent Plan Foundation of NUPT, NUPTSF,
   under Grant NY216001, and in part by the Open Foundation of the State
   Key Laboratory of Information Security of China under Grant 2017-MS-15.
CR Ahmed M, 2014, IBM J RES DEV, V58, DOI 10.1147/JRD.2013.2288068
   Anthony D, 2013, IEEE SECUR PRIV, V11, P25, DOI 10.1109/MSP.2013.104
   Bahga A, 2013, IEEE J BIOMED HEALTH, V17, P894, DOI 10.1109/JBHI.2013.2257818
   Beimel A, 1996, THESIS
```

Benaloh J., 2009, P 2009 ACM WORKSH CL, P103, DOI DOI 10.1145/1655008.1655024
Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P506
Boneh D, 2001, LECT NOTES COMPUTER, V2248, P514, DOI DOI 10.1007/3-540-45682-1_30
Canim M, 2012, IEEE T INF TECHNOL B, V16, P166, DOI 10.1109/TITB.2011.2171701
Cao N, 2014, IEEE T PARALL DISTR, V25, P222, DOI 10.1109/TPDS.2013.45
Changji Wang, 2013, International Journal of Intelligent Information and Database Systems, V7, P389
Chen XF, 2016, IEEE T COMPUT, V65, P3184, DOI 10.1109/TC.2015.2512870
Chen XF, 2015, IEEE T INF FOREN SEC, V10, P69, DOI 10.1109/TIFS.2014.2363765
Chu CK, 2014, IEEE T PARALL DISTR, V25, P468, DOI 10.1109/TPDS.2013.112
D'Souza R, 2011, LECT NOTES COMPUT SC, V7107, P290
Dunning LA, 2013, IEEE T INF FOREN SEC, V8, P402, DOI 10.1109/TIFS.2012.2235831
Fan CI, 2014, IEEE T COMPUT, V63, P1951, DOI 10.1109/TC.2013.83
Gao C, 2018, CLUSTER COMPUT, P1, DOI DOI 10.1007/S10586-017-1649-Y
Goyal V, 2008, LECT NOTES COMPUT SC, V5126, P579, DOI 10.1007/978-3-540-70583-3_47
Haas S, 2011, INT J MED INFORM, V80, pE26, DOI 10.1016/j.ijmedinf.2010.10.001
Lesk M, 2013, IEEE SECUR PRIV, V11, P19, DOI 10.1109/MSP.2013.78
Li J, 2018, COMPUT SECUR, V72, P1, DOI [10.1080/10641963.2018.1469639, 10.1016/j.cose.2017.08.007]
Li J, 2015, IEEE T COMPUT, V64, P3569, DOI 10.1109/TC.2015.2401017
Li J, 2015, IEEE T PARALL DISTR, V26, P1206, DOI 10.1109/TPDS.2014.2318320
Li J, 2015, IEEE T COMPUT, V64, P425, DOI 10.1109/TC.2013.208
Li J, 2014, IEEE T PARALL DISTR, V25, P2201, DOI 10.1109/TPDS.2013.271
Li JW, 2016, IEEE T COMPUT, V65, P2386, DOI 10.1109/TC.2015.2389960
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Li P, 2017, FUTURE GENER COMP SY, V74, P76, DOI 10.1016/j.future.2017.02.006
Li T, 2017, J COMPUT SYST SCI, V89, P80, DOI 10.1016/j.jcss.2016.12.004
Fernandez-Aleman JL, 2013, J BIOMED INFORM, V46, P541, DOI 10.1016/j.jbi.2012.12.003
Miyaji A, 2001, IEICE T FUND ELECTR, VE84A, P1234
Ostrovsky R., ATTRIBUTE BASED ENCR
Ostrovsky R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P195
Pervez Z, 2012, J SUPERCOMPUT, V62, P431, DOI 10.1007/s11227-011-0727-9
Rosenthal A, 2010, J BIOMED INFORM, V43, P342, DOI 10.1016/j.jbi.2009.08.014
Seo SH, 2014, IEEE T KNOWL DATA EN, V26, P2107, DOI 10.1109/TKDE.2013.138
Shen J, 2018, J NETW COMPUT APPL, V106, P117, DOI 10.1016/j.jnca.2018.01.003
Sun JY, 2010, IEEE T PARALL DISTR, V21, P754, DOI 10.1109/TPDS.2009.124
Sun WH, 2014, IEEE INFOCOM SER, P226, DOI 10.1109/INFOCOM.2014.6847943
Tong Y, 2014, IEEE J BIOMED HEALTH, V18, P419, DOI 10.1109/JBHI.2013.2294932
Wang HQ, 2014, IET INFORM SECUR, V8, P114, DOI 10.1049/iet-ifs.2012.0271
Wu D, 2010, INT CONF COMP SCI, P268, DOI 10.1109/ICCSIT.2010.5563744
Xhafa F, 2015, MULTIMED TOOLS APPL, V74, P3441, DOI 10.1007/s11042-013-1829-6
Zhang YH, 2017, INFORM SCIENCES, V379, P42, DOI 10.1016/j.ins.2016.04.015
NR 45
TC 1
Z9 1
U1 1
U2 3
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SC Computer Science; Engineering; Telecommunications
GA GJ7FS
UT WOS:000435551600001
OA DOAJ Gold
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PT J
AU Jee, H
   Lee, HD
   Lee, SY
AF Jee, Hyunseok
   Lee, Hae-Dong
   Lee, Sae Yong
TI Evidence-Based Cutoff Threshold Values from Receiver Operating
   Characteristic Curve Analysis for Knee Osteoarthritis in the 50-Year-Old
   Korean Population: Analysis of Big Data from the National Health
   Insurance Sharing Service
SO BIOMED RESEARCH INTERNATIONAL
LA English
DT Article
ID MUSCLE STRENGTH; GLUCOSAMINE; SULFATE
AB We aimed to investigate the characteristics of patients with osteoarthritis
(OA), using the data of all Koreans registered in the National Health Insurance
Sharing Service Database (NHISS DB), and to provide ideal alternative cutoff
thresholds for alleviating OA symptoms. Patients with OA (codes M17 and M17.1-
M17.9 in the Korean Standard Classification of Disease and Causes of Death) were
analyzed using SAS software. Optimal cutoff thresholds were determined using
receiver operating characteristic curve analysis. The 50-year age group was the
most OA pathogenic group (among 40 similar to 70 years, n = 2088). All exercise
types affected the change of body mass index (p < 0.05) and the sex difference
in blood pressure (BP) (p < 0.01). All types of exercise positively affected the
loss of waist circumference and the balance test (standing time on one leg in
seconds) (p < 0.01). The cutoff threshold for the time in seconds from standing
up from a chair to walking 3 m and returning to the same chair was 8.25 (80%
sensitivity and 100% specificity). By using the exercise modalities, categorized
multiple variables, and the cutoff threshold, an optimal alternative exercise
program can be designed for alleviating OA symptoms in the 50-year age group.
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FX This study was supported by the Ministry of Education and the National
   Research Foundation of Korea (NRF-2015S1A5B8036349).
CR Chang AH, 2013, OSTEOARTHR CARTILAGE, V21, P1668, DOI
[10.1016/j.joca.2013.08.007, 10.1016/j.joca2013.08.007]
   Clegg DO, 2006, NEW ENGL J MED, V354, P795, DOI 10.1056/NEJMoa052771
   Colak TK, 2017, RHEUMATOL INT, V37, P399, DOI 10.1007/s00296-016-3646-5
   de Zwart AH, 2015, J RHEUMATOL, V42, P1218, DOI 10.3899/jrheum.140517
   Kim HY, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0158918
   Kim KI, 2017, KOREAN J INTERN MED, V32, P199, DOI 10.3904/kjim.2016.218
   Lee SG, 2011, ANN GERIATR MED RES, V15, P8, DOI 10.4235/jkgs.2011.15.1.8
   Lim JY, 2010, ANN GERIATR MED RES, V14, P8, DOI 10.4235/jkgs.2010.14.1.8
   Lin SH, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0178292
   Moyer RF, 2014, OSTEOARTHR CARTILAGE, V22, P1989, DOI
10.1016/j.joca.2014.06.034
   Moyer RF, 2015, NAT REV RHEUMATOL, V11, P65, DOI 10.1038/nrrheum.2014.211
   Runhaar J, 2016, SEMIN ARTHRITIS RHEU, V45, pS42, DOI
10.1016/j.semarthrit.2015.11.001
   Segal NA, 2011, PHYSICIAN SPORTSMED, V39, P44, DOI 10.3810/psm.2011.11.1938
   Yamagami R, 2017, KNEE, V24, P390, DOI 10.1016/j.knee.2016.12.004
NR 14
TC 1
Z9 1
U1 0
U2 9
PU HINDAWI LTD
PI LONDON
PA ADAM HOUSE, 3RD FLR, 1 FITZROY SQ, LONDON, W1T 5HF, ENGLAND
SN 2314-6133
EI 2314-6141
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JI Biomed Res. Int.
PY 2018
AR 2013671
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PT J
AU Wen, CH
   Ou, SM
   Guo, XB
   Liu, CF
   Shen, YB
   You, N
   Cai, WH
   Shen, WJ
   Wang, XQ
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   Tan, HZ
AF Wen, Can-Hong
   Ou, Shao-Min
   Guo, Xiao-Bo
   Liu, Chen-Feng
   Shen, Yan-Bo
   You, Na
   Cai, Wei-Hong
   Shen, Wen-Jun
   Wang, Xue-Qin
   Tan, Hai-Zhu
TI B-CAN: a resource sharing platform to improve the operation,
   visualization and integrated analysis of TCGA breast cancer data
SO ONCOTARGET
LA English
DT Article
DE TCGA; breast cancer; data customization; data visualization; private
   data center
ID GENOMICS
AB Breast cancer is a high-risk heterogeneous disease with myriad subtypes and
complicated biological features. The Cancer Genome Atlas (TCGA) breast cancer
database provides researchers with the large-scale genome and clinical data via
web portals and FTP services. Researchers are able to gain new insights into
their related fields, and evaluate experimental discoveries with TCGA. However,
it is difficult for researchers who have little experience with database and
bioinformatics to access and operate on because of TCGA's complex data format
and diverse files. For ease of use, we build the breast cancer (B-CAN) platform,
which enables data customization, data visualization, and private data center.
The B-CAN platform runs on Apache server and interacts with the backstage of
MySQL database by PHP. Users can customize data based on their needs by
combining tables from original TCGA database and selecting variables from each
table. The private data center is applicable for private data and two types of
customized data. A key feature of the B-CAN is that it provides single table
display and multiple table display. Customized data with one barcode
corresponding to many records and processed customized data are allowed in
Multiple Tables Display. The B-CAN is an intuitive and high-efficient data-
sharing platform.
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   Excellent Young Scholar (11322108), NSFC (11271383), NSFC (11401600),
   NSFC (61502292), The Science and Technology Planning Project of
   Guangdong Province(2017A010101030), The Engineering and Technology
   Research Center of Guangdong Higher Education Institutes (GCZX_A1306),
   Shantou Science and Technology Project (2015-98), Science and Technology
   Planning Project of Guangdong Province (2016B090920095).
CR Andersen J, 2014, CANCER RES, V74, DOI 10.1158/1538-7445.AM2014-4272
   Bell D, 2011, NATURE, V474, P609, DOI 10.1038/nature10166
   Cerami E, 2012, CANCER DISCOV, V2, P401, DOI 10.1158/2159-8290.CD-12-0095
   Chin L, 2011, NAT MED, V17, P297, DOI 10.1038/nm.2323
   Colaprico A, 2016, NUCLEIC ACIDS RES, V44, DOI 10.1093/nar/gkv1507
   Coleman R, 2015, LANCET, V386, P1353, DOI 10.1016/S0140-6736(15)60908-4
   David A, 2015, INT J COMPUT APPL, V111, P42
   Dowsett M, 2015, LANCET, V386, P1341, DOI 10.1016/S0140-6736(15)61074-1
   Jacobsen A., 2013, EGDSR R BASED API AC
   Karabatak M, 2009, EXPERT SYST APPL, V36, P3465, DOI
10.1016/j.eswa.2008.02.064
   Koch A, 2015, BMC GENOMICS, V16, DOI 10.1186/s12864-015-1847-z
   Laurent J., 2015, INTERACTIVE DATA VIS
   Lawson DA, 2015, NATURE, V526, P131, DOI 10.1038/nature15260
   Mathes I, 2011, CHALL ACH EB E WORK, P16
   Medvedeva YA, 2015, DATABASE-OXFORD, DOI 10.1093/database/bav067
   Robbins DE, 2013, BIOINFORMATICS, V29, P1333, DOI
10.1093/bioinformatics/btt141
   Samur MK, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0106397
   Samur MK, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0056228
   Tutt A, 2015, CANCER RES, V75, DOI 10.1158/1538-7445.SABCS14-S3-01
   Wan YW, 2016, BIOINFORMATICS, V32, P952, DOI 10.1093/bioinformatics/btv677
   Wiznerowicz KT, 2014, CONT ONCOL, V19, P68
   Yip S, 2009, CLIN CANCER RES, V15, P4622, DOI 10.1158/1078-0432.CCR-08-3012
   Zhao Q, 2015, BRIEF BIOINFORM, V16, P291, DOI 10.1093/bib/bbu003
NR 23
TC 1
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U1 1
U2 4
PU IMPACT JOURNALS LLC
PI ORCHARD PARK
PA 6666 E QUAKER ST, STE 1, ORCHARD PARK, NY 14127 USA
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JI Oncotarget
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BP 108778
EP 108785
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WC Oncology; Cell Biology
SC Oncology; Cell Biology
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AU Litchman, ML
   Allen, NA
   Colicchio, VD
   Wawrzynski, SE
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   Hendricks, KL
   Berg, CA
AF Litchman, Michelle L.
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   Colicchio, Vanessa D.
   Wawrzynski, Sarah E.
   Sparling, Kerri M.
   Hendricks, Krissa L.
   Berg, Cynthia A.
TI A Qualitative Analysis of Real-Time Continuous Glucose Monitoring Data
   Sharing with Care Partners: To Share or Not to Share?
SO DIABETES TECHNOLOGY & THERAPEUTICS
LA English
DT Article
DE Type 1 diabetes; Blog; Real-time continuous glucose monitor; Data
   sharing; Care partner
ID DIABETES MANAGEMENT; SPOUSAL SUPPORT; OLDER-ADULTS; HEALTH;
   HYPOGLYCEMIA; INVOLVEMENT; OUTCOMES; IMPACT
AB Background: Little research exists regarding how real-time continuous glucose
monitoring (RT-CGM) data sharing plays a role in the relationship between
patients and their care partners. Objective: To (1) identify the benefits and
challenges related to RT-CGM data sharing from the patient and care partner
perspective and (2) to explore the number and type of individuals who share and
follow RT-CGM data. Methods: This qualitative content analysis was conducted by
examining publicly available blogs focused on RT-CGM and data sharing. A
thematic analysis of blogs and associated comments was conducted. Results: A
systematic appraisal of personal blogs examined 39 blogs with 206 corresponding
comments. The results of the study provided insight about the benefits and
challenges related to individuals with diabetes sharing their RT-CGM data with a
care partner(s). The analysis resulted in three themes: (1) RT-CGM data sharing
enhances feelings of safety, (2) the need to communicate boundaries to avoid
judgment, and (3) choice about sharing and following RT-CGM data. RT-CGM data
sharing occurred within dyads (n=46), triads (n=15), and tetrads (n=2).
Conclusions: Adults and children with type 1 diabetes and their care partners
are empowered by the ability to share and follow RT-CGM data. Our findings
suggest that RT-CGM data sharing between an individual with diabetes and their
care partner can complicate relationships. Healthcare providers need to engage
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patients and care partners in discussions about best practices related to RT-CGM sharing and following to avoid frustrations within the relationship.

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CR August KJ, 2013, J FAM PSYCHOL, V27, P712, DOI 10.1037/a0034181
Berg CA, 2013, HEALTH PSYCHOL, V32, P719, DOI 10.1037/a0029427
Berg CA, 2011, J PEDIATR PSYCHOL, V36, P329, DOI 10.1093/jpepsy/jsq088
Denecke K, 2009, INFORM SCIENCES, V179, P1870, DOI 10.1016/j.ins.2009.01.025
Ellis DA, 2007, J PEDIATR PSYCHOL, V32, P907, DOI 10.1093/jpepsy/jsm009
Forlenza GP, 2017, DIABETES TECHNOL THE, V19, pS13, DOI 10.1089/dia.2017.0034
Hilliard ME, 2015, CURR DIABETES REV, V11, P261, DOI 10.2174/1573399811666150421123448
Iida M, 2010, PERS SOC PSYCHOL B, V36, P780, DOI 10.1177/0146167210369897
Khan CM, 2013, HEALTH PSYCHOL, V32, P739, DOI 10.1037/a0028609
Lee JM, 2017, DIABETES TECHNOL THE, V19, P209, DOI 10.1089/dia.2016.0312
Litchman Michelle L, 2017, J Diabetes Sci Technol, V11, P988, DOI 10.1177/1932296817702657
Lyons RF, 1998, J SOC PERS RELAT, V15, P579, DOI 10.1177/0265407598155001
Mayberry LS, 2016, J DIABETES RES, DOI 10.1155/2016/7586385
Miles M. B., 1994, QUALITATIVE DATA ANA
Miller EA, 2010, AM J PUBLIC HEALTH, V100, P1514, DOI 10.2105/AJPH.2009.175125
Morgan D L, 1993, Qual Health Res, V3, P112, DOI 10.1177/104973239300300107
Pettus Jeremy, 2017, J Diabetes Sci Technol, V11, P138, DOI 10.1177/1932296816663747
Pickup JC, 2015, DIABETES CARE, V38, P544, DOI 10.2337/dc14-1855
Polonsky William H, 2016, J Diabetes Sci Technol, V10, P892, DOI 10.1177/1932296816643542
Punthakee Z, 2012, DIABETES CARE, V35, P787, DOI 10.2337/dc11-1855
Ritholz MD, 2014, DIABETIC MED, V31, P47, DOI 10.1111/dme.12276
Sandelowski M, 2000, RES NURS HEALTH, V23, P334, DOI 10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
Sparling KP, 2015, CAN FOLLOW YOUR CGM
Tesch R., 1990, QUALITATIVE RES ANAL
Wiebe DJ, 2016, AM PSYCHOL, V71, P526, DOI 10.1037/a0040355
Wilson E, 2015, INT J QUAL METH, V14, DOI 10.1177/1609406915618049
Yaffe K, 2013, JAMA INTERN MED, V173, P1300, DOI 10.1001/jamainternmed.2013.6176

NR 27
TC 1
Z9 1
U1 1
U2 3

PU MARY ANN LIEBERT, INC
PI NEW ROCHELLE
PA 140 HUGUENOT STREET, 3RD FL, NEW ROCHELLE, NY 10801 USA
SN 1520-9156
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J9 DIABETES TECHNOL THE
JI Diabetes Technol. Ther.

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PD JAN
PY 2018
VL 20
IS 1
BP 25
EP 31
DI 10.1089/dia.2017.0285
EA NOV
EY 2017
PG 7
WC Endocrinology & Metabolism
SC Endocrinology & Metabolism
GA FS4MQ
UT WOS:000417202300001
PM 29154685
DA 2019-08-06
ER

PT J
AU Bhartiya, S
   Mehrotra, D
   Girdhar, A
AF Bhartiya, Shalini
   Mehrotra, Deepti
   Girdhar, Anup
TI Proposing hierarchy-similarity based access control framework: A
   multilevel Electronic Health Record data sharing approach for
   interoperable environment
SO JOURNAL OF KING SAUD UNIVERSITY-COMPUTER AND INFORMATION SCIENCES
LA English
DT Article
DE Access control policies; Electronic Health Records (EHR); Hierarchical
   Similarity Analyzer (HSA); Interoperable healthcare environment;
   Security
ID VERIFICATION
AB Interoperability in healthcare environment deals with sharing of patient's
Electronic Health Records (EHR) with fellow professionals in inter as well as
intra departments or organizations. Healthcare environment experiences frequent
shifting of doctors, paramedical staff in inter as well as intra departments or
hospitals. The system exhibits dynamic attributes of users and resources managed
through access control policies defined for that environment. Rules obtained on
merging of such policies often generate policy-conflicts thereby resulting in
undue data leakages to unintended users. This paper proposes an access control
framework that applies a Hierarchy Similarity Analyzer (HSA) on the policies
need to be merged. It calculates a Security_Level (SL) and assigns it to the
users sharing data. The SL determines the authorized amount of data that can be
shared on successful collaboration of two policies. The proposed framework
allows integration of independent policies and identifies the possible policy-
conflicts arising due to attribute disparities in defined rules. The framework
is implemented on XACML policies and compared with other access models designed
using centralized and decentralized approaches. Conditional constraints and
properties are defined that generate policy-conflicts as prevalent in the
policies. (C) 2015 The Authors. Production and hosting by Elsevier B.V. on
behalf of King Saud University.
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CR Al Abdulmohsin IM, 2009, COMPUT ELECTR ENG, V35, P556, DOI
10.1016/j.compeleceng.2008.08.003
   Azeez NA, 2013, SAIEE AFR RES J, V104, P54, DOI 10.23919/SAIEE.2013.8531866
   Bankauskaite V., 2007, EUROPEAN OBSERVATORY
   Bertino E., 1994, DATABASE SECURITY, VVIII, P199
   Bhartiya S., 2013, LECT NOTES COMPUTER, V8040, P52
   Bhartiya Shalini, 2015, Int J Electron Healthc, V8, P25
   Carmagnola F., 2000, USER ADAPTED INTERAC, V21, P285
   Chandramouli R, 2000, P 23 NAT INF SYST SE
   Ciampi Mario, 2010, International Journal of Advanced Media and Communication,
V4, P154, DOI 10.1504/IJAMC.2010.032141
   Cimatti A., 2002, Computer Aided Verification. 14th International Conference,
CAV 2002. Proceedings (Lecture Notes in Computer Science Vol.2404), P359
   Fisler K, 2005, PROC INT CONF SOFTW, P196
   Hu V., 2013, NIST SPEC PUBL
   Hu VC, 2011, INT J SOFTW ENG KNOW, V21, P103, DOI 10.1142/S021819401100513X
   Hwang J., 2010, ACPT TOOL MODELLING
   Karp A, 2010, PROCEEDINGS OF THE 5TH INTERNATIONAL CONFERENCE ON INFORMATION
WARFARE AND SECURITY, P202
   Koleini M., 2011, P 13 INT C FORM ENG
   Lin D, 2007, SACMAT'07: PROCEEDINGS OF THE 12TH ACM SYMPOSIUM ON ACCESS
CONTROL MODELS AND TECHNOLOGIES, P1
   Martin E, 2007, P 3 INT WORKSH SOFTW, P5
   Nyanchama M, 1999, ACM T INFORM SYSTEM, V2, P3, DOI DOI 10.1145/300830.300832
   Sandhu RS, 1996, COMPUTER, V29, P38, DOI 10.1109/2.485845
   Xiao L, 2010, COMPUT SECUR, V29, P331, DOI 10.1016/j.cose.2009.08.002
   Yang N., 2008, J INFORM ASSURANCE S, P51
   Zidat S., 2006, Journal of Computer Sciences, V2, P558
NR 23
TC 1
Z9 1
U1 0
U2 2
PU ELSEVIER SCIENCE BV
PI AMSTERDAM
PA PO BOX 211, 1000 AE AMSTERDAM, NETHERLANDS
SN 1319-1578
EI 2213-1248
J9 J KING SAUD UNIV-COM
JI J. King Saud Univ.-Comput. Inf. Sci.
PD OCT
PY 2017
VL 29
IS 4
BP 505
EP 519
DI 10.1016/j.jksuci.2015.08.005
PG 15
WC Computer Science, Information Systems
SC Computer Science
GA FL2MG
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OA DOAJ Gold
DA 2019-08-06
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PT J
AU Halder, JB
   Benton, J
   Jule, AM
   Guerin, PJ
   Olliaro, PL
   Basanez, MG
   Walker, M
AF Halder, Julia B.
   Benton, Joanne
   Jule, Amellie M.
   Guerin, Phillipe J.
   Olliaro, Piero L.
   Basanez, Maria-Gloria
   Walker, Martin
TI Systematic review of studies generating individual participant data on
   the efficacy of drugs for treating soil-transmitted helminthiases and
   the case for data-sharing
SO PLOS NEGLECTED TROPICAL DISEASES
LA English
DT Review
ID LUMBRICOIDES INFECTION INTENSITY; ANTHELMINTIC RESISTANCE; MEBENDAZOLE
   TREATMENT; SCHISTOSOMA-MANSONI; NEMATODE INFECTIONS; NECATOR-AMERICANUS;
   HUMAN VOLUNTEERS; PUBLIC-HEALTH; EGG COUNTS; KATO-KATZ
AB Background
   Preventive chemotherapy and transmission control (PCT) by mass drug
administration is the cornerstone of the World Health Organization (WHO)'s
policy to control soil-transmitted helminthiases (STHs) caused by Ascaris
lumbricoides (roundworm), Trichuris trichiura (whipworm) and hookworm species
(Necator americanus and Ancylostama duodenale) which affect over 1 billion
people globally. Despite consensus that drug efficacies should be monitored for
signs of decline that could jeopardise the effectiveness of PCT, systematic
monitoring and evaluation is seldom implemented. Drug trials mostly report
aggregate efficacies in groups of participants, but heterogeneities in design
complicate classical meta analyses of these data. Individual participant data
(IPD) permit more detailed analysis of drug efficacies, offering increased
sensitivity to identify atypical responses potentially caused by emerging drug
resistance.
   Methodology
   We performed a systematic literature review to identify studies concluding
after 2000 that collected IPD suitable for estimating drug efficacy against STH.
We included studies that administered a variety of anthelmintics with follow ups
less than 60 days after treatment. We estimated the number of IPD and extracted
cohort- and study-level meta-data.
   Principal findings
   We estimate that there exist individual data on approximately 35,000
participants from 129 studies conducted in 39 countries, including 34 out of 103
countries where PCT is recommended. We find significant heterogeneity in
diagnostic methods, times of outcome assessment, and the reported measure of
efficacy. We also quantify cohorts comprising pre-school age children, pregnant
women, and co-infected participants, including with HIV.
   Conclusions
   We argue that establishing a global IPD repository would improve the capacity
to monitor and evaluate the efficacy of anthelmintic drugs, respond to changes
and safeguard the ongoing effectiveness of PCT. Establishing a fair, transparent
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data governance policy will be key for the engagement of the global STH community.

Author summary

Soil-transmitted helminthiases (STHs) caused by roundworm, whipworm or hookworm-affect over one billion of the world's poorest people mostly living in low and middle income countries, exerting a major health and economic toll. These infections are controlled by regular mass drug distribution to affected populations. But with very few alternative medicines, the effectiveness of treatment programmes is vulnerable to the potential emergence of drug resistance. Despite a recent scale-up of mass drug distribution, systematic monitoring and evaluation of the efficacy of treatment is too rarely undertaken and our knowledge of how the drugs are performing largely based on information from clinical trials. However, the design and reporting of information from these trials is very variable which makes it difficult to form a comprehensive picture of the status and trends in drug efficacy. Here, we present a systematic review of published studies completed since 2000, characterise variation in their design, implementation and reporting and estimate the abundance of individual participant data. We argue that the co-ordinated sharing of these individual data would greatly increase the capacity of the global health community to monitor effectively drug efficacy, to respond accordingly to changes, and thereby to safeguard the effectiveness of STH control.

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FU UNICEF/UNDP/World Bank WHO Special Programme for Research and Training in Tropical Disease (TDR)
FX This investigation received financial support from the UNICEF/UNDP/World Bank WHO Special Programme for Research and Training in Tropical Disease (TDR). The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

CR Albonico M, 2004, INT J PARASITOL, V34, P1205, DOI 10.1016/j.ijpara.2004.08.001
Albonico M, 2004, MOL BIOCHEM PARASIT, V134, P281, DOI 10.1016/j.molbiopara.2003.12.008
Albonico M, 2003, B WORLD HEALTH ORGAN, V81, P343
Albonico M, 2002, ANN TROP MED PARASIT, V96, P717, DOI 10.1179/000349802125001942
ANDERSON RM, 1985, T ROY SOC TROP MED H, V79, P812, DOI 10.1016/0035-9203(85)90128-2

[Anonymous], 2012, ENDING NEGLECT REACH
Basanez MG, 2012, PLOS NEGLECT TROP D, V6, DOI 10.1371/journal.pntd.0001548
Bethony J, 2006, LANCET, V367, P1521, DOI 10.1016/S0140-6736(06)68653-4
Booth M, 2003, PARASITOLOGY, V127, P525, DOI 10.1017/S0031182003004128
BUNDY DAP, 1985, T ROY SOC TROP MED H, V79, P641, DOI 10.1016/0035-9203(85)90178-6
CLINE BL, 1984, AM J TROP MED HYG, V33, P387, DOI 10.4269/ajtmh.1984.33.387
Coles GC, 2006, VET PARASITOL, V136, P167, DOI 10.1016/j.vetpar.2005.11.019
Crellen T, 2016, CLIN INFECT DIS, V63, P1151, DOI 10.1093/cid/ciw506
Cringoli G., 2006, Parassitologia (Rome), V48, P381
Danso-Appiah A, 2013, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD000528.pub2
Davis NA, 2013, MED PARAZITOL, V24, P7
Diawara A, 2013, PLOS NEGLECT TROP D, V7, DOI 10.1371/journal.pntd.0002247
Dimitri N, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0050835
Easton AV, 2017, PARASITE VECTOR, V10, DOI 10.1186/s13071-017-2164-y
Easton AV, 2016, PARASITE VECTOR, V9, DOI 10.1186/s13071-016-1314-y
FORRESTER JE, 1990, PARASITOLOGY, V100, P303, DOI 10.1017/S003118200006131X
Geary TG, 2015, J PARASITOL, V101, P125, DOI 10.1645/14-703.1
Global Atlas of Helminth Infections, 2017, GLOB ATL HELM INF
Goodman D, 2007, AM J TROP MED HYG, V76, P725, DOI 10.4269/ajtmh.2007.76.725
HALL A, 1981, T ROY SOC TROP MED H, V75, P682, DOI 10.1016/0035-9203(81)90148-6
Jule AM, 2017, AM J TROP MED HYG, V95, P371
Jule AM, 2016, PLOS NEGLECT TROP D, V10, DOI 10.1371/journal.pntd.0004784
Kaplan RM, 2012, VET PARASITOL, V186, P70, DOI 10.1016/j.vetpar.2011.11.048
Keiser J, 2008, JAMA-J AM MED ASSOC, V299, P1937, DOI 10.1001/jama.299.16.1937
Kotze AC, 2014, INT J PARASITOL-DRUG, V4, P164, DOI 10.1016/j.ijpddr.2014.07.007
Kramer CV, 2014, COCHRANE DB SYST REV, DOI 10.1002/14651858.CD000053.pub3
MAXWELL C, 1987, AM J TROP MED HYG, V37, P126, DOI 10.4269/ajtmh.1987.37.126
Modjarrad K, 2016, PLOS MED, V13, DOI 10.1371/journal.pmed.1001935
Moorthy VS, 2016, B WORLD HEALTH ORGAN, V94, P234
Mueller-Langer F, 2013, HEALTH ECON POLICY L, V8, P185, DOI 10.1017/S1744133112000321
Ndyomugyenyi R, 2008, AM J TROP MED HYG, V79, P856, DOI 10.4269/ajtmh.2008.79.856
Olliaro PL, 2015, PLOS NEGLECT TROP D, V9, DOI 10.1371/journal.pntd.0003821
Redman E, 2015, PLOS NEGLECT TROP D, V9, DOI 10.1371/journal.pntd.0003494
Rose H, 2015, VET REC, V176, DOI 10.1136/vr.102982
Speich B, 2012, PLOS NEGLECT TROP D, V6, DOI 10.1371/journal.pntd.0001685
Sunish IP, 2015, INDIAN J MED RES, V141, P330
Turner HC, 2016, LANCET INFECT DIS, V16, P838, DOI 10.1016/S1473-3099(15)00268-6
Vercruysse J, 2012, CURR OPIN INFECT DIS, V25, P703, DOI 10.1097/QCO.0b013e328358993a
Vercruysse J, 2011, INT J PARASITOL-DRUG, V1, P14, DOI 10.1016/j.ijpddr.2011.09.002
Vines TH, 2014, CURR BIOL, V24, P94, DOI 10.1016/j.cub.2013.11.014
Vos T, 2016, LANCET, V388, P1545, DOI 10.1016/S0140-6736(16)31678-6
Walker M, 2016, PARASITE VECTOR, V9, DOI 10.1186/s13071-016-1312-0
Walker M, 2014, TRENDS PARASITOL, V30, P528, DOI 10.1016/j.pt.2014.08.004
Webster JP, 2014, PHILOS T R SOC B, V369, DOI 10.1098/rstb.2013.0434
WHO, 2012, ACC WORK OV GLOB IMP
WHO, 2006, PREV CHEM HUM HELM
WHO, 2017, UPD GLOB STAT IMPL P
Williams JR, 2008, EMERG THEMES EPIDEMI, V5, DOI 10.1186/1742-7622-5-17

```
   World Health Organization, 1991, BAS LAB METH MED PAR
   World Health Organization, 2015, NUMB CHILDR PRESAC S
   World Health Organization, 2013, ASS EFF ANTH DRUGS S
   Zhang Jian-Hui, 2008, Zhongguo Ji Sheng Chong Xue Yu Ji Sheng Chong Bing Za
Zhi, V26, P6
   Zwang J, 2017, PARASITE VECTOR, V10, DOI 10.1186/s13071-016-1958-7
   Zwang J, 2014, PLOS NEGLECT TROP D, V8, DOI 10.1371/journal.pntd.0003286
NR 59
TC 1
Z9 1
U1 0
U2 4
PU PUBLIC LIBRARY SCIENCE
PI SAN FRANCISCO
PA 1160 BATTERY STREET, STE 100, SAN FRANCISCO, CA 94111 USA
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J9 PLOS NEGLECT TROP D
JI Plos Neglect. Trop. Dis.
PD OCT
PY 2017
VL 11
IS 10
AR e0006053
DI 10.1371/journal.pntd.0006053
PG 20
WC Infectious Diseases; Parasitology; Tropical Medicine
SC Infectious Diseases; Parasitology; Tropical Medicine
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PT J
AU Baier, AW
   Snyder, DJ
   Leahy, IC
   Patak, LS
   Brustowicz, RM
AF Baier, Amanda W.
   Snyder, Daniel J.
   Leahy, Izabela C.
   Patak, Lance S.
   Brustowicz, Robert M.
TI A Shared Opportunity for Improving Electronic Medical Record Data
SO ANESTHESIA AND ANALGESIA
LA English
DT Article
ID HEALTH INFORMATION-TECHNOLOGY; CLINICAL-RESEARCH; PRIMARY-CARE;
   CHALLENGES; DATABASES; REUSE
AB With the recent rapid adoption of electronic medical records (EMRs), studies
reporting results based on EMR data have become increasingly common. While
analyzing data extracted from our EMR for a retrospective study, we identified
various types of erroneous data entries. This report investigates the root
causes of the incompleteness, inconsistency, and inaccuracy of the medical
records analyzed in our study. While experienced health information management
professionals are well aware of the many shortcomings with EMR data, the aims of
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this case study are to highlight the significance of the negative impact of erroneous EMR data, to provide fundamental principles for managing EMRs, and to provide recommendations to help facilitate the successful use of electronic health data, whether to inform clinical decisions or for clinical research.

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CR AHIMA, 2011, J AHIMA, V82, P42
AHIMA, 2008, J AHIMA, V79, P69
Anand V, 2012, PEDIATRICS, V129, pE1275, DOI 10.1542/peds.2011-2875
Bayley KB, 2013, MED CARE, V51, pS80, DOI 10.1097/MLR.0b013e31829b1d48
Bellazzi R, 2011, METHOD INFORM MED, V50, P536, DOI 10.3414/ME11-06-0002
Blumenthal D, 2009, NEW ENGL J MED, V360, P1477, DOI 10.1056/NEJMp0901592
Botsis Taxiarchis, 2010, Summit Transl Bioinform, V2010, P1
Buntin MB, 2011, HEALTH AFFAIR, V30, P464, DOI 10.1377/hlthaff.2011.0178
BYAR DP, 1991, STAT MED, V10, P663, DOI 10.1002/sim.4780100417
de Lusignan S, 2006, FAM PRACT, V23, P253, DOI 10.1093/fampra/cmi106
Dean BB, 2009, MED CARE RES REV, V66, P611, DOI 10.1177/1077558709332440
Hasan Sharique, 2006, AMIA Annu Symp Proc, P324
Hemila Harri, 2012, Clin Transl Allergy, V2, P6, DOI 10.1186/2045-7022-2-6
Hersh WR, 2013, MED CARE, V51, pS30, DOI 10.1097/MLR.0b013e31829b1dbd
Hogan WR, 1997, J AM MED INFORM ASSN, V4, P342, DOI 10.1136/jamia.1997.0040342
Hripcsak G, 2011, J BIOMED DISCOV COLL, V6, DOI 10.5210/disco.v6i0.3581
Institute of Medicine Committee on Patient Safety and Health Information Technology, 2011, HLTH IT PAT SAF BUIL
Jones SS, 2014, ANN INTERN MED, V160, P48, DOI 10.7326/M13-1531
Kohn LT, 2000, REPORT COMMITTEE QUA
Koppel R, 2005, JAMA-J AM MED ASSOC, V293, P1197, DOI 10.1001/jama.293.10.1197
Leviss J., 2013, HIT MISS LESSONS LEA
Madden JM, 2016, J AM MED INFORM ASSN, V23, P1143, DOI 10.1093/jamia/ocw021
MCDONALD CJ, 1991, STAT MED, V10, P511, DOI 10.1002/sim.4780100404
Meeks DW, 2014, J AM MED INFORM ASSN, V21, P1053, DOI 10.1136/amiajnl-2013-002578
Opmeer BC, 2016, JAMA-J AM MED ASSOC, V315, P201, DOI 10.1001/jama.2015.15419
Padilla Miguel A, 2004, J Mod Appl Stat Methods, V3, P406
Ridgely M.S., 2012, ST LOUIS U J HLTH L, V5, P257
Rostami R, 2009, CLIN TRIALS, V6, P141, DOI 10.1177/1740774509102590
Safran C, 2007, J AM MED INFORM ASSN, V14, P1, DOI 10.1197/jamia.M2273
Sahoo Umakanta, 2003, Qual Assur, V10, P117
Silow-Carroll Sharon, 2012, Issue Brief (Commonw Fund), V17, P1
Terry AL, 2010, FAM PRACT, V27, P121, DOI 10.1093/fampra/cmp068
Weiner MG, 2009, ANN INTERN MED, V151, P359, DOI 10.7326/0003-4819-151-5-200909010-00141
Weiskopf NG, 2013, J AM MED INFORM ASSN, V20, P144, DOI 10.1136/amiajnl-2011-000681
Wells Brian J, 2013, EGEMS (Wash DC), V1, P1035, DOI 10.13063/2327-9214.1035
West SL, 2009, HEALTH INFORM J, V15, P108, DOI 10.1177/1460458209102972
Zeng X, 2009, PERSPECT HLTH INF MA, V6, p1f
NR 37

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TC 1
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U2 10
PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
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SN 0003-2999
J9 ANESTH ANALG
JI Anesth. Analg.
PD SEP
PY 2017
VL 125
IS 3
BP 952
EP 957
DI 10.1213/ANE.0000000000002134
PG 6
WC Anesthesiology
SC Anesthesiology
GA FE1PN
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PM 28632540
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PT J
AU Learned, K
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AF Learned, Katrina
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   Goldstein, Theodore
   Salama, Sofie R.
   Haussler, David
   Morozova, Olena
   Bjork, Isabel
TI A critical evaluation of genomic data sharing: Barriers to accessing
   pediatric cancer genomic datasets: a Treehouse Childhood Cancer
   Initiative experience
SO CANCER RESEARCH
LA English
DT Meeting Abstract
CT Annual Meeting of the American-Association-for-Cancer-Research (AACR)
CY APR 01-05, 2017
CL Washington, DC
SP Amer Assoc Canc Res
NR 0
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TC 1
Z9 1
U1 0
U2 0
PU AMER ASSOC CANCER RESEARCH
PI PHILADELPHIA
PA 615 CHESTNUT ST, 17TH FLOOR, PHILADELPHIA, PA 19106-4404 USA
SN 0008-5472
EI 1538-7445
J9 CANCER RES
JI Cancer Res.
PD JUL
PY 2017
VL 77
SU 13
MA LB-338
DI 10.1158/1538-7445.AM2017-LB-338
PG 2
WC Oncology
SC Oncology
GA GR3MV
UT WOS:000442496700450
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ER

PT J
AU Nadauld, L
   Haslem, D
   Tittel, PD
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   James, TB
   Ford, J
AF Nadauld, Lincoln
   Haslem, Derrick
   Tittel, Paul D.
   Tameishi, Mariko
   Brown, Thomas
   Ford, James
TI OPeN: the oncology precision network data sharing consortium
SO CANCER RESEARCH
LA English
DT Meeting Abstract
CT Annual Meeting of the American-Association-for-Cancer-Research (AACR)
CY APR 01-05, 2017
CL Washington, DC
SP Amer Assoc Canc Res
NR 0
TC 1
Z9 1
U1 0
U2 0
PU AMER ASSOC CANCER RESEARCH
PI PHILADELPHIA
PA 615 CHESTNUT ST, 17TH FLOOR, PHILADELPHIA, PA 19106-4404 USA
SN 0008-5472
EI 1538-7445
J9 CANCER RES
JI Cancer Res.
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PD JUL
PY 2017
VL 77
SU 13
MA 998
DI 10.1158/1538-7445.AM2017-998
PG 2
WC Oncology
SC Oncology
GA GR3MV
UT WOS:000442496702438
DA 2019-08-06
ER

PT J
AU Mahlmann, L
   Halfmann, SSG
   von Wyl, A
   Brand, A
AF Mahlmann, Laura
   Halfmann, Sebastian Schee Gen.
   von Wyl, Agnes
   Brand, Angela
TI Attitudes towards Personal Genomics and Sharing of Genetic Data among
   Older Swiss Adults: A Qualitative Study
SO PUBLIC HEALTH GENOMICS
LA English
DT Article
DE Altruism; Citizen science; Data protection; Data sharing;
   Direct-to-consumer personal genomics; Older adults; Personalized
   medicine; Privacy; Research participation
ID TO-CONSUMER GENOMICS; RESEARCH PARTICIPANTS PERSPECTIVES; HEALTH-CARE;
   INFORMED-CONSENT; CLINICAL UTILITY; MEDICINE; TESTS; IMPACT; CHALLENGES;
   MOTIVATION
AB Objective: To assess the willingness of older Swiss adults to share genetic
data for research purposes and to investigate factors that might impact their
willingness to share data. Methods: Semi-structured interviews were conducted
among 40 participants (19 male and 21 female) aged between 67 and 92 years,
between December 2013 and April 2014 attending the Seniorenuniversitat Zurich,
Switzerland. All interviews were audio-recorded, transcribed verbatim, and
anonymized. For the analysis of the interviews, an initial coding scheme was
developed, refined over time, and applied afterwards to all interviews. Results:
The majority of participants were in favor of placing genetic data to research's
disposal. Participant's motivations to share data were mainly driven by
altruistic reasons and by contributing to the greater good. Furthermore, several
factors which might impact the willingness to share data such as sharing data
with private companies, generational differences, differences between sharing
genetic data or health data, and sharing due to financial incentives were
highlighted. Last, some participants indicated concerns regarding data sharing
such as misuse of data, the fear of becoming a transparent citizen, and data
safety. However, 20% of the participants express confidence in data protection.
Even participants who were skeptical in the beginning of the interviews admitted
the benefits of data sharing. Discussion: Overall, this study suggests older
citizens are willing to share their data for research purposes. However, most of
them will only contribute if their data is appropriately protected and if they
trust the research institution to use the shared data responsibly. More
transparency and detailed information regarding the data usage are urgently
needed. There is a great need to increase the engagement of older adults in
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research since they present a large segment of our society-one which is often underexamined in research. Conclusion: Increased focus on general public engagement, especially of older adults, in scientific research activities known as "citizen science" is needed to further strengthen the uptake of personalized medicine. (c) 2018 S. Karger AG, Basel

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CR Abul-Husn NS, 2014, PHARMACOGEN PERS MED, V7, P227, DOI 10.2147/PGPM.S48887
[Anonymous], 2013, GREEN PAP CIT SCI EU
Bell Elizabeth A, 2014, AMIA Annu Symp Proc, V2014, P1699
Beresford AR, 2012, ECON LETT, V117, P25, DOI 10.1016/j.econlet.2012.04.077
Bloss CS, 2014, J MED GENET, V51, P83, DOI 10.1136/jmedgenet-2013-101909
Bloss CS, 2013, J MED GENET, V50, P393, DOI 10.1136/jmedgenet-2012-101207
Boeldt DL, 2015, CLIN GENET, V87, P225, DOI 10.1111/cge.12419
Bunnik EM, 2013, EUR J HUM GENET, V21, P596, DOI 10.1038/ejhg.2012.237
Carrascal Juan Pablo, 2013, P 22 INT C WORLD WID, P189, DOI [10.1145/2488388, DOI 10.1145/2488388.2488406]
Cohen JP, 2012, NEW BIOTECHNOL, V29, P751, DOI 10.1016/j.nbt.2012.02.001
Critchley C, 2015, PUBLIC UNDERST SCI, V24, P731, DOI 10.1177/0963662513519937
Critchley C, 2015, PUBLIC HEALTH GENOM, V18, P160, DOI 10.1159/000375441
Egglestone C, 2012, 13 EAHIL C BRUSS JUL
Egglestone C, 2013, J GENET COUNS, V22, P565, DOI 10.1007/s10897-013-9582-6
Erikson EH, 1986, VITAL INVOLVEMENT OL
European Alliance for Personalised Medicine, 2014, MEPS BRIEF PAP 2014
European Commission, 2014, ADV 2016 2017 HOR 20
Evans JP, 2010, GENET MED, V12, P342, DOI 10.1097/GIM.0b013e3181deb308
Facio FM, 2011, EUR J HUM GENET, V19, P1213, DOI 10.1038/ejhg.2011.123
Field A, 2010, GENET TEST MOL BIOMA, V14, P731, DOI 10.1089/gtmb.2010.1514
Green MJ, 2003, ANN INTERN MED, V138, P571, DOI 10.7326/0003-4819-138-7-200304010-00013
Grosse SD, 2006, GENET MED, V8, P448, DOI 10.1097/01.gim.0000227935.26763.c6
Haeusermann T, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0177158
Haga SB, 2011, PUBLIC HEALTH GENOM, V14, P319, DOI 10.1159/000324705
Halfmann SSG, 2017, PERS MED, V14, P63, DOI 10.2217/pme-2016-0061
Howard HC, 2010, EMBO REP, V11, P579, DOI 10.1038/embor.2010.105
Kalokairinou L, 2015, MED LAW INT, V15, P97, DOI DOI 10.1177/
Kasraian L, 2012, BLOOD TRANSFUS-ITALY, V10, P186, DOI 10.2450/2011.0039-11
Kaufman D, 2009, GENET MED, V11, P329, DOI 10.1097/GIM.0b013e31819994f8
Kerath SM, 2013, BMC PUBLIC HEALTH, V13, DOI 10.1186/1471-2458-13-114
Lehrach H, 2012, PERS MED, V9, P105, DOI [10.2217/pme.12.9, 10.2217/PME.12.9]
Mahlmann L, 2016, APPL TRANSL GENOM, V8, P9, DOI 10.1016/j.atg.2016.01.009
McCarty CA, 2007, COMMUNITY GENET, V10, P2, DOI 10.1159/000096274
McCarty CA, 2011, AM J MED GENET A, V155A, P737, DOI 10.1002/ajmg.a.33896
McGuire AL, 2008, GENET MED, V10, P46, DOI 10.1097/GIM.0b013e31815f1e00
Middleton A, 2017, PERS MED, V14, P249, DOI 10.2217/pme-2017-0001
Murray ABV, 2010, TRENDS GENET, V26, P459, DOI 10.1016/j.tig.2010.08.001
National Human Genome Research Institute, 2016, COST SEQ HUM GEN
Niemiec E, 2016, APPL TRANSL GENOM, V8, P23, DOI 10.1016/j.atg.2016.01.005

Ogino S, 2012, EXPERT REV MOL DIAGN, V12, P621, DOI [10.1586/ERM.12.46, 10.1586/erm.12.46]
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Ostergren JE, 2015, PUBLIC HEALTH GENOM, V18, P216, DOI 10.1159/000431250
Roberts J Scott, 2013, Curr Genet Med Rep, V1, P182
Rogers R. W., 1983, SOCIAL PSYCHOPHYSIOL, P153, DOI DOI 10.1002/9780470479216.CORPSY0897
Sanderson SC, 2016, EUR J HUM GENET, V24, P14, DOI 10.1038/ejhg.2015.118
Schmidlen TJ, 2016, J GENET COUNS, V25, P385, DOI 10.1007/s10897-015-9883-z
Shabani M, 2014, EXPERT REV MOL DIAGN, V14, P1053, DOI 10.1586/14737159.2014.961917
Snyderman R, 2014, PERS MED, V11, P365, DOI [10.2217/PME.14.22, 10.2217/pme.14.22]
Sterckx S, 2013, GENET MED, V15, P923, DOI 10.1038/gim.2013.164
Sulmasy DP, 2015, GENET MED, V17, P331, DOI 10.1038/gim.2014.111
Trinidad Susan Brown, 2012, AJOB Prim Res, V3, P3
Trinidad SB, 2010, GENET MED, V12, P486, DOI 10.1097/GIM.0b013e3181e38f9e
Vayena E, 2012, PUBLIC HEALTH GENOM, V15, P352, DOI 10.1159/000343792
Vayena E., 2015, PHILOS TECHNOLOGY, V28, P479, DOI DOI 10.1007/S13347-015-0204-0)
Vayena E, 2015, J MED ETHICS, V41, P310, DOI 10.1136/medethics-2014-102026
Zeissig E.-M, 2017, HUMAN ASPECTS IT AGE, P181
NR 56
TC 1
Z9 1
U1 1
U2 2
PU KARGER
PI BASEL
PA ALLSCHWILERSTRASSE 10, CH-4009 BASEL, SWITZERLAND
SN 1662-4246
EI 1662-8063
J9 PUBLIC HEALTH GENOM
JI Pub. Health Genomics
PY 2017
VL 20
IS 5
BP 293
EP +
DI 10.1159/000486588
PG 14
WC Genetics & Heredity; Public, Environmental & Occupational Health
SC Genetics & Heredity; Public, Environmental & Occupational Health
GA GD5PW
UT WOS:000430559900004
PM 29414817
DA 2019-08-06
ER

PT S
AU Galletta, A
Bonanno, L
Celesti, A
Marino, S
Bramanti, P
Villari, M
AF Galletta, Antonino
Bonanno, Lilla

Celesti, Antonio
Marino, Silvia
Bramanti, Placido
Villari, Massimo
GP IEEE
TI An Approach to Share MRI Data Over the Cloud Preserving Patients'
Privacy
SO 2017 IEEE SYMPOSIUM ON COMPUTERS AND COMMUNICATIONS (ISCC)
SE IEEE Symposium on Computers and Communications ISCC
LA English
DT Proceedings Paper
CT IEEE Symposium on Computers and Communications (ISCC)
CY JUL 03-07, 2017
CL Heraklion, GREECE
DE Clinical data; Cloud; storage; patient; security; privacy
AB Patients' data security and privacy is fundamental in the perspective of moving clinical data over the Cloud. Indeed, this concern has slowed down the adoption of Cloud services in the healthcare context. In fact, clinical operators are reluctant to open Hospital Information Systems (HIS) to external Cloud services. In this paper, we discuss system developed at the IRCCS "Bonino Pulejo" clinical and research centre (Italy) that is able to solve this concern. Such a system is based on two software components that are anonymizer and splitter. The first collects anonymize clinical data, whereas the second obfuscates and stores data in multiple Cloud storage providers. Thus, only authorized clinical operators can access data over the Cloud. A case of study considering real Magnetic Resonance Imaging (MRI) data is analysed in order to assess the performance of the whole system.
C1 [Galletta, Antonino; Celesti, Antonio; Villari, Massimo] Univ Messina, Dept Engn, Messina, Italy.
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OI Bonanno, Lilla/0000-0002-0282-405X; Galletta,
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FU FP7 Project frontierCities [632853]
FX This work was partially supported by the FP7 Project frontierCities
under grant agreement no. 632853.
CR Bhagwat D, 2006, P 14 IEEE INT S MOD, DOI [10.1109/MASCOTS.2006.42, DOI 10.1109/MASCOTS.2006.42]
Celesti Antonio, 2013, 2013 IEEE International Symposium on Parallel and Distributed Processing, Workshops and PhD Forum (IPDPSW), P1490, DOI 10.1109/IPDPSW.2013.266
Celesti A., 2017, IEEE J BIOMEDICAL HL
Celesti A, 2016, J NETW COMPUT APPL, V59, P208, DOI 10.1016/j.jnca.2014.09.021
Chadwick DW, 2014, J GRID COMPUT, V12, P3, DOI 10.1007/s10723-013-9283-2
Fazio M, 2014, 2014 28TH INTERNATIONAL CONFERENCE ON ADVANCED INFORMATION NETWORKING AND APPLICATIONS WORKSHOPS (WAINA), P779, DOI 10.1109/WAINA.2014.162
Huo Y., 2011, COMP MAN CAMAN 2011, P1
Kai Fan, 2012, 2012 1st IEEE International Conference on Communications in China (ICCC 2012), P57, DOI 10.1109/ICCChina.2012.6356951
Leavitt N, 2013, COMPUTER, V46, P22, DOI 10.1109/MC.2013.326
Wu Hai-Jia, 2010, Proceedings 2010 9th International Conference on Grid and Cloud Computing (GCC 2010), P30, DOI 10.1109/GCC.2010.19

```
   You LL, 2011, ACM T STORAGE, V7, DOI 10.1145/1970348.1970351
   Yu Zhang, 2012, Proceedings of the 2012 IEEE 36th IEEE Annual Computer
Software and Applications Conference Workshops (COMPSACW), P26, DOI
10.1109/COMPSACW.2012.15
   Zhang N, 2011, IEEE INT CONF TRUST, P1592, DOI 10.1109/TrustCom.2011.221
NR 13
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 1530-1346
BN 978-1-5386-1629-1
J9 IEEE SYMP COMP COMMU
PY 2017
BP 94
EP 99
PG 6
WC Computer Science, Information Systems; Engineering, Electrical &
   Electronic; Telecommunications
SC Computer Science; Engineering; Telecommunications
GA BJ6OR
UT WOS:000426895800017
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ER

PT S
AU Michalas, A
   Weingarten, N
AF Michalas, Antonis
   Weingarten, Noam
BE Bamidis, PD
   Konstantinidis, ST
   Rodrigues, PP
TI HealthShare: Using Attribute-Based Encryption for Secure Data Sharing
   Between Multiple Clouds
SO 2017 IEEE 30TH INTERNATIONAL SYMPOSIUM ON COMPUTER-BASED MEDICAL SYSTEMS
   (CBMS)
SE IEEE International Symposium on Computer-Based Medical Systems
LA English
DT Proceedings Paper
CT 30th IEEE International Symposium on Computer-Based Medical Systems
   (IEEE CBMS)
CY JUN 22-24, 2017
CL Aristotle Univ Thessaloniki, Thessaloniki, GREECE
SP IEEE, Aristotle Univ Thessaloniki Res Comm, Univ Nottingham, ePBLnet,
SmokeFreeBrain, LLM Care Hlth & Social Care Ecosystem, Open Knowledge Fdn
Chapter Greece, MEDical Curriculum INnovat, Widening Access Virtual Educ
Scenarios, Intelligent Parkinson Early Detect Guiding Novel Support Intervent,
Ubiquitous iNteroperable Care Ageing People
HO Aristotle Univ Thessaloniki
DE eHealth; Security; Cloud Computing; EHR Protection; Access Control;
   Policies; Attribute-Based Encryption
AB In this invited paper, we propose HealthShare - a forward-looking approach
for secure ehealth data sharing between multiple organizations that are hosting
patients' data in different clouds. The proposed protocol is based on a
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Revocable Key-Policy Attribute-Based Encryption scheme and allows users to share encrypted health records based on a policy that has been defined by the data owner (i.e. patient, a member of the hospital, etc). Furthermore, access to a malicious or compromised user/organization can be easily revoked without the need to generate fresh encryption keys.

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CR Dimitriou T., 2012, 2012 5 INT C NEW TEC, P1
Dimitriou T, 2014, AD HOC NETW, V15, P53, DOI 10.1016/j.adhoc.2013.04.013
Dolev D., 1983, INFORM THEORY IEEE T, V29
Dowsley R., 2016, TECH REP
Michalas A., 2011, 2011 IEEE Symposium on Computers and Communications (ISCC 2011), P752, DOI 10.1109/ISCC.2011.5983930
Michalas A, 2010, 2010 IEEE International Conference on Information Theory and Information Security, P568, DOI 10.1109/ICITIS.2010.5689528
Michalas A., 2016, 2016 INT C INT TECHN, P589
Michalas A., 2012, INT J COMPUTER RES, V19, P79
Michalas A., 2014, COMP COMM ISCC 2014, P1
Michalas A., 2012, SARN S SARNOFF 2012, P1
Michalas A., 2011, WIR COMM VEH TECHN I, P1
Michalas A, 2015, INT CONF UTIL CLOUD, P618, DOI 10.1109/UCC.2015.108
Michalas A, 2014, 2014 IEEE 16TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATIONS AND SERVICES (HEALTHCOM), P212, DOI 10.1109/HealthCom.2014.7001843
Michalas A, 2012, INT CONF INTERNET, P589
Michalas A, 2011, INT J DIGIT CRIME FO, V3, P14, DOI 10.4018/jdcf.2011010102
Paladi N., 2014, P 2014 INT WORKSH SE
Paladi N, 2017, IEEE T CLOUD COMPUT, V5, P405, DOI 10.1109/TCC.2016.2525991
Sahai A, 2012, LECT NOTES COMPUT SC, V7417, P199
Verginadis Yiannis, 2015, Proceedings of the 5th International Conference on Cloud Computing and Services Science (CLOSER 2015), P206
Verginadis Y., 2017, PAASWORD HOLISTIC DA, P1
Yigzaw K., 2016, IEEE ACCESS, P1
Yigzaw KY, 2017, BMC MED INFORM DECIS, V17, DOI 10.1186/s12911-016-0389-x

NR 22
TC 1
Z9 1
U1 0
U2 2

PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2372-9198
BN 978-1-5386-1710-6
J9 COMP MED SY
PY 2017
BP 811
EP 815
DI 10.1109/CBMS.017.30
PG 5

WC Computer Science, Information Systems; Computer Science, Interdisciplinary Applications; Engineering, Biomedical; Medical Informatics
SC Computer Science; Engineering; Medical Informatics
GA BJ4DC

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UT WOS:000424864800160
DA 2019-08-06
ER

PT J
AU Montgomery, J
AF Montgomery, Jonathan
TI Data Sharing and the Idea of Ownership
SO NEW BIOETHICS-A MULTIDISCIPLINARY JOURNAL OF BIOTECHNOLOGY AND THE BODY
LA English
DT Article
DE health data; property; ownership; personalised medicine; commons;
   privacy
ID INFORMATION
AB Ideas about ownership are sometimes used in discussions of data sharing in
personalised medicine. Personal health data are thought by many to be 'theirs'.
Paradoxically, personalised medicine (at least in the context of genomics)
relies on the aggregation of private data into a dataset that is held as a form
of knowledge commons. When the notions of private and common property that lie
behind this discourse are made explicit we can use thinking about the
justifications and jurisprudence of property both to clarify the persuasiveness
and limits of such claims, and also how they differ from other principles that
are at stake in the interplay between individual and collective goods in the
delivery of personalised medicine. This shows that ownership might more
plausibly lie with health professionals than patients. In a socialised medicine
system, such as the NHS, such professionals are agents of the state and
ownership would lie with the commons rather than any individual. Common rather
than private ownership of genomic information may be more appropriate.
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OI Montgomery, Jonathan/0000-0002-4592-0930
CR Archard D., 1993, INT J CHILDRENS RIGH, V1, P293
   British Society for Genetic Medicine Joint Committee on Medical Genetics,
2011, CONS CONF GEN PRACT
   Coggon J, 2011, CAMB LAW J, V70, P523, DOI 10.1017/S0008197311000845
   Dheensa S, 2016, J MED ETHICS, V42, P174, DOI 10.1136/medethics-2015-102781
   Honore A., 1960, OXFORD ESSAYS JURISP, P104
   Laslett P., 1689, 2 TREATISES GOVT
   Montgomery J., 1988, MOD LAW REV, V51, P323
   Nozick R., 1974, ANARCHY STATE UTOPIA
   Parker M, 2004, BRIT MED J, V329, P165, DOI 10.1136/bmj.329.7458.165
   RYAN A, 1987, PROPERTY
   Sulston John, 2002, COMMON THREAD STORY
   WALDRON JEREMY, 1988, RIGHT PRIVATE PROPER
NR 12
TC 1
Z9 1
U1 1
U2 3
PU TAYLOR & FRANCIS LTD
PI ABINGDON
PA 2-4 PARK SQUARE, MILTON PARK, ABINGDON OR14 4RN, OXON, ENGLAND
SN 2050-2877
EI 2050-2885
J9 NEW BIOETH
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JI New Bioeth.
PY 2017
VL 23
IS 1
SI SI
BP 81
EP 86
DI 10.1080/20502877.2017.1314893
PG 6
WC Ethics
SC Social Sciences - Other Topics
GA FV9PM
UT WOS:000424920600010
PM 28517982
DA 2019-08-06
ER

PT J
AU An, XB
   Hu, JH
   Do, KA
AF An, Xuebei
   Hu, Jianhua
   Do, Kim-Anh
TI SIFORM: shared informative factor models for integration of
   multi-platform bioinformatic data
SO BIOINFORMATICS
LA English
DT Article
ID CELL LUNG-CANCER; NONCONCAVE PENALIZED LIKELIHOOD;
   ESTROGEN-RECEPTOR-ALPHA; PROGNOSTIC-SIGNIFICANCE; VARIABLE SELECTION;
   CYCLIN B1; NETWORK ANALYSIS; NEVER SMOKERS; EXPRESSION; 4E-BP1
AB Motivation: High-dimensional omic data derived from different technological
platforms have been extensively used to facilitate comprehensive understanding
of disease mechanisms and to determine personalized health treatments. Numerous
studies have integrated multi-platform omic data; however, few have efficiently
and simultaneously addressed the problems that arise from high dimensionality
and complex correlations.
   Results: We propose a statistical framework of shared informative factor
models that can jointly analyze multi-platform omic data and explore their
associations with a disease phenotype. The common disease-associated sample
characteristics across different data types can be captured through the shared
structure space, while the corresponding weights of genetic variables directly
index the strengths of their association with the phenotype. Extensive
simulation studies demonstrate the performance of the proposed method in terms
of biomarker detection accuracy via comparisons with three popular regularized
regression methods. We also apply the proposed method to The Cancer Genome Atlas
lung adenocarcinoma dataset to jointly explore associations of mRNA expression
and protein expression with smoking status. Many of the identified biomarkers
belong to key pathways for lung tumorigenesis, some of which are known to show
differential expression across smoking levels. We discover potential biomarkers
that reveal different mechanisms of lung tumorigenesis between light smokers and
heavy smokers.
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FU National Institute of Health [R01CA158113, CCSG P30 CA016672]; Moonshot Programs Funding at M.D. Anderson
FX This work was supported in part by the National Institute of Health Grants R01CA158113, CCSG P30 CA016672, and the Moonshot Programs Funding at M.D. Anderson.

CR Arinaga M, 2003, ONCOL REP, V10, P1381
BOCK KW, 1994, PHARMACOGENETICS, V4, P209, DOI 10.1097/00008571-199408000-00005
Bovelstad HM, 2007, BIOINFORMATICS, V23, P2080, DOI 10.1093/bioinformatics/btm305
Brand TM, 2011, DISCOV MED, V12, P419
Chari R, 2010, BMC SYST BIOL, V4, DOI 10.1186/1752-0509-4-67
Chekouo T, 2015, BIOMETRICS, V71, P428, DOI 10.1111/biom.12266
Chen PW, 2013, TRENDS MOL MED, V19, P410, DOI 10.1016/j.molmed.2013.04.001
Collier AC, 2002, HUM REPROD, V17, P2564, DOI 10.1093/humrep/17.10.2564
Cooper WA, 2013, J THORAC DIS, V5, pS479, DOI 10.3978/j.issn.2072-1439.2013.08.03
Cooper WA, 2009, HISTOPATHOLOGY, V55, P28, DOI 10.1111/j.1365-2559.2009.03331.x
Di Bernardo MC, 2009, LUNG CANCER, V65, P237, DOI 10.1016/j.lungcan.2008.11.012
Ding L, 2008, NATURE, V455, P1069, DOI 10.1038/nature07423
Dumstorf CA, 2010, MOL CANCER THER, V9, P3158, DOI 10.1158/1535-7163.MCT-10-0413
Fan JQ, 2004, ANN STAT, V32, P928, DOI 10.1214/009053604000000256
Fan JQ, 2001, J AM STAT ASSOC, V96, P1348, DOI 10.1198/016214501753382273
Fan YY, 2013, J R STAT SOC B, V75, P531, DOI 10.1111/rssb.12001
Fumarola C, 2014, BIOCHEM PHARMACOL, V90, P197, DOI 10.1016/j.bcp.2014.05.011
Gingras AC, 1998, GENE DEV, V12, P502, DOI 10.1101/gad.12.4.502
Giunti S, 2013, INT J ENDOCRINOL, DOI 10.1155/2013/803171
Grabauskiene S, 2014, J SURG RES, V187, P6, DOI 10.1016/j.jss.2013.12.016
Gross SM, 2015, BIOSTATISTICS, V16, P326, DOI 10.1093/biostatistics/kxu047
Ha MJ, 2015, BIOINFORMATICS, V31, P3413, DOI 10.1093/bioinformatics/btv406
Han SW, 2006, CANCER RES, V66, P315, DOI 10.1158/0008-5472.CAN-05-2367
Hastie T., 2000, GENOME BIOL, V1, DOI DOI 10.1186/GB-2000-1-2-RESEARCH0003
Hunter DR, 2005, ANN STAT, V33, P1617, DOI 10.1214/009053605000000200
Ideker Trey, 2002, Bioinformatics, V18 Suppl 1, pS233
Kawai H, 2005, CLIN CANCER RES, V11, P5084, DOI 10.1158/1078-0432.CCR-05-0200
Kim S, 2013, BIOMETRICS, V69, P582, DOI 10.1111/biom.12035
Kristensen VN, 2014, NAT REV CANCER, V14, P299, DOI 10.1038/nrc3721
Kuykendall A, 2014, CANCER CONTROL, V21, P67, DOI 10.1177/107327481402100110
Langfelder P, 2008, BMC BIOINFORMATICS, V9, DOI 10.1186/1471-2105-9-559
Lee HW, 2015, INT J CLIN EXP PATHO, V8, P3955
Li B, 2011, BMC BIOINFORMATICS, V12, DOI 10.1186/1471-2105-12-323
Li J, 2013, NAT METHODS, V10, P1046, DOI [10.1038/NMETH.2650, 10.1038/nmeth.2650]
Lovly C, 2015, EGFR MUTATIONS NONSM
Lv TF, 2015, ONCOTARGET, V6, P33006, DOI 10.18632/oncotarget.5026
Ma Jianwei, 2008, Chinese Journal of Clinical Oncology, V5, P87, DOI 10.1007/s11805-008-0087-2
Ma YF, 2015, TUMOR BIOL, V36, P8085, DOI 10.1007/s13277-015-3478-z
Mankoo PK, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0024709
Nebert DW, 2000, EUR J PHARMACOL, V410, P107, DOI 10.1016/S0014-2999(00)00809-8
Ni Y, 2014, CANCER INFORM, V13, P39, DOI 10.4137/CIN.S13786
Nitta RT, 2011, ONCOGENE, V30, P234, DOI 10.1038/onc.2010.414
Olivo-Marston SE, 2010, CARCINOGENESIS, V31, P1778, DOI 10.1093/carcin/bgq156
Pankov R, 2002, J CELL SCI, V115, P3861, DOI 10.1242/jcs.00059

```
   Ren JH, 2012, ENVIRON MOL MUTAGEN, V53, P78, DOI 10.1002/em.20680
   Rhodes DR, 2005, NAT GENET, V37, pS31, DOI 10.1038/ng1570
   Robert C, 1999, CLIN CANCER RES, V5, P2094
   Samet JM, 2009, CLIN CANCER RES, V15, P5626, DOI 10.1158/1078-0432.CCR-09-
0376
   Sanchez-Cespedes M, 2001, CANCER RES, V61, P1309
   Sarris EG, 2012, PHARMACEUTICALS, V5, P1236, DOI 10.3390/ph5111236
   SCHWARZ G, 1978, ANN STAT, V6, P461, DOI 10.1214/aos/1176344136
   Seki N, 2010, LUNG CANCER, V70, P329, DOI 10.1016/j.lungcan.2010.03.006
   Serke M, 2007, Pneumologie, V61, P162, DOI 10.1055/s-2007-959159
   Sun S, 2007, NAT REV CANCER, V7, P778, DOI 10.1038/nrc2190
   Tibshirani R, 1996, J ROY STAT SOC B MET, V58, P267
   Voiles L, 2014, ONCOL REP, V32, P1897, DOI 10.3892/or.2014.3438
   Witten DM, 2009, STAT APPL GENET MOL, V8, DOI 10.2202/1544-6115.1470
   Witten DM, 2009, BIOSTATISTICS, V10, P515, DOI 10.1093/biostatistics/kxp008
   Yano T, 2008, CANCER, V113, P1012, DOI 10.1002/cncr.23679
   Yano T, 2011, INT J CLIN ONCOL, V16, P287, DOI 10.1007/s10147-010-0160-8
   Yoshida T, 2004, ANN ONCOL, V15, P252, DOI 10.1093/annonc/mdh073
   Zhang SH, 2012, NUCLEIC ACIDS RES, V40, P9379, DOI 10.1093/nar/gks725
   Zou H, 2005, J R STAT SOC B, V67, P301, DOI 10.1111/j.1467-9868.2005.00503.x
   Zou H, 2008, ANN STAT, V36, P1509, DOI 10.1214/009053607000000802
   Zou H, 2007, ANN STAT, V35, P2173, DOI 10.1214/009053607000000127
   Zou H, 2006, J AM STAT ASSOC, V101, P1418, DOI 10.1198/016214506000000735
NR 66
TC 1
Z9 1
U1 0
U2 7
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 1367-4803
EI 1460-2059
J9 BIOINFORMATICS
JI Bioinformatics
PD NOV 1
PY 2016
VL 32
IS 21
BP 3279
EP 3290
DI 10.1093/bioinformatics/btw295
PG 12
WC Biochemical Research Methods; Biotechnology & Applied Microbiology;
   Computer Science, Interdisciplinary Applications; Mathematical &
   Computational Biology; Statistics & Probability
SC Biochemistry & Molecular Biology; Biotechnology & Applied Microbiology;
   Computer Science; Mathematical & Computational Biology; Mathematics
GA EC2VZ
UT WOS:000387983700009
PM 27381342
OA Green Published, Bronze
DA 2019-08-06
ER

PT J
AU Askenazi, M
   Fenyo, D
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AF Askenazi, Manor
   Fenyo, David
TI OpenSlice: Quantitative data sharing from HyperPeaks to global ion
   chromatograms (GICs)
SO PROTEOMICS
LA English
DT Article
DE Bioinformatics; Databases; Data mining; Data processing and analysis
ID DATA FORMAT; PROTEOMICS; CANCER
AB Data sharing in the field of MS has advanced greatly thanks to innovations
such as the standardized formats, data repositories, and publications guidelines.
However, there is currently no data sharing mechanism that enables real-time
data browsing and deep linking on a large scale: unrestricted data access
(particularly at the quantitative level) ultimately requires the user to
download a local copy of the relevant data files (e.g., in order to generate
extracted ion chromatograms [XICs]). In this technical resource, we present a
set of technologies (collectively termed OpenSlice) that enable the user to
quantitatively query hundreds of hours of proteomics discovery data (i.e.,
nontargeted acquisition) in real time: the user is able to effectively generate
XICs for arbitrary masses on the fly and across the entire dataset (so-called
global ion chromatograms), interacting with the results through a very intuitive
browser-based interface. A key design consideration underlying the OpenSlice
approach is the notion that every aspect of the acquired data must be accessible
through a RESTful uniform resource locator based application programming
interface, up to and including individual chromatographic peaks (hence
HyperPeaks). A publicly accessible demonstration of this technology based on the
Clinical Proteomics Tumor Analysis Consortium CompRef dataset is made available
at http://compref.fenyolab.org.
C1 [Askenazi, Manor] Biomed Hosting LLC, Arlington, MA USA.
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FU National Institutes of Health, National Cancer Institute through CPTAC
   from Leidos [13XS068]; National Institute of Standards and Technology
   [70NANB13H200]
FX This work was supported by funding provided by the National Institutes
   of Health, National Cancer Institute through CPTAC contract 13XS068 from
   Leidos, and by the National Institute of Standards and Technology though
   cooperative agreement 70NANB13H200.
CR Askenazi M., 2011, MOL CELL PROTEOMICS, V10
   Cottingham Katie, 2009, J Proteome Res, V8, P4887, DOI 10.1021/pr900912g
   Deutsch E, 2008, PROTEOMICS, V8, P2776, DOI 10.1002/pmic.200890049
   Jones AR, 2012, MOL CELL PROTEOMICS, V11, DOI 10.1074/mcp.M111.014381
   Mertins P, 2016, NATURE, V534, P55, DOI 10.1038/nature18003
   Nesvizhskii AI, 2014, NAT METHODS, V11, P1114, DOI [10.1038/NMETH.3144,
10.1038/nmeth.3144]
   Ruby S, 2007, RESTFUL WEB SERVICES
   Ruggles KV, 2016, MOL CELL PROTEOMICS, V15, P1060, DOI
10.1074/mcp.M115.056226
   Shah AR, 2010, J AM SOC MASS SPECTR, V21, P1784, DOI
10.1016/j.jasms.2010.06.014
   Vizcaino JA, 2013, NUCLEIC ACIDS RES, V41, pD1063, DOI 10.1093/nar/gks1262
   Zhang B, 2014, NATURE, V513, P382, DOI 10.1038/nature13438
   Zhang H., 2016, CELL IN PRESS
NR 12
TC 1
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Z9 1
U1 0
U2 2
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 1615-9853
EI 1615-9861
J9 PROTEOMICS
JI Proteomics
PD SEP
PY 2016
VL 16
IS 18
SI SI
BP 2495
EP 2501
DI 10.1002/pmic.201600096
PG 7
WC Biochemical Research Methods; Biochemistry & Molecular Biology
SC Biochemistry & Molecular Biology
GA DZ4FJ
UT WOS:000385813600009
PM 27436706
DA 2019-08-06
ER

PT J
AU Kuchinke, W
   Krauth, C
   Bergmann, R
   Karakoyun, T
   Woollard, A
   Schluender, I
   Braasch, B
   Eckert, M
   Ohmann, C
AF Kuchinke, Wolfgang
   Krauth, Christian
   Bergmann, Rene
   Karakoyun, Toeresin
   Woollard, Astrid
   Schluender, Irene
   Braasch, Benjamin
   Eckert, Martin
   Ohmann, Christian
TI Legal assessment tool (LAT): an interactive tool to address privacy and
   data protection issues for data sharing
SO BMC MEDICAL INFORMATICS AND DECISION MAKING
LA English
DT Article
ID CONDUCT; MODEL; CODE
AB Background: In an unprecedented rate data in the life sciences is generated
and stored in many different databases. An ever increasing part of this data is
human health data and therefore falls under data protected by legal regulations.
As part of the BioMedBridges project, which created infrastructures that connect
more than 10 ESFRI research infrastructures (RI), the legal and ethical
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prerequisites of data sharing were examined employing a novel and pragmatic approach.

Methods: We employed concepts from computer science to create legal requirement clusters that enable legal interoperability between databases for the areas of data protection, data security, Intellectual Property (IP) and security of biosample data. We analysed and extracted access rules and constraints from all data providers (databases) involved in the building of data bridges covering many of Europe's most important databases. These requirement clusters were applied to five usage scenarios representing the data flow in different data bridges: Image bridge, Phenotype data bridge, Personalised medicine data bridge, Structural data bridge, and Biosample data bridge. A matrix was built to relate the important concepts from data protection regulations (e.g. pseudonymisation, identifyability, access control, consent management) with the results of the requirement clusters. An interactive user interface for querying the matrix for requirements necessary for compliant data sharing was created.

Results: To guide researchers without the need for legal expert knowledge through legal requirements, an interactive tool, the Legal Assessment Tool (LAT), was developed. LAT provides researchers interactively with a selection process to characterise the involved types of data and databases and provides suitable requirements and recommendations for concrete data access and sharing situations. The results provided by LAT are based on an analysis of the data access and sharing conditions for different kinds of data of major databases in Europe.

Conclusions: Data sharing for research purposes must be opened for human health data and LAT is one of the means to achieve this aim. In summary, LAT provides requirements in an interactive way for compliant data access and sharing with appropriate safeguards, restrictions and responsibilities by introducing a culture of responsibility and data governance when dealing with human data.

C1 [Kuchinke, Wolfgang; Krauth, Christian; Bergmann, Rene; Karakoyun, Toeresin; Braasch, Benjamin; Eckert, Martin] Heinrich Heine Univ, Dusseldorf, Germany.
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FU European Commission by Research Infrastructures of the FP7 Capacities Specific Programme [284209]
FX The BioMedBridges project is funded by the European Commission by Research Infrastructures of the FP7 Capacities Specific Programme (Grant agreement number 284209).

CR Allison D., 2012, J SOFTWARE ENG APPL, V2012, P200, DOI DOI 10.4236/JSEA.2012.53026
ANDS (Australian National Data Service), GUID ETH CONS DAT SH
[Anonymous], WHOS ELSI GENETICS R
[Anonymous], WORK SENS DAT
[Anonymous], 2009, SMART20070059
[Anonymous], 2015, BIOMEDBRIDGES
[Anonymous], 2016, INF MAN GLOSS
Bhimani N., 2016, UCL 0122
Breaux TD, 2006, RE'06: 14TH IEEE INTERNATIONAL REQUIREMENTS ENGINEERING CONFERENCE, PROCEEDINGS, P49
Brittain J, 2007, TOMCAT DEFINITIVE GU
Cappelli A, 2007, P WORKSH COMP SEM IW
Casellas N, 2010, PAL ALT CAL 2010 AAA
Data Management Task Force, 2009, E IRG REP DAT MAN

ESFRI, 2013, EUR RES INFR GLOB IM, V113
Expert Advisory Group on Data Access, 2015, GOV DAT ACC
Gaur S, 2015, TRANSLATING SIMPLE L
Goodman KW, 2013, J AM MED INFORM ASSN, V20, P141, DOI 10.1136/amiajnl-2012-001035
Grabmair M, 2005, FR ART INT, V134, P107
HumGen, INT DAT LEG SOC ETH
Ian A, 2004, SCENARIOS STORIES US
ICH Expert Working Group, 1996, GUID GOOD CLIN PRACT
Jiang XQ, 2014, BMC MED INFORM DECIS, V14, DOI 10.1186/1472-6947-14-S1-S1
Knoppers BM, 2014, HUM GENET, V133, P895, DOI 10.1007/s00439-014-1432-6
Kuchinke W, 2014, INT J MED INFORM, V83, P941, DOI [10.1016/j.ijmedinf.7014.08.009, 10.1016/j.ijmedinf.2014.08.009]
Lee LM, 2009, JAMA-J AM MED ASSOC, V302, P82, DOI 10.1001/jama.2009.958
LINDHOLM T, 1999, JAVA VIRTUAL MACHINE
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
McCallister Erika, 2010, SPECIAL PUBLICATION
Nielsen F, 2016, REPOSITIVE 0229
Ohmann C, 2013, BIOMEDBRIDGES 1231
Pohl K, 1997, ENCY COMPUTER SCI TE, V36
Poulin D., 1993, Fourth International Conference on Artificial Intelligence and Law. Proceedings of the Conference, P90
Rahmouni HB, 2011, METHOD INFORM MED, V50, P326, DOI 10.3414/ME10-01-0075
Rahmouni HB, 2009, P 11 INT PROT C AMST
Rahmouni HB, 2009, P 22 IEEE INT S ALB
Ramingwong L, 2012, INT J ENG SCI TECHNO, V4, P2997
S Bartling, 2014, OPENING SCI
Shabani Mahsa, 2015, Life Sci Soc Policy, V11, P3, DOI 10.1186/s40504-014-0022-7
Sutcliffe A, 2003, 11TH IEEE INTERNATIONAL REQUIREMENTS ENGINEERING CONFERENCE, PROCEEDINGS, P320
Uhlir PF, 2013, NSGIC C 24 27 FEB 20
van Engers TM, 2003, 16 ANN C, P398
van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
Yu F, 2014, BMC MED INFORM DECIS, V14, DOI 10.1186/1472-6947-14-S1-S3
NR 43
TC 1
Z9 1
U1 1
U2 2
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1472-6947
J9 BMC MED INFORM DECIS
JI BMC Med. Inform. Decis. Mak.
PD JUL 7
PY 2016
VL 16
AR 81
DI 10.1186/s12911-016-0325-0
PG 19
WC Medical Informatics
SC Medical Informatics
GA VF6DY
UT WOS:000443254900001
PM 27751180
OA DOAJ Gold, Green Published

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PT J
AU Carter, JG
Sherbon, BJ
Viney, IS
AF Carter, James G.
Sherbon, Beverley J.
Viney, Ian S.
TI United Kingdom health research analyses and the benefits of shared data
SO HEALTH RESEARCH POLICY AND SYSTEMS
LA English
DT Article
ID BURDEN

AB Background: To allow research organisations to co-ordinate activity to the benefit of national and international funding strategies requires assessment of the funding landscape; this, in turn, relies on a consistent approach for comparing expenditure on research. Here, we discuss the impact and benefits of the United Kingdom's Health Research Classification System (HRCS) in national landscaping analysis of health research and the pros and cons of performing large-scale funding analyses.

Methods: The first United Kingdom health research analysis (2004/2005) brought together the 11 largest public and charity funders of health research to develop the HRCS and use this categorisation to examine United Kingdom health research. The analysis was revisited in 2009/2010 and again in 2014. The most recent quinquennial analysis in 2014 compiled data from 64 United Kingdom research organisations, accounting for 91% of all public/charitable health research funding in the United Kingdom. The three analyses summarise the United Kingdom's health research expenditure in 2004/2005, 2009/2010 and 2014, and can be used to identify changes in research activity and disease focus over this 10 year period.

Results: The 2004/2005 analysis provided a baseline for future reporting and evidence for a United Kingdom Government review that recommended the co-ordination of United Kingdom health research should be strengthened to accelerate the translation of basic research into clinical and economic benefits. Through the second and third analyses, we observed strategic prioritisation of certain health research activities and disease areas, with a strong trend toward increased funding for more translational research, and increases in specific areas such as research on prevention.

Conclusions: The use of HRCS in the United Kingdom to analyse the research landscape has provided benefit both to individual participatory funders and in coordinating initiatives at a national level. A modest amount of data for each project is sufficient for a nationwide assessment of health research funding, but achieving coverage of the United Kingdom portfolio relies on sourcing these details from a large number of individual funding agencies. The effort needed to compile this data could be minimised if funders routinely shared or published this information in a standard and accessible way. The United Kingdom approach to landscaping analyses could be readily adapted to suit other groups or nations, and global availability of research funding data would support better national and international coordination of health research.

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EM james.carter@headoffice.mrc.ac.uk
OI Carter, James/0000-0003-1860-9677; Sherbon, Beverley/0000-0002-4298-5499
CR [Anonymous], 2002, WHO GLOB BURD DIS DA

```
   Association of Medical Research Charities, 2011, AMRC ANN REP 2010 11
   Association of Medical Research Charities, 2014, AMRC ANN REV 2013 14
   Cooksey D, 2006, REV UK HLTH RES FUND
   Curran B, 2014, OUTPUTS OUTCOMES IMP
   Department for Business Innovation and Skills, 2010, ALL SCI RES FUND 201
   ESF Science Policy Briefing, 2011, ESF SCI POL BRIEF HL
   European Science Foundation, 2011, EUR SCI FDN MED FORM
   Glover M, 2014, BMC MED, V12, DOI 10.1186/1741-7015-12-99
   *GOV OFF SCI, 2007, TACKL OB FUT CHOIC P
   Haskel J., 2014, EC SIGNIFICANCE UK S
   Health & Social Care Information Centre, 2014, HLTH SURV ENGL 2013
   Hinrichs S, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0364-x
   Kinge JM, 2014, HEALTH RES POLICY SY, V12, DOI 10.1186/1478-4505-12-64
   Medical Research Council, REV UK MENT HLTH RES
   National Institute of Health Research Evaluation, 2013, TRIALS STUD FUND DAT
   Nicolau I, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0042479
   NPRI Report Group, 2015, IN OUTC FUT APPR
   Research Council UK, 2013, GAT RES FUND DAT 201
   Scarborough P, 2011, J PUBLIC HEALTH-UK, V33, P527, DOI 10.1093/pubmed/fdr033
   Sussex J, 2016, BMC MED, V14, DOI 10.1186/s12916-016-0564-z
   UK All-Party Parliamentary Group (APPG) on Global Health, 2015, UKS CONTR
HLTH GLOB
   UK Clinical Research Collaboration, UK HLTH RES AN 2004
   Viergever RF, 2011, HEALTH RES POLICY SY, V9, DOI 10.1186/1478-4505-9-12
   WHO, GLOBAL BURDEN DIS
NR 25
TC 1
Z9 1
U1 0
U2 2
PU BIOMED CENTRAL LTD
PI LONDON
PA 236 GRAYS INN RD, FLOOR 6, LONDON WC1X 8HL, ENGLAND
SN 1478-4505
J9 HEALTH RES POLICY SY
JI Health Res. Policy Syst.
PD JUN 24
PY 2016
VL 14
AR 48
DI 10.1186/s12961-016-0116-1
PG 9
WC Health Policy & Services
SC Health Care Sciences & Services
GA DQ6HG
UT WOS:000379304600001
PM 27342284
OA DOAJ Gold, Green Published
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ER

PT J
AU Lewin, JH
   Vis, DJ
   Voest, EE
   Liao, R
   Nederlof, PM
   Conley, BA
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   Solit, DB
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   Caulfield, M
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   Esserman, L
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   Siu, LL
   Lawler, M
AF Lewin, Jeremy Howard
   Vis, Daniel J.
   Voest, Emile E.
   Liao, Rachel
   Nederlof, Petra M.
   Conley, Barbara A.
   Solit, David B.
   Corless, Christopher L.
   Campregher, Paulo V.
   Tyrell, Vanessa
   Chong, George
   Watson, Michael
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   Maughan, Tim
   Caulfield, Mark
   Lazar, Vladimir
   Esserman, Laura
   Sawyers, Charles L.
   Siu, Lillian L.
   Lawler, Mark
TI Determining barriers to effective data sharing in cancer genomic
   sequencing initiatives: A Global Alliance for Genomics and Health
   (GA4GH) survey.
SO JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Meeting Abstract
CT Annual Meeting of the American-Society-of-Clinical-Oncology (ASCO)
CY JUN 03-07, 2016
CL Chicago, IL
SP Amer Soc Clin Oncol
C1 Princess Margaret Canc Ctr, Toronto, ON, Canada.
   Netherlands Canc Inst, Amsterdam, Netherlands.
   Global Alliance Genom & Hlth, Cambridge, MA USA.
   Antoni Van Leeuwenhoek Hosp, Netherlands Canc Inst, Amsterdam, Netherlands.
   Natl Canc Inst, Rockville, MD USA.
   Mem Sloan Kettering Canc Ctr, 1275 York Ave, New York, NY 10021 USA.
   OHSU Knight Canc Inst, Portland, OR USA.
   Hosp Israelita Albert Einstein, Sao Paulo, Brazil.
   Childrens Canc Inst, Sydney, NSW, Australia.
   McGill Univ, Dept Pathol, Segal Canc Ctr, Jewish Gen Hosp, Montreal, PQ,
Canada.
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Queen Mary Univ London, London, England.
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NR 0
TC 1
Z9 1
U1 0
U2 1
PU AMER SOC CLINICAL ONCOLOGY
PI ALEXANDRIA
PA 2318 MILL ROAD, STE 800, ALEXANDRIA, VA 22314 USA
SN 0732-183X
EI 1527-7755
J9 J CLIN ONCOL
JI J. Clin. Oncol.
PD MAY 20
PY 2016
VL 34
IS 15
SU S
MA 11502
DI 10.1200/JCO.2016.34.15_suppl.11502
PG 2
WC Oncology
SC Oncology
GA EZ4WF
UT WOS:000404712500508
DA 2019-08-06
ER

PT J
AU [Anonymous]
AF [Anonymous]
TI Don't wait to share data on Zika
SO NATURE MICROBIOLOGY
LA English
DT Editorial Material
AB During public health emergencies, such as the current increase in microcephaly and neurological syndromes potentially associated with the Zika virus outbreak, a rapid and coordinated response necessitates the immediate sharing of data. Nature Microbiology policy is fully aligned with this imperative.
CR [Anonymous], 2015, NATURE GENET, V47, P1101
[Anonymous], ZIK RES LIT
[Anonymous], 2015, NATURE MED, V21, P1235
[Anonymous], 2016, NATURE, V530, P5
Hufton A., 2016, SCI DATA UPDATES
Leducq J. -B., 2015, PREPRINT
Leducq JB, 2016, NAT MICROBIOL, V1, DOI [10.1038/NMICROBIOL.2015.3, 10.1038/nmicrobiol.2015.3]
Nature, 2016, NATURE, V530, P129
Racaniello V., 2016, VIROLOGY BLOG 0128
Samarasekera U., 2016, LANCET
Wigington C. H., 2015, PREPRINT
Wigington CH, 2016, NAT MICROBIOL, V1, DOI [10.1038/nmicrobiol.2015.24, 10.1038/NMICROBIOL.2015.24]

```
NR 12
TC 1
Z9 1
U1 0
U2 0
PU NATURE PUBLISHING GROUP
PI LONDON
PA MACMILLAN BUILDING, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
EI 2058-5276
J9 NAT MICROBIOL
JI NAT. MICROBIOL
PD MAR
PY 2016
VL 1
IS 3
AR 16028
DI 10.1038/NMICROBIOL.2016.28
PG 1
WC Microbiology
SC Microbiology
GA DW4HU
UT WOS:000383604600017
PM 27572177
OA Bronze
DA 2019-08-06
ER

PT J
AU Prey, JE
   Polubriaginof, F
   Kuperman, GJ
   Tiase, V
   Collins, SA
   Vawdrey, DK
AF Prey, Jennifer E.
   Polubriaginof, Fernanda
   Kuperman, Gilad J.
   Tiase, Victoria
   Collins, Sarah A.
   Vawdrey, David K.
TI International perspectives on sharing clinical data with patients
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Personal health records; Consumer health information; Health information
   technology; Patients; International perspectives
ID CARE; HEALTH; OUTCOMES; SUPPORT
AB Objective: Engaging patients in their care has become a topic of increasing
importance, and enabling patients to have access to their clinical data is a key
aspect of such engagement. We investigated, on an international scale, the
current state of approaches for providing patients with access to their own
clinical information.
   Methods: Individuals from 28 countries were invited to participate in a
cross-sectional semi-structured interview. Interview questions focused on social
and cultural influences that affected patient engagement activities, government
support for current and planned initiatives, data ownership models, and
technical issues.
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Results: Interviews were conducted with individuals from 16 countries representing six continents. Respondents reported substantive initiatives for providing information to patients in the majority of countries interviewed. These initiatives were diverse in nature and stage of implementation. Discussion: Enabling patient access to data is occurring on an international scale. There is considerable variability in the level of maturity, the degree of government involvement, the technical infrastructure, and the plans for future development across the world. As informaticians, we are still in the early stages of deploying patient engagement technologies and have yet to identify optimal strategies in this arena.

Conclusion: Efforts to improve patient access to data are active on a global-scale. There are many open questions about best practices and much can be learned by adopting an international perspective to guide future implementation efforts. (C) 2015 Elsevier Ireland Ltd. All rights reserved.

C1 [Prey, Jennifer E.; Polubriaginof, Fernanda; Kuperman, Gilad J.; Vawdrey, David K.] Columbia Univ, Dept Biomed Informat, New York, NY 10027 USA.

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FU AHRQ HHS [1R36HS021393-01, R01HS21816]; NLM NIH HHS [T15 LM00707]

CR Adler-Milstein J, 2014, HEALTH AFFAIR, V33, P1559, DOI 10.1377/hlthaff.2014.0424

Adler-Milstein J, 2012, JAMA-J AM MED ASSOC, V307, P1695, DOI 10.1001/jama.2012.525

Blumenthal D, 2015, J GEN INTERN MED, V30, pS42, DOI 10.1007/s11606-014-3071-y

Collins SA, 2011, J AM MED INFORM ASSN, V18, pi2

Coulter A, 2012, J AMBUL CARE MANAG, V35, P80, DOI 10.1097/JAC.0b013e318249e0fd

Dearne K., 2014, ANAL COMMONWEALTH GO

DONABEDIAN A, 1988, JAMA-J AM MED ASSOC, V260, P1743, DOI 10.1001/jama.260.12.1743

Dykes P C, 2014, AMIA ANN S P

Furukawa MF, 2014, HEALTH AFFAIR, V33, P1672, DOI 10.1377/hlthaff.2014.0445

Giardina TD, 2014, J AM MED INFORM ASSN, V21, P737, DOI 10.1136/amiajnl-2013-002239

Goetz T., 2011, DECISION TREE MAKE B

Hibbard JH, 2013, HEALTH AFFAIR, V32, P207, DOI 10.1377/hlthaff.2012.1061

Hogberg KM, 2015, CANCER NURS, V38, P145, DOI 10.1097/NCC.0000000000000145

Ministry of Medical Services & Ministry of Public Health and Sanitation, 2011, KEN NAT E HLTH STRAT

Osborn R, 2012, J AMBUL CARE MANAG, V35, P118, DOI 10.1097/JAC.0b013e31824a579b

Sarkar U, 2014, JAMA-J AM MED ASSOC, V311, P357, DOI 10.1001/jama.2013.285825

Trillium Bridge, 2014, BRIDG GPATIENT SUMM

Trossman Susan, 2013, Am Nurse, V45, P10

Wolfe BA, 2006, AMIA ANN S P

NR 19

TC 1

Z9 1

U1 1

U2 15

PU ELSEVIER IRELAND LTD

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PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
   IRELAND
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WC Computer Science, Information Systems; Health Care Sciences & Services;
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SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA CZ8NS
UT WOS:000367357000016
PM 26631956
DA 2019-08-06
ER

PT J
AU Rappert, B
   Bezuidenhout, L
AF Rappert, Brian
   Bezuidenhout, Louise
TI Data sharing in low-resourced research environments
SO PROMETHEUS
LA English
DT Article
ID MIDDLE-INCOME SETTINGS; PUBLIC-HEALTH RESEARCH; OPEN ACCESS;
   CREDIBILITY; SCIENCE
AB 'Open data' has recently emerged as a label for renewed attempts to promote
scientific exchange. As part of such efforts, the posting of data online is
often portrayed as commonly beneficial: individual scientists accrue greater
prominence while at the same time fostering communal knowledge. Yet, how
scientists in non-Western research settings assess such calls for openness has
been the subject of little empirical study. Based on extended fieldwork with
biochemistry laboratories in sub-Sahara Africa, this paper examines a variety of
reasons why scientists opt for closure over openness with regard to their own
data. We argue that the heterogeneity of research environments calls into
question many of the presumptions made as part of open data. Inequalities in
research environments can mean that moves towards sharing create binds and
dilemmas. These observations suggest that those promoting openness must
critically examine current research governance and funding systems that continue
to perpetuate disparities. The paper proposes an innovative approach to
facilitating openness: coupling the sharing of data with enabling scientists to
redress their day-to-day research environment demands. Such a starting basis
provides an alternative but vital link between the aspirations for science aired
today as part of international discussions and the daily challenges of
undertaking research in low-resourced environments.
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FU Leverhulme Trust [RPG-2013-153]
FX The research for this paper was supported by the Leverhulme Trust under the award entitled 'Beyond the digital divide' [grant number RPG-2013-153].
CR Alter GC, 2015, J EMPIR RES HUM RES, V10, P317, DOI 10.1177/1556264615591561
Ankeny Rachel A, 2015, POSTGENOMICS PERSPEC, P126
Barry JJ, 2012, THIRD WORLD Q, V33, P125, DOI 10.1080/01436597.2012.628107
Bezuidenhout L, 2017, CRIT PUBLIC HEALTH, V27, P39, DOI 10.1080/09581596.2016.1252832
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Bull S, 2015, J EMPIR RES HUM RES, V10, P225, DOI 10.1177/1556264615594767
Carr D, 2015, J EMPIR RES HUM RES, V10, P314, DOI 10.1177/1556264615593485
CODATA, 2014, CODATA WORKSH OP DAT
CODATA, 1997, BITS POW ISS GLOB AC
CSU, 2015, OP DAT BIG DAT WORLD
de Vries J, 2015, TRENDS GENET, V31, P117, DOI 10.1016/j.tig.2014.11.004
de Vries J, 2011, BMC MED ETHICS, V12, DOI 10.1186/1472-6939-12-5
European Commission, 2011, COM2011882 EUR COMM
European Science Foundation, 2008, ESF DFG WORKSH SEPT
Fecher B, 2015, REPUTATION EC RESULT
Fecher B, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0118053
Ferguson L., 2014, WILEY EXCHANGES
Hagstrom W. O, 1965, SCI COMMUNITY
Hayden C, 2010, J CULTURAL EC, V3, P85, DOI DOI 10.1080/17530351003617602
Hessels L. K., 2009, SCI PUBL POLICY, V36, P387, DOI DOI 10.3152/030234209X442034
Hessels LK, 2011, MINERVA, V49, P215, DOI 10.1007/s11024-011-9167-1
Kelly AH, 2012, VALUE TRANSNATIONAL
Lamberton D. M., 2001, Prometheus, V19, P223, DOI 10.1080/08109020110072199
Latour Bruno, 1979, LAB LIFE
Leisyte L., 2008, HIGH EDUC POLICY, V21, P377, DOI DOI 10.1057/HEP.2008.14
Leonelli S, 2013, B SCI TECHNOL SOC, V33, P6, DOI DOI 10.1177/0270467613496768
Leonelli S., 2013, GEO GEOGRAPHY ENV, V2, P12
Leonelli S, 2012, SOC STUD SCI, V42, P214, DOI 10.1177/0306312711436265
MacDonald S., 1998, INFORM INNOVATION MA
Mahmuda I, 2014, SCI TECHNOL SOC, V19, P249, DOI 10.1177/0971721814529879
Mauthner NS, 2013, SOC EPISTEMOL, V27, P47, DOI 10.1080/02691728.2012.760663
OECD, 2015, MAK OP DAT REAL OECD, V25
OECD, 2007, OECD PRINC GUID ACC
Olmos-Penuela J, 2015, MINERVA, V53, P381, DOI 10.1007/s11024-015-9283-4
Open Knowledge International, 2016, OP DEF 2 0
Oyelaran-Oyeyinka B., 2006, SCI TECHNOL SOC, V11, P239, DOI DOI 10.1177/097172180601100201
Packer K, 1996, SCI TECHNOL HUM VAL, V21, P427, DOI 10.1177/016224399602100403
Parker M, 2015, J EMPIR RES HUM RES, V10, P217, DOI 10.1177/1556264615593494
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pisani E, 2010, LANCET, V375, P703, DOI 10.1016/S0140-6736(09)61486-0
RCUK, 2013, RCUK POL OP ACC SUPP
Research Information Network and the British Library, 2009, PATT INF US EXCH CAS
RIN/NESTA, 2010, OP ALL CAS STUD OP R

```
   RIP A, 1994, HIGH EDUC, V28, P3, DOI 10.1007/BF01383569
   Royal Society, 2012, SCI OPEN ENTERPRISE
   Tangcharoensathien V, 2010, B WORLD HEALTH ORGAN, V88, P468, DOI
10.2471/BLT.10.079129
   Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
   Wessels B, 2014, PROMETHEUS, V32, P49, DOI 10.1080/08109028.2014.956505
   Zeitlyn D, 2003, RES POLICY, V32, P1287, DOI 10.1016/S0048-7333(03)00053-2
NR 50
TC 1
Z9 1
U1 1
U2 3
PU ROUTLEDGE JOURNALS, TAYLOR & FRANCIS LTD
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J9 PROMETHEUS
JI Prometheus
PY 2016
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DI 10.1080/08109028.2017.1325142
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WC Social Sciences, Interdisciplinary
SC Social Sciences - Other Topics
GA FP5QM
UT WOS:000417674000004
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PT S
AU Chen, CL
   Hu, JX
   Fan, CL
   Wang, KH
AF Chen, Chin-Ling
   Hu, Jin-Xin
   Fan, Chun-Long
   Wang, Kun-hao
GP IEEE
TI Design of a secure medical data sharing system via an authorized
   mechanism
SO 2016 IEEE INTERNATIONAL CONFERENCE ON SYSTEMS, MAN, AND CYBERNETICS
   (SMC)
SE IEEE International Conference on Systems Man and Cybernetics Conference
   Proceedings
LA English
DT Proceedings Paper
CT IEEE International Conference on Systems, Man, and Cybernetics (SMC)
CY OCT 09-12, 2016
CL Budapest, HUNGARY
SP IEEE
DE authentication; security; cloud; medical; digital envelope
AB In recent years, the electronic medical records can be easily stored with the
rapid development of health care technology and cloud computing. However, the
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patient's medical information security is currently concern issue. Despite of many literatures discussed about it, these literatures still face many security challenges. Therefore, we propose an authentication scheme based on cloud environment. In our scheme, we allow people to use the digital develop mechanism to achieve the sharing medical data. By the way, the biometric fingerprint feature and digital signature are used to ensure the security of medical information in our scheme.

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Taiwan, R.O.C., under contract number MOST 104-2221-E-324-012, MOST
105-2622-E-212-008 -CC2 and MOST103-2632-E-324-001-MY3.

CR Chen CL, 2014, J MED SYST, V38, DOI 10.1007/s10916-014-0112-3
Chen CL, 2012, SECUR COMMUN NETW, V5, P725, DOI 10.1002/sec.367
Chiou SY, 2016, J MED SYST, V40, DOI 10.1007/s10916-016-0453-1
Ferreira C., 2015, 26 MED INF EUR C MIE
Han JG, 2014, LECT NOTES COMPUT SC, V8713, P73, DOI 10.1007/978-3-319-11212-1_5
Hendre A., 2015, 8 INT C CLOUD COMP I
Wang MQ, 2016, CONCURR COMP-PRACT E, V28, P1237, DOI 10.1002/cpe.3623
World Health Organization, URB POP DAT COUNTR

NR 8
TC 1
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PU IEEE
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PA 345 E 47TH ST, NEW YORK, NY 10017 USA
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J9 IEEE SYS MAN CYBERN
PY 2016
BP 2478
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WC Computer Science, Cybernetics; Computer Science, Information Systems
SC Computer Science
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UT WOS:000402634702061
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AU Lee, JE
Sung, JH

   Barnett, ME
   Norris, K
AF Lee, Jae Eun
   Sung, Jung Hye
   Barnett, M. Edwina
   Norris, Keith
TI User-Friendly Data-Sharing Practices for Fostering Collaboration within
   a Research Network: Roles of a Vanguard Center for a Community-Based
   Study
SO INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH AND PUBLIC HEALTH
LA English
DT Article
DE data-sharing practice; research network; role of coordinating center
ID AFRICAN-AMERICANS; PUBLIC-HEALTH; JACKSON; QUALITY; IMPACT; FIELD; CARE

AB Although various attempts have been made to build collaborative cultures for data sharing, their effectiveness is still questionable. The Jackson Heart Study (JHS) Vanguard Center (JHSVC) at the NIH-funded Research Centers in Minority Institutions (RCMI) Translational Research Network (RTRN) Data Coordinating Center (DCC) may be a new concept in that the data are being shared with a research network where a plethora of scientists/researchers are working together to achieve their common goal. This study describes the current practices to share the JHS data through the mechanism of JHSVC. The JHS is the largest single-site cohort study to prospectively investigate the determinants of cardiovascular disease among African-Americans. It has adopted a formal screened access method through a formalized JHSVC mechanism, in which only a qualified scientist(s) can access the data. The role of the DCC was to help RTRN researchers explore hypothesis-driven ideas to enhance the output and impact of JHS data through customized services, such as feasibility tests, data querying, manuscript proposal development and data analyses for publication. DCC has implemented these various programs to facilitate data utility. A total of 300 investigators attended workshops and/ or received training booklets. DCC provided two online and five onsite workshops and developed/distributed more than 250 copies of the booklet to help potential data users understand the structure of and access to the data. Information on data use was also provided through the RTRN website. The DCC efforts led to the production of five active manuscript proposals, seven completed publications, 11 presentations and four NIH grant proposals. These outcomes resulted from activities during the first four years; over the last couple of years, there were few new requests. Our study suggested that DCC-customized services enhanced the accessibility of JHS data and their utility by RTRN researchers and helped to achieve the principal goal of JHSVC of scientific productivity. In order to achieve long-term success, the following, but not limited to these, should be addressed in the current data sharing practices: preparation of new promotional strategies in response to changes in technology and users' needs, collaboration with the Network statisticians, harmonization of the JHS data with the other local-based heart datasets to meet the needs of the potential users from the broader geographical areas, adoption of the RTRN comprehensive data-sharing policy to broaden the variety of research topics and implementation of an ongoing monitoring program to evaluate its success.

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FX This study is supported by Grant Number U54MD008149 (RCMI Translational Research Network) from the National Institute on Minority Health and Health Disparities, National Institutes of Health. Keith Norris is supported, in part, by NIH Grants UL1TR000124 and P30-AG021684.
CR Akylbekova EL, 2009, CIRC-ARRHYTHMIA ELEC, V2, P427, DOI 10.1161/CIRCEP.109.858894
[Anonymous], 2013, PRINCIPLE RESPECT HU
Ball CA, 2004, NAT BIOTECHNOL, V22, P1179, DOI 10.1038/nbt0904-1179
Brownstein C.A., 2015, HUM MUTAT, V8
Chan M, 2010, PLOS MED, V7, DOI 10.1371/journal.pmed.1000223
Cook DA, 2003, CRIT CARE MED, V31, P1676, DOI 10.1097/01.CCM.0000065273.63224.A8
Dentler K, 2013, STUD HEALTH TECHNOL, V192, P313, DOI 10.3233/978-1-61499-289-9-313
DEWALD WG, 1986, AM ECON REV, V76, P587
Fecher B, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0118053
Fleming E., 2008, ETHNIC DIS, V18, P155
Fleming ES, 2008, ETHN DIS S2, V18, P161
Ganzinger M., 2013, STUD HLTH TECHNOL IN, V192
Gebreab S.Y., 2015, J AM HEART ASS, V4
Gebreab SY, 2012, SOC SCI MED, V75, P1697, DOI 10.1016/j.socscimed.2012.06.003
Gibbons M., 1994, NEW PRODUCTION KNOWL
Gunn JM, 2002, MED J AUSTRALIA, V177, P63
Hammatt ZH, 2011, J HEALTH CARE POOR U, V22, P8, DOI 10.1353/hpu.2011.0157
Hickson DA, 2012, AM J PUBLIC HEALTH, V102, P1362, DOI 10.2105/AJPH.2011.300444
Hochedlinger N, 2015, STUD HEALTH TECHNOL, V212, P27, DOI 10.3233/978-1-61499-524-1-27
Hudson J, 1996, J ECON PERSPECT, V10, P153, DOI 10.1257/jep.10.3.153
Keku E, 2005, ETHNIC DIS, V15, P62
Laine C, 2007, ANN INTERN MED, V146, P450, DOI 10.7326/0003-4819-146-6-200703200-00154
LaVigne D.A., 2013, J BEHAV HLTH, V2, P159
Lee J.E., 2010, ETHNIC DIS, V20, P5
Lee S, 2005, SOC STUD SCI, V35, P673, DOI 10.1177/0306312705052359
Liu CT, 2012, DIABETOLOGIA, V55, P2970, DOI 10.1007/s00125-012-2656-4
Martin Sebastien, 2013, Electronic Journal of e-Government, V11, P348
McCullough BD, 2009, ECON ANAL POLICY, V39, P117, DOI 10.1016/S0313-5926(09)50047-1
Murray CJL, 2007, LANCET, V369, P862, DOI 10.1016/S0140-6736(07)60415-2
*NUFF COUNC BIOETH, 2013, LINK US BIOL HLTH DA
Palmer RH, 1996, MED CARE, V34, pSS40
Piwowar HA, 2008, PLOS MED, V5, P1315, DOI 10.1371/journal.pmed.0050183
Ried K., 2006, BMC FAM PRACT, V7
Rosenblat TS, 2004, Q J ECON, V119, P971, DOI 10.1162/0033553041502199
Stokols D, 2008, AM J PREV MED, V35, pS77, DOI 10.1016/j.amepre.2008.05.002
Sung JH, 2014, J CARDIOVASC MED, V15, P371, DOI 10.2459/JCM.0b013e32836411d6
Taylor HA, 2005, ETHNIC DIS, V15, pS4

```
   Tullos BW, 2013, INT J CARDIOVAS IMAG, V29, P891, DOI 10.1007/s10554-012-
0145-y
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Varda D, 2012, AM J PUBLIC HEALTH, V102, P564, DOI 10.2105/AJPH.2011.300286
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wartenberg D, 2010, AM J PUBLIC HEALTH, V100, P407, DOI
10.2105/AJPH.2009.166249
   Williams N., 2013, INT J HYPERTENS, V2013
   Wilson JG, 2005, ETHNIC DIS, V15, pS30
   Wyatt SB, 2003, ETHNIC DIS, V13, P438
   ZIMAN J, 1994, PROMETHEUS BOUND SCI
NR 46
TC 1
Z9 1
U1 0
U2 4
PU MDPI
PI BASEL
PA ST ALBAN-ANLAGE 66, CH-4052 BASEL, SWITZERLAND
SN 1660-4601
J9 INT J ENV RES PUB HE
JI Int. J. Environ. Res. Public Health
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PY 2016
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DI 10.3390/ijerph13010034
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WC Environmental Sciences; Public, Environmental & Occupational Health
SC Environmental Sciences & Ecology; Public, Environmental & Occupational
   Health
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PT J
AU Hahn, C
   Kwon, H
   Hur, J
AF Hahn, Changhee
   Kwon, Hyunsoo
   Hur, Junbeom
TI Efficient Attribute-Based Secure Data Sharing with Hidden Policies and
   Traceability in Mobile Health Networks
SO MOBILE INFORMATION SYSTEMS
LA English
DT Article
ID ENCRYPTION; ACCESS; SYSTEM
AB Mobile health (also written as mHealth) provisions the practice of public
health supported by mobile devices. mHealth systems let patients and healthcare
providers collect and share sensitive information, such as electronic and
personal health records (EHRs) at any time, allowing more rapid convergence to
optimal treatment. Key to achieving this is securely sharing data by providing
enhanced access control and reliability. Typically, such sharing follows
policies that depend on patient and physician preferences defined by a set of
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attributes. In mHealth systems, not only the data but also the policies for sharing it may be sensitive since they directly contain sensitive information which can reveal the underlying data protected by the policy. Also, since the policies usually incur linearly increasing communication costs, mHealth is inapplicable to resource-constrained environments. Lastly, access privileges may be publicly known to users, so a malicious user could illegally share his access privileges without the risk of being traced. In this paper, we propose an efficient attribute-based secure data sharing scheme in mHealth. The proposed scheme guarantees a hidden policy, constant-sized ciphertexts, and traces, with security analyses. The computation cost to the user is reduced by delegating approximately 50% of the decryption operations to the more powerful storage systems.

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CR Alshehri S., 2012, Proceedings of the 2012 IEEE International Conference on Data Engineering Workshops (ICDEW 2012), P143, DOI 10.1109/ICDEW.2012.68
Bethencourt J, 2007, P IEEE S SECUR PRIV, P321, DOI 10.1109/SP.2007.11
Bobba R., 2009, ASIACCS 09, P262
Boneh D, 2005, LECT NOTES COMPUT SC, V3494, P440
Boneh D., 2001, Advances in Cryptology - CRTPTO 2001. 21st Annual International Cryptology Conference, Proceedings (Lecture Notes in Computer Science Vol.2139), P213
Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P56
Bradshaw R. W., 2004, P 11 ACM C COMP COMM, P146, DOI DOI 10.1145/1030083.1030104
Chen C, 2011, LECT NOTES COMPUT SC, V6980, P84, DOI 10.1007/978-3-642-24316-5_8
De Caro A., 2011, 2011 IEEE Symposium on Computers and Communications (ISCC 2011), P850, DOI 10.1109/ISCC.2011.5983948
Germanakos P., 2005, P WORKSH PERS E HLTH, P67
Goyal V, 2008, LECT NOTES COMPUT SC, V5126, P579, DOI 10.1007/978-3-540-70583-3_47
Guo LK, 2012, INT CON DISTR COMP S, P224, DOI 10.1109/ICDCS.2012.45
Hur J, 2013, IEEE T PARALL DISTR, V24, P2171, DOI 10.1109/TPDS.2012.61
Ibraimi L, 2009, LECT NOTES COMPUT SC, V5932, P309, DOI 10.1007/978-3-642-10838-9_23
Jovanov E, 2003, IEEE ENG MED BIOL, V22, P49, DOI 10.1109/MEMB.2003.1213626
Jovanov E., 2006, M HLTH EMERGING MOBI, P33
Jung TH, 2013, IEEE INFOCOM SER, P2625
Kapadia A., 2007, NDSS, V7, P179
Kate A, 2007, LECT NOTES COMPUT SC, V4776, P95
Li J, 2009, LECT NOTES COMPUT SC, V5735, P347
Liu Z., 2013, P ACM SIGSAC C COMP, P475

Liu Z, 2013, IEEE T INF FOREN SEC, V8, P76, DOI 10.1109/TIFS.2012.2223683
Narayanan H A J, 2011, 2011 IEEE Consumer Communications and Networking Conference (CCNC 2011), P247, DOI 10.1109/CCNC.2011.5766466
Poulymenopoulou M., 2011, P 4 ACM INT C PERVAS
Sahai A, 2005, LECT NOTES COMPUT SC, V3494, P457
Shamir A., 1984, LNCS, P47, DOI [DOI 10.1007/3-540-39568-7, 10.1007/3-540-39568-7_5]
United States Department of Health & Human Services, 2011, HLTH INF PRIV
Wang FH, 2005, HEALTH PLACE, V11, P131, DOI 10.1016/j.healthplace.2004.02.003
Waters B, 2011, LECT NOTES COMPUT SC, V6571, P53, DOI 10.1007/978-3-642-19379-8_4
Wolf JA, 2013, JAMA DERMATOL, V149, P422, DOI 10.1001/jamadermatol.2013.2382
Zhou Z-G, 2015, CHIN J CANCER, V1, P1
Zhou ZB, 2010, PROCEEDINGS OF THE 17TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY (CCS'10), P753, DOI 10.1145/1866307.1866420
NR 32
TC 1
Z9 1
U1 3
U2 9
PU HINDAWI LTD
PI LONDON
PA ADAM HOUSE, 3RD FLR, 1 FITZROY SQ, LONDON, W1T 5HF, ENGLAND
SN 1574-017X
EI 1875-905X
J9 MOB INF SYST
JI Mob. Inf. Syst.
PY 2016
AR 6545873
DI 10.1155/2016/6545873
PG 13
WC Computer Science, Information Systems; Telecommunications
SC Computer Science; Telecommunications
GA DS3RZ
UT WOS:000380701700001
OA DOAJ Gold
DA 2019-08-06
ER

PT J
AU Naci, H
Cooper, J
Mossialos, E
AF Naci, Huseyin
Cooper, Jacob
Mossialos, Elias
TI Timely publication and sharing of trial data: opportunities and challenges for comparative effectiveness research in cardiovascular disease
SO EUROPEAN HEART JOURNAL-QUALITY OF CARE AND CLINICAL OUTCOMES
LA English
DT Review
DE Transparency; Open access; Data sharing; Comparative effectiveness research; network meta-analysis
AB There is growing enthusiasm for the timely publication and sharing of clinical trial data. The rationale for open access includes greater transparency, reproducibility, and efficiency of the research enterprise. In cardiovascular diseases, routinely sharing clinical trial data would create opportunities for

undertaking comparative effectiveness research, providing much needed evidence on how different interventions compare to each other on key outcomes. Access to individual patient-level data would strengthen the validity of such research. Novel methodological approaches like network meta-analyses using individual patient-level data could reliably compare interventions that have not been compared with each other in head-to-head trials. However, there are significant practical, methodological, financial, and legal challenges to this utopian open access that need to be continually addressed. Sharing clinical trial data openly will only occur when the previously tolerated process of clinical research involving direct ownership and secrecy is abandoned for a new culture in which medical science is open to all of its stakeholders. With this new culture, data will be accessible, reanalysis will be considered commonplace, and comparative effectiveness research through novel synthesis approaches, such as network meta-analyses, can thrive-as long as measures are taken to adequately ensure the goal remains to promote public health.

C1 [Naci, Huseyin; Cooper, Jacob; Mossialos, Elias] London Sch Econ & Polit Sci, Dept Social Policy, LSE Hlth, London, England.
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CR Amiodarone Trials Meta-Analysis Investigators, 1997, LANCET, DOI [10.1016/s0140-6736(97)05281-1, DOI 10.1016/S0140-6736(97)05281-1]
[Anonymous], 2015, STATEMENT PUBLIC DIS
[Anonymous], 2013, PHARMA IND ANNOUNCES
[Anonymous], 2015, PLOS ONE DATA AVAILA
Association of the British Pharmaceutical Industry, 2014, CLASS 1 RAILR STAT, P1
Baigent C, 2005, LANCET, V366, P1267, DOI 10.1016/S0140-6736(05)67394-1
Bardy GH, 2005, NEW ENGL J MED, V352, P225, DOI 10.1056/NEJMoa043399
Caldwell DM, 2005, BRIT MED J, V331, P897, DOI 10.1136/bmj.331.7521.897
Cancer Research UK, 2014, DAT SHAR GUID CANC
Chalmers I, 2014, LANCET, V383, P156, DOI 10.1016/S0140-6736(13)62229-1
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Chan AW, 2005, BRIT MED J, V330, P753, DOI 10.1136/bmj.38356.424606.8F
Chin B., BIOPHARMACEUTICAL SE, DOI [10.1056/NEJMsa1409364#tarticleTop, DOI 10.1056/NEJMSA1409364#TARTICLETOP]
Coombes R, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e6909
Cope S, 2012, BMC PULM MED, V12, DOI 10.1186/1471-2466-12-29
Donegan S, 2012, STAT MED, V31, P3840, DOI 10.1002/sim.5470
Doshi P, 2013, TRENDS PHARMACOL SCI, V34, P645, DOI 10.1016/j.tips.2013.10.006
Doshi P, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001201
Ebrahim S, 2014, JAMA-J AM MED ASSOC, V312, P1024, DOI 10.1001/jama.2014.9646
Eichler HG, 2013, NEW ENGL J MED, V369, P1577, DOI 10.1056/NEJMp1310771
European Agency for Safety and Health at Work, 2014, EU ACT PLAN CHILDH O, P1, DOI [10.1177/1742271X0301100302, DOI 10.1016/S0022-3913(12)00047-9]
Frye RL, 2009, NEW ENGL J MED, V360, P2503, DOI DOI 10.1056/NEJM0A0805796
Fulcher J, 2015, LANCET, V385, P1397, DOI 10.1016/S0140-6736(14)61368-4
Godlee F, 2012, BMJ-BRIT MED J, V345, DOI 10.1136/bmj.e7888
Hlatky MA, 2012, J AM COLL CARDIOL, V60, P569, DOI 10.1016/j.jacc.2011.12.057
Institute of Medicine, 2015, SHAR CLIN TRIAL DAT
Ioannidis JPA, 2014, LANCET, V383, P166, DOI 10.1016/S0140-6736(13)62227-8
Ioannidis JPA, 1998, JAMA-J AM MED ASSOC, V279, P281, DOI 10.1001/jama.279.4.281
Jansen JP, 2013, BMC MED, V11, DOI 10.1186/1741-7015-11-159
Jansen JP, 2012, RES SYNTH METHODS, V3, P177, DOI 10.1002/jrsm.1048
Jansen JP, 2011, VALUE HEALTH, V14, P417, DOI 10.1016/j.jval.2011.04.002
Kearney PM, 2008, LANCET, V371, P117, DOI 10.1016/S0140-6736(08)60104-X

KMIETOWICZ Z, 2014, BMJ-BRIT MED J, V348, DOI DOI 10.1136/BMJ.G1361
Kotecha D, 2014, LANCET, V384, P2235, DOI 10.1016/S0140-6736(14)61373-8
Krumholz HM, 2014, CIRC-CARDIOVASC QUAL, V7, P499, DOI 10.1161/CIRCOUTCOMES.114.001166
Krumholz HM, 2013, ANN INTERN MED, V158, P910, DOI 10.7326/0003-4819-158-12-201306180-00009
Krumholz HM, 2012, CIRC-CARDIOVASC QUAL, V5, P141, DOI 10.1161/CIRCOUTCOMES.112.965848
Krzyzanowska MK, 2003, JAMA-J AM MED ASSOC, V290, P495, DOI 10.1001/jama.290.4.495
Lambert PC, 2002, J CLIN EPIDEMIOL, V55, P86, DOI 10.1016/S0895-4356(01)00414-0
Lewington S, 2007, LANCET, V370, P1829
Loder E, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2373
McGauran N, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-37
Medical Research Council, 2015, DAT SHAR POP PAT STU
Mello MM, 2013, NEW ENGL J MED, V369, P1651, DOI 10.1056/NEJMhle1309073
Mihaylova B, 2012, LANCET, V380, P581, DOI 10.1016/S0140-6736(12)60367-5
Moscicki R., 2013, RESPONSIBLE SHARING, P1
Naci H, 2015, ANNU REV PHARMACOL, V55, P169, DOI 10.1146/annurev-pharmtox-010814-124614
National Institutes of Health, 2013, NIH DAT SHARB POL
Nordic Trial Alliance Working Group, 2015, REP TRANSP REG CLIN
Palmerini T, 2015, J AM COLL CARDIOL, V65, P1092, DOI 10.1016/j.jacc.2014.12.046
Ploug T, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2146
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Ross JS, 2012, CIRC-CARDIOVASC QUAL, V5, P238, DOI 10.1161/CIRCOUTCOMES.112.965798
Ross JS, 2012, BMJ-BRIT MED J, V344, DOI 10.1136/bmj.d7292
Ross JS, 2009, ARCH INTERN MED, V169, P1976, DOI 10.1001/archinternmed.2009.394
Rothwell PM, 2005, LANCET, V365, P176, DOI 10.1016/S0140-6736(05)17709-5
Saramago P, 2012, STAT MED, V31, P3516, DOI 10.1002/sim.5442
Schmid CH, 2004, J CLIN EPIDEMIOL, V57, P683, DOI 10.1016/j.jclinepi.2003.12.001
Sismondo S, 2008, SOC SCI MED, V66, P1909, DOI 10.1016/j.socscimed.2008.01.010
Song F, 2010, HEALTH TECHNOL ASSES, V14, P1, DOI 10.3310/hta14080
Sox HC, 2010, ANN INTERN MED, V153, P469, DOI 10.7326/0003-4819-153-7-201010050-00269
Stern JM, 1997, BMJ-BRIT MED J, V315, P640, DOI 10.1136/bmj.315.7109.640
Stewart LA, 2002, EVAL HEALTH PROF, V25, P76, DOI 10.1177/0163278702025001006
Sun X, 2014, JAMA-J AM MED ASSOC, V311, P405, DOI 10.1001/jama.2013.285063
Sun X, 2012, BMJ-BRIT MED J, V344, DOI 10.1136/bmj.e1553
Sundstrom J, 2014, LANCET, V384, P591, DOI 10.1016/S0140-6736(14)61212-5
Sutton A, 2008, PHARMACOECONOMICS, V26, P753, DOI 10.2165/00019053-200826090-00006
Sydes MR, 2015, TRIALS, V16, DOI 10.1186/s13063-015-0604-6
The Academy of Medical Sciences, 2014, CLIN TRIALS DAT SHAR, P1
The Parliamentary Office of Science and Technology, 2014, TRANSP CLIN TRIAL DA, P1
Tunis SR, 2010, STAT MED, V29, P1963, DOI 10.1002/sim.3818
Turner EH, 2008, NEW ENGL J MED, V358, P252, DOI 10.1056/NEJMsa065779
US Food and Drug Administration, 2013, AV MASK IDENT SUMM S
van Walraven C, 2002, JAMA-J AM MED ASSOC, V288, P2441, DOI 10.1001/jama.288.19.2441
Veroniki AA, 2015, BMJ OPEN, V5, DOI 10.1136/bmjopen-2014-007103

```
   Wellcome Trust, 2013, DEV STRAT CLIN TRIAL
   Wellcome Trust, 2015, ASS RES POT ACC CLIN, P1
   Welton NJ, 2009, AM J EPIDEMIOL, V169, P1158, DOI 10.1093/aje/kwp014
   Whittington CJ, 2004, LANCET, V363, P1341, DOI 10.1016/S0140-6736(04)16043-1
NR 79
TC 1
Z9 1
U1 0
U2 0
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 2058-5225
EI 2058-1742
J9 EUR HEART J-QUAL CAR
JI Eur. Heart J.
PD NOV
PY 2015
VL 1
IS 2
BP 58
EP 65
DI 10.1093/ehjqcco/qcv012
PG 8
WC Cardiac & Cardiovascular Systems
SC Cardiovascular System & Cardiology
GA VC8GO
UT WOS:000434728800003
PM 29474595
OA Green Published, Bronze
DA 2019-08-06
ER

PT J
AU Howard, S
   Lang, A
   Youle, C
   Vyas, H
   Sharples, S
   Shaw, D
AF Howard, Sam
   Lang, Alexandra
   Youle, Caroline
   Vyas, Harish
   Sharples, Sarah
   Shaw, Dominick
TI Exploring the attitudes of adolescents with asthma towards monitoring
   and sharing of data on their inhaler use
SO EUROPEAN RESPIRATORY JOURNAL
LA English
DT Meeting Abstract
DE Adolescents; Asthma - management; E-health
C1 [Howard, Sam; Lang, Alexandra; Sharples, Sarah] Univ Nottingham, Human
Factors Res Grp, Fac Engn, Nottingham, England.
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Nottingham, England.
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NR 0
```

```
TC 1
Z9 1
U1 0
U2 0
PU EUROPEAN RESPIRATORY SOC JOURNALS LTD
PI SHEFFIELD
PA 442 GLOSSOP RD, SHEFFIELD S10 2PX, ENGLAND
SN 0903-1936
EI 1399-3003
J9 EUR RESPIR J
JI Eur. Resp. J.
PD SEP 1
PY 2015
VL 46
SU 59
MA OA4773
DI 10.1183/13993003.congress-2015.OA4773
PG 2
WC Respiratory System
SC Respiratory System
GA VH2QW
UT WOS:000451979400418
DA 2019-08-06
ER

PT J
AU Morozova, O
   Newton, Y
   Cline, M
   Zhu, JC
   Learned, K
   Stuart, J
   Salama, S
   Arceci, R
   Haussler, D
AF Morozova, Olena
   Newton, Yulia
   Cline, Melissa
   Zhu, Jingchun
   Learned, Katrina
   Stuart, Josh
   Salama, Sofie
   Arceci, Robert
   Haussler, David
TI Treehouse Childhood Cancer Project: a resource for sharing and multiple
   cohort analysis of pediatric cancer genomics data
SO CANCER RESEARCH
LA English
DT Meeting Abstract
CT 106th Annual Meeting of the American-Association-for-Cancer-Research
   (AACR)
CY APR 18-22, 2015
CL Philadelphia, PA
SP Amer Assoc Canc Res
C1 [Morozova, Olena; Newton, Yulia; Cline, Melissa; Zhu, Jingchun; Learned,
Katrina; Stuart, Josh; Salama, Sofie; Haussler, David] Univ Calif Santa Cruz,
Santa Cruz, CA 95064 USA.
   [Arceci, Robert] Phoenix Childrens Hosp, Phoenix, AZ USA.
```

```
NR 0
TC 1
Z9 1
U1 0
U2 0
PU AMER ASSOC CANCER RESEARCH
PI PHILADELPHIA
PA 615 CHESTNUT ST, 17TH FLOOR, PHILADELPHIA, PA 19106-4404 USA
SN 0008-5472
EI 1538-7445
J9 CANCER RES
JI Cancer Res.
PD AUG 1
PY 2015
VL 75
SU 15
MA LB-212
DI 10.1158/1538-7445.AM2015-LB-212
PG 2
WC Oncology
SC Oncology
GA DF8HA
UT WOS:000371597100309
DA 2019-08-06
ER

PT J
AU Wang, ZQ
AF Wang, Zhiqiang
TI Data sharing in Indigenous health research: guidelines needed
SO MEDICAL JOURNAL OF AUSTRALIA
LA English
DT Editorial Material
C1 [Wang, Zhiqiang] Univ Queensland, Brisbane, Qld, Australia.
RP Wang, ZQ (reprint author), Univ Queensland, Brisbane, Qld, Australia.
EM z.wang@uq.edu.au
FU NHMRC [APP1042343]
FX I am supported by an NHMRC Senior Research Fellowship (APP1042343).
CR Goodhill GJ, 2014, NATURE, V509, P33, DOI 10.1038/509033b
   Kowal P, 2012, INT J EPIDEMIOL, V41, P1639, DOI 10.1093/ije/dys210
   Kush R, 2014, NEW ENGL J MED, V370, P2163, DOI 10.1056/NEJMp1401444
   National Health and Medical Research Council, 2015, NHMRC FUND RUL 2015
   Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
   O'Dowd A, 2014, BMJ-BRIT MED J, V348, DOI 10.1136/bmj.g3685
   Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
   van Panhuis WG, 2014, BMC PUBLIC HEALTH, V14, DOI 10.1186/1471-2458-14-1144
   Walport M, 2011, LANCET, V377, P537, DOI 10.1016/S0140-6736(10)62234-9
   Wang ZQ, 2014, INT J EPIDEMIOL, V43, P1986, DOI 10.1093/ije/dyu154
NR 10
TC 1
Z9 1
U1 0
U2 4
PU AUSTRALASIAN MED PUBL CO LTD
PI PYRMONT
PA LEVEL 2, 26-32 PYRMONT BRIDGE RD, PYRMONT, NSW 2009, AUSTRALIA
SN 0025-729X
EI 1326-5377
```

```
J9 MED J AUSTRALIA
JI Med. J. Aust.
PD JUL 6
PY 2015
VL 203
IS 1
BP 12
EP +
DI 10.5694/mja14.01707
PG 3
WC Medicine, General & Internal
SC General & Internal Medicine
GA VA9BU
UT WOS:000410608700005
PM 26126555
OA Bronze
DA 2019-08-06
ER

PT J
AU Werbelow, SE
AF Werbelow, Shaun E.
TI RULE OF REASON WITHOUT A RHYME: USING "BIG DATA" TO BETTER ANALYZE
   ACCOUNTABLE CARE ORGANIZATIONS UNDER THE MEDICARE SHARED SAVINGS PROGRAM
SO NEW YORK UNIVERSITY LAW REVIEW
LA English
DT Article
ID HEALTH-CARE; ANTITRUST; HOSPITALS; EFFICIENCY; WELFARE; MERGERS; PROFIT;
   REFORM; GOALS; LAW
AB Accountable Care Organizations (ACOs), a major component of the Affordable
Care Act, seek to provide patients with better quality health care at a lower
cost and have been praised for their ability to help repair our country's broken
health care system. Despite their potential benefits, however, ACOs also raise
significant antitrust concerns concerns that may pit consumer surplus and total
surplus against one another. In an attempt to address these concerns, the
Department of Justice and Fair Trade Commission announced that they will use
market share screens and rule of reason treatment to evaluate ACOs participating
in the Medicare Shared Savings Program. The use of market share screens and rule
of reason treatment allows the antitrust agencies to avoid prioritizing either
consumer surplus, or total surplus in the first instance but leaves open two
critical questions: What will the rule of reason treatment afforded to ACOs look
like? And how will the antitrust agencies ultimately determine whether ACOs
benefit or harm consumers? In order to address these questions, this Note
proposes that the antitrust agencies use the "big data" collected under the
Affordable Care Act to conduct a structured rule of reason review of ACOs that
takes into account both the consumer surplus and total surplus through a burden-
shifting framework.
CR Abramson Bruce, 2012, ACCOUNTABLE CARE L P
   AM. HEALTH INS, 2010, ACCOUNTABLE CARE ORG, P3
   AM. HOSP. ASS'N, 2011, THE WORK AHEAD ACTIV, P2
   [Anonymous], 2011, FED REG, V76, P956
   [Anonymous], 2004, FED REGISTER, V69
   Baicker K, 2004, HEALTH AFFAIR, V23, pW4184, DOI 10.1377/hlthaff.W4.184
   BAKER JB, 2001, UWLA L REV, V33, P3
   Baker Jonathan B., N Y U L REV, V77, P135
   Baker Jonathan B., 2001, UWLA L REV, V33, P4
   Baker Jonathan B., N Y U L REV, V77, P142
   Barnett Thomas O., 2005, COLUM BUS L REV, P297
```

Barnett Thomas O., 2005, COLUM BUS L REV, P293
BEARDEN DJ, 1995, BAYLOR L REV, V47, P285
Berenson RA, 2010, AM J MANAG CARE, V16, P721
Berenson RA, 2010, HEALTH AFFAIR, V29, P699, DOI 10.1377/hlthaff.2009.0715
Berenson Robert A., 2010, HEALTH AFF, V29, P700
Blair RD, 2012, ANTITRUST LAW J, V78, P471
BORK ROBERT H., 1993, THE ANTITRUST PARADO, P50
BOWERS LIORA, 2011, ACCOUNTABLE CARE ORG, P13
BRODLEY JF, 1987, NEW YORK U LAW REV, V62, P1020
Bruns Patricia M, 2012, J Contemp Health Law Policy, V28, P268
Bruns Patricia M., 2012, J CONTEMP HEALTH L P, V28, P271
Burke Taylor, 2009, J HLTH BIOMEDICAL L, V5, P151
Burke Taylor, 2009, J HEALTH BIOMEDICAL, V5, P171
Carlton DW, 2007, J ECON PERSPECT, V21, P155, DOI 10.1257/jep.21.3.155
CMS (Centers for Medicare and Medicaid Services), 2011, FED REGISTER, V76
Connor RA, 1997, HEALTH AFFAIR, V16, P62, DOI 10.1377/hlthaff.16.6.62
CTRS. FOR MEDICARE & MEDICAID SERVS, 2012, PIONEER ACCOUNTABLE
Ctrs. for Medicare & Medicaid Servs, NHE FACT SHEET
Devers K, 2009, CAN ACCOUNTABLE CARE, P1
DOLAN EMMA L., 2010, ACCOUNTABLE CARE ORG, P11
Dorn SD, 2011, CLIN GASTROENTEROL H, V9, P750, DOI 10.1016/j.cgh.2011.02.032
DRANOVE D, 1988, J HEALTH ECON, V7, P47, DOI 10.1016/0167-6296(88)90004-5
Elhauge Einer, 2010, THE FRAGMENTATION OF, P1
FED. TRADE COMM'N & U.S. DEP'T OF JUSTICE, 2000, ANTITRUST GUIDELINES, P3
Federal Trade Commission; Department of Justice, 2011, FED REGISTER, V76, P67026
First H, 2009, COMPET POLICY INT, V5, P199
First Harry, 2009, COMPETITION POLY INT, V5, P200
Fisher Elliott, 2013, WALL ST J, pA17
Fisher ES, 2007, HEALTH AFFAIR, V26, pW44, DOI 10.1377/hlthaff.26.1.w44
Fisher Elliott S., 2006, HEALTH AFF, V26, pw55
Frakt AB, 2011, MILBANK Q, V89, P90, DOI 10.1111/j.1468-0009.2011.00621.x
Gavil AI, 2012, SOUTH CALIF LAW REV, V85, P733
Gavil Andrew I., 2012, SOUTH CALIF LAW REV, V85, P760
GINSBURG PAUL B., WIDE VARIATION IN HO, P4
Glazer Ken, 2011, ANTITRUST SOURCE, P7
GOSFIELD AG, 1994, AM J LAW MED, V20, P169
Greaney TL, 2011, NEW ENGL J MED, V364, pE1, DOI 10.1056/NEJMp1013404
Greaney Thomas L., 2010, HEALTH L OUTLOOK, V3, P6
Greaney Thomas L., 2012, REGULATORS AS MARKET, P6
Heyer K., 2006, COMPET POLICY INT, V2, P29
HOVENKAMP HERBERT, 2005, THE ANTITRUST ENTERP, P31
Hyman David A., 2010, THE FRAGMENTATION OF, P21
INST. OF MED. OF THE NAT'L ACADS, 2007, REW PROV PERF AL IN, P4
Institute of Medicine Committee on Quality of Healthcare in America, 2001, CROSSING THE QUALITY
Kasper Andrew A., 2011, NC L REV, V90, P203
Kasper Andrew A., 2011, N C L REV, V90, P220
LANDE RH, 1982, HASTINGS LAW J, V34, P65
LAVE JR, 1990, YALE J REGUL, V7, P499
Lave Judith R., 1990, YALE J REG, V7, P505
Liang BA, 2004, AM J LAW MED, V30, P501, DOI 10.1177/009885880403000403
Lloyd Christopher, 2013, MHMD NEWSLINK, V5, P1
Maedgen Bryan J., 1995, BAYLOR L REV, V47, P288
Mantel Jessica L, 2012, Seton Hall Law Rev, V42, P1393
MARSHALL ALFRED, 1936, PRINCIPLES EC, P124
MASS. ATT'Y GEN, 2010, EXAMINATION OF HEALT, P16
McClellan M, 2010, HEALTH AFFAIR, V29, P982, DOI 10.1377/hlthaff.2010.0194

```
   Medicare Program, 2004, FED REGISTER
   MOORE KEITH D., 2011, MCMANIS CONSULTING A, P3
   MUHLESTEIN DAVID, 2012, LEAVITT PARTNERS CTR, P11
   Numerof Rita E., 2011, BACKGROUNDER, P2
   Oliker Dave, 2010, HEALTH CARE PERSPECT
   Orbach BY, 2011, J COMPET LAW ECON, V7, P133, DOI 10.1093/joclec/nhq019
   ORDOVER JA, 1983, CALIF LAW REV, V71, P535, DOI 10.2307/3480165
   Orentlicher D, 2012, AM J LAW MED, V38, P326, DOI 10.1177/009885881203800204
   Orentlicher David, 2010, Ann Health Law, V19, P449
   Orentlicher David, 2010, ANNALS HEALTH L, V19, P462
   Pear Robert, 2011, N Y TIMES, pA19
   Pear Robert, 2010, N Y TIMES
   Peinar Gregory J., 2011, ANTITRUST SOURCE, P2
   Pham HH, 2007, NEW ENGL J MED, V356, P1130, DOI 10.1056/NEJMsa063979
   Piraino TA, 2001, IOWA LAW REV, V86, P1137
   Pittman R., 2007, COMPET POLICY INT, V3-2, P205
   Pittman Russell, 2007, COMPETITION POLY INT, V3, P207
   Ragone Tara Adams, 2012, Seton Hall Law Rev, V42, P1443
   Ragone Tara Adams, 2012, SETON HALL L REV, V42, P1447
   Richman BD, 2011, JAMA-J AM MED ASSOC, V305, P602, DOI 10.1001/jama.2011.111
   Robinson J, 2011, HEALTH AFFAIR, V30, P1265, DOI 10.1377/hlthaff.2011.0220
   Rosch J. Thomas, 2012, COMMNICATION, P26
   Rosch T, 2007, COLUM BUS L REV, P353
   Ross Douglas C., 2010, FTC TO GIVE ANTITRUS
   Rowe EL, 2012, U ILLINOIS LAW REV, P1855
   Rowe Elizabeth L., 2012, U ILL L REV, V2012, P1881
   RTI INT'L & TELLIGEN, 2011, ACCOUNTABLE CARE ORG, P3
   Salop Steven C., 2010, LOV CONSUMER L REV, V22, P338
   Salop Steven C., 2010, LOY CONSUMER L REV, V22, P336
   Shortell SM, 2010, HEALTH AFFAIR, V29, P1293, DOI 10.1377/hlthaff.2010.0453
   Singer Toby G., 2011, CPI ANTITRUST CHRON, V3
   Squires DA, 2012, ISSUE BRIEF COMMONW, V10, P1
   THE LEWIN GRP, 2009, ANALYSIS OF HOSPITAL, P1
   Town Robert, 2006, RESEARCH WORKING PAP, P31
   U.S. DEP'T OF JUSTICE & FED. TRADE COMM'N, 1996, STATEMENT OF ANTITRU
   U.S. DEP'T OF JUSTICE & FED. TRADE COMM'N, 1996, TRADE COMMN STATEMEN, P49
   U.S. Dept. of Health & Human Service, 2002, CONFR NEW HLTH CAR C, P7
   *US DEP HHS, 2010, HLTH PEOPL 2020, P3
   VOGT WILLIAM B., 2006, HOW HAS HOSPITAL CON, P4
   WILLIAMSON OE, 1968, AM ECON REV, V58, P18
   Zabawa Barbara J, 2012, Seton Hall Law Rev, V42, P1471
   Zabawa Barbara J., 2012, SETON HALL L REV, V42, P1491
   Zwanziger J, 2006, HEALTH AFFAIR, V25, P197, DOI 10.1377/hlthaff.25.1.197
NR 110
TC 1
Z9 1
U1 0
U2 0
PU NEW YORK UNIV SCHOOL LAW
PI NEW YORK
PA 110 WEST THIRD ST, NEW YORK, NY 10012 USA
SN 0028-7881
J9 NEW YORK U LAW REV
JI N. Y. Univ. Law Rev.
PD APR
PY 2015
VL 90
IS 1
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BP 361
EP 395
PG 35
WC Law
SC Government & Law
GA CG2AK
UT WOS:000353077100008
DA 2019-08-06
ER

PT S
AU Beier, M
   Jansen, C
   Mayer, G
   Penzel, T
   Rodenbeck, A
   Siewert, R
   Wu, J
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AF Beier, Maximilian
   Jansen, Christoph
   Mayer, Geert
   Penzel, Thomas
   Rodenbeck, Andrea
   Siewert, Rene
   Wu, Jie
   Krefting, Dagmar
GP IEEE
TI Multicenter Data Sharing for Collaboration in Sleep Medicine
SO 2015 15TH IEEE/ACM INTERNATIONAL SYMPOSIUM ON CLUSTER, CLOUD AND GRID
   COMPUTING
SE IEEE-ACM International Symposium on Cluster Cloud and Grid Computing
LA English
DT Proceedings Paper
CT 2015 15th IEEE ACM International Symposium on Cluster Cloud and Grid
   Computing (CCGrid 2015)
CY MAY 04-07, 2015
CL Shenzhen, PEOPLES R CHINA
SP IEEE, ACM, TCSC, Argonne Natl Lab, Shenzhen Inst Adv Technol, Chinese Acad
Sci, Sugon, NVIDIA, Ass Comp Machinery
DE sleep; biosignal; polysomnography; XNAT; Cloud; OpenStack; REST
ID EXCHANGE; FORMAT
AB Clinical Sleep Research is an inherent multidisciplinary field, as many
health issues may affect a person's sleep conditions and sleep disorders may
cause several health problems. Many patients with chronic sleep disorders suffer
from different further medical conditions - called multimorbidity. Due to the
high variety of the reasons and the courses of sleep disorders, individual cases
are difficult to compare. Therefore there is a high demand for sleep researchers
to collaborate with each other to reach necessary participant numbers and
multidisciplinary expertise. To date, inter-institutional sleep research is
poorly supported by IT systems. In particular the heterogeneity and the quality
variations within the acquired biosignal data - caused by different biosignal
recorders or different measurement procedures - are impeding common biosignal
data processing. In this manuscript we introduce a virtual research platform
supporting inter-institutional data sharing and processing. The infrastructure
is based on XNAT - a free and open-source neuroimaging research platform - a
loosely coupled service oriented architecture and scalable virtualization in the
backend. The system is capable of local pseudonymization of biosignal data,
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mapping to a standardized set of parameters and automatic quality assessment. Terms and quality measures are derived from the "Manual for the Scoring of Sleep and Associated Events" of the American Academy of Sleep Medicine, the de-facto standard for diagnostic biosignal analysis in sleep medicine.

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CR Adult Obstructive Sleep Apnea Task Force of the American Academy of Sleep Medicine, 2009, J CLIN SLEEP MED JCS, V5, P263
Azarbarzin A., 2015, SLEEP
Blomberg Niklas, 2014, PRINCIPLES DATA MANA
COLEMAN RM, 1982, JAMA-J AM MED ASSOC, V247, P997, DOI 10.1001/jama.247.7.997
Field L, 2013, REALISING FULL POTEN
Fraser M., 2005, VIRTUAL RES ENV OVER
Guilleminault C, 2001, BRAIN, V124, P1482, DOI 10.1093/brain/124.8.1482
Hedner J, 2011, EUR RESPIR J, V38, P635, DOI 10.1183/09031936.00046710
KEMP B, 1992, ELECTROEN CLIN NEURO, V82, P391, DOI 10.1016/0013-4694(92)90009-7
Kemp B, 2003, CLIN NEUROPHYSIOL, V114, P1755, DOI 10.1016/S1388-2457(03)00123-8
Kendzerska T, 2014, PLOS MED, V11, DOI 10.1371/journal.pmed.1001599
Krefting D, 2009, FUTURE GENER COMP SY, V25, P326, DOI 10.1016/j.future.2008.05.005
Luca G, 2013, J SLEEP RES, V22, P482, DOI 10.1111/jsr.12044
Marcus DS, 2007, NEUROINFORMATICS, V5, P11, DOI 10.1385/NI:5:1:11
Olabarriaga S., 2006, 2 IEEE INT C E SCI G, P53
Owens J, 2014, PEDIATRICS, V134, pE921, DOI 10.1542/peds.2014-1696
Quan SF, 2011, SLEEP, V34, P303, DOI 10.1093/sleep/34.3.303
Rappelsberger P, 2001, KLIN NEUROPHYSIOL, V32, P76, DOI 10.1055/s-2001-16206
Redolfi Alberto, 2009, FUTURE NEUROLOGY, V4
Richardson Leonard, RESTFUL WEB SERVICES
Roth T, 2007, J CLIN SLEEP MED, V3, P7, DOI DOI 10.1080/08098130802697269
Schlogl A, 1999, CLIN NEUROPHYSIOL, V110, P2165, DOI 10.1016/S1388-2457(99)00172-8
Shahand S., 2014, CONCURRENCY COMPUTAT
Shanahan L, 2014, J AM ACAD CHILD PSY, V53, P550, DOI 10.1016/j.jaac.2013.12.029
Wilkins-Diehr N, 2007, CONCURR COMP-PRACT E, V19, P743, DOI 10.1002/cpe.1098
Wu J., 2014, 14 IEEE ACM INT S CL, P764
Xiao Q, 2014, AM J EPIDEMIOL, V180, P997, DOI 10.1093/aje/kwu222

NR 27
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2376-4414
BN 978-1-4799-8006-2
J9 IEEE ACM INT SYMP
PY 2015
BP 880

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EP 889
DI 10.1109/CCGrid.2015.148
PG 10
WC Computer Science, Hardware & Architecture; Computer Science, Information
   Systems; Computer Science, Software Engineering
SC Computer Science
GA BF2RL
UT WOS:000380493100107
DA 2019-08-06
ER

PT B
AU Li, Y
   Liu, Q
   Xiong, JJ
   Wang, J
AF Li, Yao
   Liu, Qiang
   Xiong, Jiajun
   Wang, Jian
GP IEEE
TI Research on data-sharing and intelligent CNC machining system
SO 2015 IEEE INTERNATIONAL CONFERENCE ON MECHATRONICS AND AUTOMATION
LA English
DT Proceedings Paper
CT IEEE International Conference on Mechatronics & Automation
CY AUG 02-05, 2015
CL Beijing, PEOPLES R CHINA
SP Beijing Inst Tech, Tianjian Univ Technol, HIT, Robot Soc Japan, JSME, SICE,
UEC, CAA, Chinese Mech Engn Soc, CIE Life Elect Soc
DE data; sharing; intelligent; machining; CNC
AB Intelligent manufacturing deeply fused with information technology is the
core of traditional manufacturing revolution. Facing challenges, Chinese
government puts forward "China Manufacturing 2025" project. CNC machining is a
general manufacturing method. To improve efficiency, reduce cost, ensure quality
effectively, researchers on CNC machining have focused on virtual machine tool,
cloud manufacturing, wireless manufacturing. However, low level of information
shared among different systems is a common disadvantage. Intelligent CNC
machining is an intelligent application orienting to equipment, production and
service. It is an important aspect for network industry to transform and
innovate from consumption domain to industry domain. Intelligent CNC machining
system integrates traditional processing technology and information technology.
A shared CNC machining database has been established to ensure machining data
shared among different platforms, and it also is the bridge across data -wide
gap. Combined with open and high performance CNC system, CNC machining online
monitoring module, intelligent CNC machining optimization module, intelligent
CNC machining efficiency simulation platform and machine tool health diagnosis
platform, cyber physical system for CNC machining has been formed. Finally, a
prototype system has been developed. The application proves that the data -
sharing and intelligent CNC machining system is reliable and effective.
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8506(07)60022-5
   Gao R., T CHINESE SOC AGR MA, V2, p[139, 200]
```

```
   Li Bo-hu, 2010, Computer Integrated Manufacturing Systems, V16, P1
   Li  Y., 2014, COMPUTER INTEGRATED, V20
   Lydon  B., 2013, IND 4 0 GAINING MOME
   Matthieu R., 2012, ROBOTICS COMPUTER IN, V28, P375
   Wang LH, 2013, CIRP J MANUF SCI TEC, V6, P263, DOI
10.1016/j.cirpj.2013.07.001
NR 7
TC 1
Z9 1
U1 2
U2 8
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-4799-7098-8
PY 2015
BP 625
EP 630
PG 6
WC Automation & Control Systems; Engineering, Electrical & Electronic
SC Automation & Control Systems; Engineering
GA BF1ZH
UT WOS:000380447600112
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ER

PT B
AU Rohloff, K
   Polyakov, Y
AF Rohloff, Kurt
   Polyakov, Yuriy
GP IEEE
TI An End-to-End Security Architecture to Collect, Process and Share
   Wearable Medical Device Data
SO 2015 17TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATION &
   SERVICES (HEALTHCOM)
LA English
DT Proceedings Paper
CT 17th International Conference on E-health Networking, Application &
   Services (HealthCom)
CY OCT 13-17, 2015
CL Boston, MA
AB Embedded medical devices, such as wearable devices, are becoming increasingly
common, but data from these devices is both very private and highly vulnerable
to theft. Data needs to be collected from multiple devices to improve the
effectiveness of treatment. The medical devices, data processing sites and
intended care givers are often geographically distributed, and operate on
different time scales with collected data being aggregated for days or months
before analysis and usage. Current approaches to data security do not provide a
framework for end-to-end protection, where data can always be encrypted but
still used effectively. We present a security architecture with end-to-end
encryption that supports 1) secure collection of data from embedded medical
devices, 2) protected computing on this data in low-cost commodity cloud
environment and 3) restricts the delegation of access to this data to designated
recipients. The basis of the architecture comes from recent advances in lattice
encryption technologies. This approach leverages recent breakthroughs in
Homomorphic Encryption (HE) and Proxy Re-Encryption (PRE) that would practically
support specific data aggregation, processing and distribution needs of a secure
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medical data architecture. This architecture lowers health care data system costs by securely outsourcing computation to cloud computing environments while simultaneously reducing vulnerabilities to some of the most problematic security challenges such as insider attacks and enables additional cost savings with lower-cost embedded medical devices.
C1 [Rohloff, Kurt; Polyakov, Yuriy] New Jersey Inst Technol, Sch Comp Sci, Newark, NJ 07102 USA.
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CR Alperin-Sheriff J, 2013, LECT NOTES COMPUT SC, V8042, P1, DOI 10.1007/978-3-642-40041-4_1
Andersen A, 2014, 2014 IEEE 16TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATIONS AND SERVICES (HEALTHCOM), P225, DOI 10.1109/HealthCom.2014.7001845
Annas GJ, 2003, NEW ENGL J MED, V348, P1486, DOI 10.1056/NEJMlim035027
Archer DW, 2015, IEEE SECUR PRIV, V13, P22, DOI 10.1109/MSP.2015.3
Doroz Y., 2014, IACR CRYPTOLOGY EPRI, V2014, P39
Gentry C, 2012, LECT NOTES COMPUT SC, V7417, P850
Gentry C, 2011, LECT NOTES COMPUT SC, V6632, P129, DOI 10.1007/978-3-642-20465-4_9
Gentry C, 2009, ACM S THEORY COMPUT, P169
Goldreich O, 1997, LECT NOTES COMPUT SC, V1294, P112
GUPTA V, 2005, PERVASIVE MOB COMPUT, V1, P425
Hoffstein J., 1998, Algorithmic Number Theory. Third International Symposium, ANTS-III. Proceedings, P267
Lopez-Alt A., 2012, P 44 ANN ACM S THEOR, P1219, DOI DOI 10.1145/2213977.2214086
Maisel WH, 2010, NEW ENGL J MED, V362, P1164, DOI 10.1056/NEJMp1000745
Micciancio D., 2009, POSTQUANTUM CRYPTOGR, P147, DOI DOI 10.1007/978-3-540-88702-7_5
Nunez D, 2015, P 10 ACM S INF COMP, P179, DOI DOI 10.1145/2714576.2714585
Partala Juha, 2013, 2013 IEEE 15th International Conference on e-Health Networking, Applications and Services (Healthcom 2013), P243, DOI 10.1109/HealthCom.2013.6720675
Peikert C, 2009, ACM S THEORY COMPUT, P333
Rauscher R., 2012, 2012 IEEE Second International Conference on Healthcare Informatics, Imaging and Systems Biology (HISB), DOI 10.1109/HISB.2012.67
Rauscher R, 2014, 2014 IEEE 16TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATIONS AND SERVICES (HEALTHCOM), P231, DOI 10.1109/HealthCom.2014.7001846
Rohloff K., 2014, P 2 WORKSH APPL HOM
Salant Y, 1998, MED BIOL ENG COMPUT, V36, P549, DOI 10.1007/BF02524422
Wu D., 2012, USING HOMOMORPHIC EN
NR 22
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-4673-8325-7
PY 2015
BP 615
EP 620
PG 6
WC Computer Science, Interdisciplinary Applications; Engineering,

```
   Electrical & Electronic
SC Computer Science; Engineering
GA BF1DT
UT WOS:000380378700116
DA 2019-08-06
ER

PT J
AU Masud, M
   Hossain, MS
   Alamri, A
   Almogren, A
   Zakariah, M
AF Masud, Mehedi
   Hossain, M. Shamim
   Alamri, Atif
   Almogren, Ahmad
   Zakariah, Mohammed
TI Synchronizing Data through Update Queries in Interoperable E-Health and
   Technology Enhanced Learning Data Sharing Systems
SO JOURNAL OF UNIVERSAL COMPUTER SCIENCE
LA English
DT Article
DE e-health; collaborative environment; data synchronization; query update
AB Data interoperability and synchronization among heterogeneous data providers
in collaborative e-health systems are challenging research issues. Efficient
data management techniques promote an efficient way of sharing data. This paper
describes existing approaches to data interoperability (platform independency)
for exchanging and synchronizing data between heterogeneous data sources or
various platforms. We also illustrate an update query execution protocol, which
can reduce query execution cost and query response time. We further perform
different experiments to validate the effectiveness of the proposed approaches.
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FU Research Center of College of Computer and Information Sciences (CCIS),
   King Saud University [RC120902]
FX This work was supported by the Research Center of College of Computer
   and Information Sciences (CCIS), King Saud University through the
   research project no RC120902. The authors are grateful for this support.
CR Bertossi L. E., 2007, P INT C LOG PROGR AR, P107
   Chang Y., 1994, TMS P S SAN FRANC CA, P3
   Chen S, 2010, INT J CHIN STUD, V1, P1
   Deed Craig, 2011, International Journal of Knowledge Society Research, V2,
P25, DOI 10.4018/jksr.2011040103
   Forment M. A., 2011, INT J KNOWLEDGE SOC, V1, P44
   Green T. J., 2007, P 33 INT C VER LARG, P675
   Hossain M. S., 2011, P ACM ICIMCS 11 CHEN
   HWANG SY, 1994, DISTRIB PARALLEL DAT, V2, P151, DOI 10.1007/BF01267325
   Kermarrec A.-M., 2001, P 20 ANN ACM S PRINC, P210
   Masud M., 2007, P INT C COOP INF SYS, P169
```

```
   MASUD M. M., 2008, P 4 ANN WORKSH CYB S, P1
   Masud M, 2011, INT J SEMANT COMPUT, V5, P211, DOI 10.1142/S1793351X11001195
   Mork P., 2004, UW CSE TECHNICAL REP
   Petersen K., 1997, P 16 ACM S OP SYST P, P288, DOI DOI 10.1145/268998.266711
   Porumb C., 2000, P C ADV MESH NETW, P75
   Saito Y, 2005, ACM COMPUT SURV, V37, P42, DOI 10.1145/1057977.1057980
   Shamim Hossain M., 2014, ELSEVIER COMPUTERS H, V30, P485
   Yuksel M, 2011, IEEE T INF TECHNOL B, V15, P557, DOI
10.1109/TITB.2011.2151868
NR 18
TC 1
Z9 1
U1 0
U2 0
PU GRAZ UNIV TECHNOLGOY, INST INFORMATION SYSTEMS COMPUTER MEDIA-IICM
PI GRAZ
PA INFFELDGASSE 16C, GRAZ, A-8010, AUSTRIA
SN 0948-695X
J9 J UNIVERS COMPUT SCI
JI J. Univers. Comput. Sci.
PY 2015
VL 21
IS 11
BP 1439
EP 1453
PG 15
WC Computer Science, Software Engineering; Computer Science, Theory &
   Methods
SC Computer Science
GA DB4BI
UT WOS:000368457300005
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PT S
AU Ientilucci, EJ
AF Ientilucci, Emmett J.
BE VelezReyes, M
   Kruse, FA
TI Target Detection Assessment of the SHARE 2010/2012 Hyperspectral Data
   Collection Campaign
SO ALGORITHMS AND TECHNOLOGIES FOR MULTISPECTRAL, HYPERSPECTRAL, AND
   ULTRASPECTRAL IMAGERY XXI
SE Proceedings of SPIE
LA English
DT Proceedings Paper
CT Conference on Algorithms and Technologies for Multispectral,
   Hyperspectral, and Ultraspectral Imagery XXI
CY APR 21-23, 2015
CL Baltimore, MD
SP SPIE
DE Target detection; Hyperspectral imaging; Atmospheric Propagation;
   Radiance; LADAR
AB It has been over four years since the first SpecTIR Hyperspectral Airborne
Rochester Experiment (SHARE) was conducted in 2010. As such, a second SHARE
experiment was performed in 2012 using the same deployed target panels and HSI
sensor (i.e., specifically related to the "target detection experiment"). A
suite of sensors were flown over the target areas including multi-and
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hyperspectral imagers, as well as a LADAR sensor. Experiments were conducted to examine topics such as pixel unmixing, subpixel detection, forest health, and in-water target detection, to name a few. This paper's focus is on target detection of different colored panels deployed on different backgrounds viewed under different illumination conditions collected two years apart. Additionally, the calibration and reflectance retrieval of the data is also examined. Detection is on the standard reflectance product provided by the acquisition company. Results are illustrated in the form of ROC curves. Analysis was performed on (many) red and blue panels on backgrounds such as grass, gravel, and roof tar paper. The targets were in the open (i.e., fully illuminated), as well as heavy and light shadow, which were harder to discover than their open counterparts. Calibration of the 2012 data is good with some issues related to the 2010 data. Adjustments and corrections are discussed. Finally, discussion of where to obtain the free HSI and co-registered LADAR data set is discussed.
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CR Albano JA, 2013, PROC SPIE, V8743, DOI 10.1117/12.2015587
   Giannandrea A., 2013, P SPIE, V8743
   Herweg JA, 2012, PROC SPIE, V8390, DOI 10.1117/12.918297
   Ientilucci E., 2012, P SPIE, V8790
   Ientilucci EJ, 2003, P SOC PHOTO-OPT INS, V5075, P110, DOI 10.1117/12.488706
   Johnson R., 1998, APLLIED MULTIVARIATE
   Kay S. M., 1998, FUNDAMENTALS STAT SI
   Kraut S, 1999, IEEE T SIGNAL PROCES, V47, P2538, DOI 10.1109/78.782198
   Kraut S, 2001, IEEE T SIGNAL PROCES, V49, P1, DOI 10.1109/78.890324
   Manolakis D., 2003, Lincoln Laboratory Journal, V14, P79
   Manolakis D, 2002, IEEE SIGNAL PROC MAG, V19, P29, DOI 10.1109/79.974724
NR 11
TC 1
Z9 1
U1 1
U2 5
PU SPIE-INT SOC OPTICAL ENGINEERING
PI BELLINGHAM
PA 1000 20TH ST, PO BOX 10, BELLINGHAM, WA 98227-0010 USA
SN 0277-786X
EI 1996-756X
BN 978-1-62841-588-9
J9 PROC SPIE
PY 2015
VL 9472
AR 94720H
DI 10.1117/12.2177201
PG 11
WC Engineering, Electrical & Electronic; Optics; Physics, Applied
SC Engineering; Optics; Physics
GA BD0DU
UT WOS:000357086800016
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ER

PT S
AU Caradonna, G
   Figorito, B
   Tarantino, E
AF Caradonna, Grazia

Figorito, Benedetto
Tarantino, Eufemia
BE Gervasi, O
Murgante, B
Misra, S
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Rocha, AMAC
Torre, C
Taniar, D
Apduhan, BO
TI Sharing Environmental Geospatial Data Through an Open Source WebGIS
SO COMPUTATIONAL SCIENCE AND ITS APPLICATIONS - ICCSA 2015, PT III
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
CT 15th International Conference on Computational Science and Its Applications (ICCSA)
CY JUN 22-25, 2015
CL Banff, CANADA
SP Univ Calgary, Univ Perugia, Univ Basilicata, Monash Univ, Kyushu Sangyo Univ, Univ Minho
DE WebGIS; MapServer; Pmapper; Open data; Shared information
ID GIS
AB In recent years, people's need to participate to decision making, especially when it concerns inalienable human rights such as health and living in a healthy environment, has become increasingly manifest. In order to meet the request for environmental information sharing on the web and to make citizens feel "partakers" in the development of environmental policies, the Physical Agents Simple Operative Unit of ARPA Puglia, developed an open source WebGIS as a communication, participation and working tool for both Citizens and Technicians.

This paper proposes an efficient approach to customize and integrate an open source WebGIS system based on MapServer and Pmapper. The layout of the WebGIS was customized by filling pages in Cascading Style Sheets (CSS) to make it intuitive and easy to use. The features offered are those commonly provided by a WebGIS system, in particular: geographical navigation (pan, zoom, zoom to selection), query time and multiple layers, transparency level options, printing and exporting of current image views or pdf files. Environmental data results from a query can be downloaded in pdf, kml and shp formats. The possibility to download files is a key component of the system as it allows the average expert user to find data in an easily and processable format.

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OI Tarantino, Eufemia/0000-0002-2468-0771; Tarantino, Eufemia/0000-0002-2468-0771; Caradonna, Grazia/0000-0002-0226-7281
CR Borga G., 2007, URBAN DATA MANAGEMEN, P333
Borruso G, 2013, B ASS ITALIANA CARTO, V147, P7
Boulos Maged N Kamel, 2006, Int J Health Geogr, V5, P6, DOI 10.1186/1476-072X-5-6
Carver S., 2000, Information Infrastructure and Policy, V6, P157
Chandramali E.A.G., 2014, IDENTIFICATION WEBGI
Doyle S., 1998, Computers, Environment and Urban Systems, V22, P137, DOI 10.1016/S0198-9715(98)00014-3
Giannola E., 2013, 17 C NAZ ASITA, P769

Gkatzoflias D, 2013, COMPUT GEOSCI-UK, V52, P21, DOI
10.1016/j.cageo.2012.10.011
Kitchin R., 2003, DIALOGUES HUMAN GEOG, V3, P262
Lazzari M, 2009, J CULT HERIT, V10, pE104, DOI 10.1016/j.culher.2009.10.003
Murgante B, 2011, J BALKAN NEAR E STUD, V13, P97, DOI
10.1080/19448953.2011.550809
Netek R, 2014, LECT NOTES COMPUT SC, V8580, P394, DOI 10.1007/978-3-319-
09129-7_30
Pirotti F, 2011, T GIS, V15, P213, DOI 10.1111/j.1467-9671.2011.01248.x
Plewe B., 1997, GIS ONLINE INFORM RE
Steiniger S, 2009, INT J GEOGR INF SCI, V23, P1345, DOI
10.1080/13658810802634956
Wang Ni-hong, 2009, Journal of Forestry Research (Harbin), V20, P275, DOI
10.1007/s11676-009-0048-5
Zheng Kougen, 2000, Chinese Geographical Science, V10, P74, DOI
10.1007/s11769-000-0039-0
Zhenlong Li, 2013, Web and Wireless Geographical Information Systems. 12th
International Symposium, W2GIS 2013. Proceedings, P190, DOI 10.1007/978-3-642-
37087-8_14
NR 18
TC 1
Z9 1
U1 0
U2 7
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 0302-9743
EI 1611-3349
BN 978-3-319-21470-2; 978-3-319-21469-6
J9 LECT NOTES COMPUT SC
PY 2015
VL 9157
BP 556
EP 565
DI 10.1007/978-3-319-21470-2_40
PG 10
WC Computer Science, Theory & Methods
SC Computer Science
GA BD9NQ
UT WOS:000364989000040
DA 2019-08-06
ER

PT J
AU Fiedler, BA
AF Fiedler, Beth Ann
TI Constructing legal authority to facilitate multi-level interagency
health data sharing in the United States
SO INTERNATIONAL JOURNAL OF PHARMACEUTICAL AND HEALTHCARE MARKETING
LA English
DT Article
DE Data security; Data sharing; International Classification of Diseases;
National health policy; National security; Public heath law
AB Purpose - The purpose of this paper is to forward specific policy proposals
permitting greater sharing of health data across multi-level government agencies
with the purpose of improving rapid identification of bioterrorist attack or
disease epidemics while protecting patient privacy.

Design/methodology/approach - A systematic literature review searched the following keyword phrases: knowledge sharing in the public sector, raw data sharing, interagency information systems, federal data sharing technology network and network theory on five primary databases.

Findings - The volunteer nature of data sharing must evolve through public health policy to permit interagency data access agreements while minimizing privacy infringement. A multi-level information infrastructure network linking agencies tasked to develop medical countermeasures is recommended.

Originality/value - This study optimizes the health data collection process to create a medical countermeasure network, demonstrates the utility of operationalizing data metrics for a US federal agency and advances meaningful use of electronic medical records.

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OI Fiedler, Beth Ann/0000-0002-0745-8693

CR Alhaqbani B.S., 2008, P 10 INT C E HLTH NE, P108
Aljunid SM, 2012, VALUE HEALTH, V15, pS132, DOI 10.1016/j.jval.2011.11.004
Aquilina Kevin, 2010, Computer Law and Security Report, V26, P130, DOI 10.1016/j.clsr.2010.01.002
Berg M, 1996, SOCIOL HEALTH ILL, V18, P499, DOI 10.1111/1467-9566.ep10939100
Buxbaum P., 2010, GOVT HLTH IT, V5, P25
*CDC, 2003, SYNDR DEF DIS ASS CR
Coase RH, 1937, ECONOMICA-NEW SER, V4, P386, DOI 10.1111/j.1468-0335.1937.tb00002.x
Commission on the Prevention of Weapons of Mass Destruction Proliferation and Terrorism before Congress, 2010, PREV WMD PROL TERR R
Council on Foreign Relations, 2012, GLOB HLTH REG ISS BR
Cresswell KM, 2010, BMC MED INFORM DECIS, V10, DOI 10.1186/1472-6947-10-67
Dobbs D., 2010, ONLINE J PUBLIC HLTH, V2, P1
Eglene O, 2007, AM REV PUBLIC ADM, V37, P91, DOI 10.1177/0275074006290799
Fiedler B. A, 2011, AM SOC PUBL ADM C BA
Fiedler B. A., 2010, U CENTR FLOR 4 ANN P
Fiedler B. A., 2012, OVERCOMING MED PLURA, DOI [10.13140/RG.2.1.1730.7045, DOI 10.13140/RG.2.1.1730.7045]
Fiedler B.A., 2014, INT SERV DEL AM SOC
Fiedler B. A., 2012, GOV HLTH INF TECHN W
Frankel M., 2013, ISR J HEALTH POLICY, V2, P1
French M, 2013, SOCIOL HEALTH ILL, V35, P174, DOI 10.1111/j.1467-9566.2012.01536.x
GAO United States Government Accountability Office, 2009, BIOS DEV COLL STRAT
GRANOVETTER M, 1992, NETWORKS AND ORGANIZATIONS : STRUCTURE, FORM, AND ACTION, P25
GRANOVETTER M, 1985, AM J SOCIOL, V91, P481, DOI 10.1086/228311
Granovetter M., 1995, ADM SCI Q, V40, P619
Granovetter M, 2005, HANDBOOK OF ECONOMIC SOCIOLOGY, SECOND EDITION, P429
Granovetter Mark, 1995, IND CORP CHANGE, V4, P93, DOI DOI 10.1093/ICC/4.1.93
HANSETH O, 1997, ACCOUNTING MANAGEMEN, V7, P183, DOI DOI 10.1016/S0959-8022(97)00008-8
HANSETH O, 1998, P 20 INF SYST RES SE, P21
Homeland Security and HIM (AHIMA Practice brief), 2004, J AHIMA, V76
Iannacci F, 2010, EUR J INFORM SYST, V19, P35, DOI 10.1057/ejis.2010.3
Jones C, 1997, ACAD MANAGE REV, V22, P911, DOI 10.5465/AMR.1997.9711022109
Kapucu N, 2006, AM REV PUBLIC ADM, V36, P207, DOI 10.1177/0275074005280605
Keeling J.W., 2012, THESIS
Kierkegaard P, 2012, COMPUT LAW SECUR REV, V28, P163, DOI 10.1016/j.clsr.2012.01.003

Kman NE, 2012, ADV PREVENTIVE MED, V2012, P1
Kush RD, 2008, NEW ENGL J MED, V358, P1738, DOI 10.1056/NEJMsb0800209
LARSON A, 1992, ADMIN SCI QUART, V37, P76, DOI 10.2307/2393534
LAWLESS MW, 1989, HUM RELAT, V42, P1167, DOI 10.1177/001872678904201204
Matthews W., 2010, GOVT HLTH IT, V5, P29
Napoli PM, 2010, GOV INFORM Q, V27, P384, DOI 10.1016/j.giq.2010.06.005
Peekhaus W, 2008, GOV INFORM Q, V25, P669, DOI 10.1016/j.giq.2007.05.002
Peel M, 2010, ASLIB PROC, V62, P11, DOI 10.1108/00012531011015172
Poullet Yves, 2009, Computer Law and Security Report, V25, P211, DOI 10.1016/j.clsr.2009.03.008
POWELL WW, 1990, RES ORGAN BEHAV, V12, P295
Provan KG, 2007, J MANAGE, V33, P479, DOI 10.1177/0149206307302554
Reagans R, 2003, ADMIN SCI QUART, V48, P240, DOI 10.2307/3556658
Shortell S.M., 2006, HLTH CARE MANAGEMENT
United States Department of Health and Human Services, 2011, ICD 9 CM OFF GUID CO
United States Department of Health and Human Services (HHS), 2010, 9 REV CLIN MOD CD RO
United States Food and Drug Administration (FDA), 2008, FDAS OR FUNT
United States General Accounting Office (GAO), 2003, BIOT INF TECHN STRAT
Voskob M., 2003, DATA MINING PRIVACY
WILLIAMSON OE, 1981, AM J SOCIOL, V87, P548, DOI 10.1086/227496
NR 52
TC 1
Z9 1
U1 3
U2 4
PU EMERALD GROUP PUBLISHING LTD
PI BINGLEY
PA HOWARD HOUSE, WAGON LANE, BINGLEY BD16 1WA, W YORKSHIRE, ENGLAND
SN 1750-6123
EI 1750-6131
J9 INT J PHARM HEALTHC
JI Int. J. Pharm. Healthc. Mark.
PY 2015
VL 9
IS 2
BP 175
EP 194
DI 10.1108/IJPHM-07-2014-0045
PG 20
WC Health Policy & Services
SC Health Care Sciences & Services
GA V05PZ
UT WOS:000213885800006
DA 2019-08-06
ER

PT J
AU Wang, ZQ
Dong, B
Adegbija, O
Sina, M
Arnold, L
Pan, T
Hu, J
AF Wang, Zhiqiang
Dong, Bin

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   Adegbija, Odewumi
   Sina, Maryam
   Arnold, Luke
   Pan, Tania
   Hu, Jie
TI Data sharing: a decade since the publication of the first cohort profile
SO INTERNATIONAL JOURNAL OF EPIDEMIOLOGY
LA English
DT Letter
ID HEALTH
C1 [Wang, Zhiqiang; Dong, Bin; Adegbija, Odewumi; Sina, Maryam; Arnold, Luke;
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OI Wang, Zhiqiang/0000-0002-5839-743X;
CR Blane D, 2005, INT J EPIDEMIOL, V34, P750, DOI 10.1093/ije/dyi125
   Chen ZM, 2005, INT J EPIDEMIOL, V34, P1243, DOI 10.1093/ije/dyi174
   Ebrahim S, 2004, INT J EPIDEMIOL, V33, P1165, DOI 10.1093/ije/dyh368
   Hart CL, 2005, INT J EPIDEMIOL, V34, P28, DOI 10.1093/ije/dyh348
   Lee C, 2005, INT J EPIDEMIOL, V34, P987, DOI 10.1093/ije/dyi098
   Marmot M, 2005, INT J EPIDEMIOL, V34, P251, DOI 10.1093/ije/dyh372
   Martin RM, 2005, INT J EPIDEMIOL, V34, P742, DOI 10.1093/ije/dyi124
   Najman JM, 2005, INT J EPIDEMIOL, V34, P992, DOI 10.1093/ije/dyi119
   Syddall HE, 2005, INT J EPIDEMIOL, V34, P1234, DOI 10.1093/ije/dyi127
   Walker M, 2004, INT J EPIDEMIOL, V33, P1185, DOI 10.1093/ije/dyh295
NR 10
TC 1
Z9 1
U1 0
U2 2
PU OXFORD UNIV PRESS
PI OXFORD
PA GREAT CLARENDON ST, OXFORD OX2 6DP, ENGLAND
SN 0300-5771
EI 1464-3685
J9 INT J EPIDEMIOL
JI Int. J. Epidemiol.
PD DEC
PY 2014
VL 43
IS 6
BP 1986
EP 1987
DI 10.1093/ije/dyu154
PG 2
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA CA0AD
UT WOS:000348575500039
PM 25074405
OA Bronze
DA 2019-08-06
ER

PT J
AU Lafay, L
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   Bousquet, PJ
   Viguier, J
AF Lafay, L.
   Bousquet, Ph-J
   Viguier, J.
TI Leading policy to fight cancer based on strong and shared data (part V)
SO ONCOLOGIE
LA French
DT Article
DE Surveillance; Observation; Cancer; Registries; France; Cancer Plan
   2014-2019
AB In France, since the mid-70's, cancer monitoring and observation are based on
generalized and specialized registries. The 2003-2008 Cancer Plan increased
their coverage up to 20 % of the French territory. The 2009-2013 Cancer Plan
consolidated the system and promoted the record and production of new variables
and indicators. With the use of medico administrative databases, and their merge
with registries' databases, the implementation of the cancer communication file
and the "cancer cohort", the 2014-2019 Cancer Plan should achieve a more
operational, efficient and shared monitoring and observation system.
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CR Binder-Foucard F, 2014, REV EPIDEMIOL SANTE, V62, P95, DOI
10.1016/j.respe.2013.11.073
   Bossard N., 2013, Bulletin Epidemiologique Hebdomadaire, P559
   Bossard N., 2012, Bulletin Epidemiologique Hebdomadaire, P77
   Bousquet P. J., 2013, Bulletin Epidemiologique Hebdomadaire, P555
   Colonna M., 2013, Bulletin Epidemiologique Hebdomadaire, P566
   Danzon A., 2012, Bulletin Epidemiologique Hebdomadaire, P54
   Desandes E., 2013, Bulletin Epidemiologique Hebdomadaire, P589
   Grosclaude P., 2013, Bulletin Epidemiologique Hebdomadaire, P574
   Grunfeld JP, 2009, PLAN CANC 2009 2013
   Uhry Z., 2012, Bulletin Epidemiologique Hebdomadaire, P71
NR 10
TC 1
Z9 1
U1 0
U2 0
PU SPRINGER FRANCE
PI PARIS
PA 22 RUE DE PALESTRO, PARIS, 75002, FRANCE
SN 1292-3818
EI 1765-2839
J9 ONCOLOGIE
JI Oncologie
PD SEP
PY 2014
VL 16
SU 1
BP HS69
EP HS71
DI 10.1007/s10269-014-2427-6
PG 3
WC Oncology
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SC Oncology
GA AQ0DQ
UT WOS:000342453300021
DA 2019-08-06
ER

PT J
AU Guthrie, DM
Pitman, R
Fletcher, PC
Hirdes, JP
Stolee, P
Poss, JW
Papaioannou, A
Berg, K
Ezekiel, HJ
AF Guthrie, Dawn M.
Pitman, Robyn
Fletcher, Paula C.
Hirdes, John P.
Stolee, Paul
Poss, Jeffrey W.
Papaioannou, Alexandra
Berg, Katherine
Ezekiel, Helen Janzen
TI Data sharing between home care professionals: a feasibility study using
the RAI Home Care instrument
SO BMC GERIATRICS
LA English
DT Article
DE Home care; Rehabilitation; InterRAI; Standardized assessment;
Information sharing
ID MINIMUM DATA SET; PEOPLE; FALLS
AB Background: Across Ontario, home care professionals collect standardized
information on each client using the Resident Assessment for Home Care (RAI-HC).
However, this information is not consistently shared with those professionals
who provide services in the client's home. In this pilot study, we examined the
feasibility of sharing data, from the RAI-HC, between care coordinators and
service providers.
Methods: All participants were involved in a one-day training session on the
RAI-HC. The care coordinators shared specific outputs from the RAI-HC, including
the embedded health index scales, with their contracted physiotherapy and
occupational therapy service providers. Two focus groups were held, one with
care coordinators (n = 4) and one with contracted service providers (n = 6).
They were asked for their opinions on the positive aspects of the project and
areas for improvement.
Results: The focus groups revealed a number of positive outcomes related to
the project including the use of a falls prevention brochure and an increased
level of communication between professionals. The participants also cited
multiple areas for improvement related to data sharing (e. g., time constraints,
data being sent in a timely fashion) and to their standard practices in the
community (e. g., busy workloads, difficulties in data sharing, duplication of
assessments between professionals).
Conclusions: Home care professionals were able to share select pieces of
information generated from the RAI-HC system and this project enhanced the level
of communication between the two groups of professionals. However, a single
information session was not adequate training for the rehabilitation
professionals, who do not use the RAI-HC as part of normal practice. Better

education, ongoing support and timely access to the RAI-HC data are some ways to improve the usefulness of this information for busy home care providers.

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OI Guthrie, Dawn/0000-0003-3241-6580

FU Canadian Institutes for Health Research (Institute of Aging); Ontario Ministry of Health and Long Term Care; Ontario Home Care Research
FX This project was a true collaboration between a number of parties. The authors would like to thank the participating staff of the Waterloo Wellington CCAC who was instrumental in designing this project and seeing it through to completion. We also gratefully acknowledge the staff who participated from the following therapy providers: Red Cross Care Partners, PACE, Community Rehab and CBI Home Health. We are also grateful to Dr. Margaret Schneider for facilitating the focus groups and Ms. Nancy Curtin-Telegdi for assistance with conducting the education session. We also gratefully acknowledge the financial support provided by the Canadian Institutes for Health Research (Institute of Aging). John Hirdes' participation was supported through the Ontario Home Care Research and Knowledge Exchange Chair funded by the Ontario Ministry of Health and Long Term Care.

CR Baxter P, 2009, INT J INTEGR CARE, V9, P1
BERG K, 1989, Physiotherapy Canada, V41, P304
BERG KO, 1992, CAN J PUBLIC HEALTH, V83, pS7
Bernabei R, 2009, HAZZARDS GERIATRIC M, P69
BLACK C, 2000, ENHANCING CAPACITY S
Bleijlevens MHC, 2008, BMC PUBLIC HEALTH, V8, P1
Burrows AB, 2000, AGE AGEING, V29, P165, DOI 10.1093/ageing/29.2.165
Canadian Home Care Association, 2008, PORTR HOM CAR CAN, P1
Canadian Institute for Health Information, 2007, PUBL SECT EXP UT HOM
Community Care Access Centres, 2010, 2009 2010 CCAC QUAL, P1
Community Care Information Management, 2013, INT ASS REC IAR
Dalby DM, 2008, DEV INTERVENTI UNPUB
Division of Aging and Seniors PHAoC, 2005, REP SEN FALL CAN
Egan M, 2009, HLTH SOC CARE COMM, V17, P1
Feder G, 2000, BRIT MED J, V321, P1007, DOI 10.1136/bmj.321.7267.1007
Fletcher PC, 2002, J GERONTOL A-BIOL, V57, pM504, DOI 10.1093/gerona/57.8.M504
Gillespie LD, 2009, COCHRANE DB SYST REV, DOI [10.1002/14651858.CD007146.pub2, 10.1002/14651858.CD007146.pub3]
Health Canada Health, 2001, GOVT CAN ANN FUND FA
Hirdes JP, 2008, BMC MED, V6, DOI 10.1186/1741-7015-6-9
Hirdes JP, 2008, BMC HEALTH SERV RES, V8, DOI 10.1186/1472-6963-8-277
Hirdes JP, 2004, GERONTOLOGIST, V44, P665, DOI 10.1093/geront/44.5.665
Landi F, 2000, MED CARE, V38, P1184, DOI 10.1097/00005650-200012000-00005

```
   Lincoln Centre for Ageing and Community Care Research, 2004, REV ID EX VAL
COMP A
   Morris JN, 1997, J AM GERIATR SOC, V45, P1017, DOI 10.1111/j.1532-
5415.1997.tb02975.x
   MORRIS JN, 1994, J GERONTOL, V49, pM174, DOI 10.1093/geronj/49.4.M174
   Morris JN, 1999, RAI HOME CARE RAI HC
   OECD/EU, 2013, GOOD LIF OLD AG MON
   Patton M. Q., 2002, QUALITATIVE RES EVAL
   PODSIADLO D, 1991, J AM GERIATR SOC, V39, P142, DOI 10.1111/j.1532-
5415.1991.tb01616.x
   Rubenstein LZ, 2002, CLIN GERIATR MED, V18, P141, DOI 10.1016/S0749-
0690(02)00002-2
   Stolee Paul, 2010, Home Health Care Serv Q, V29, P37, DOI
10.1080/01621424.2010.487040
   Stolee Paul, 2010, Home Healthc Nurse, V28, P167, DOI
10.1097/01.NHH.0000369769.32246.92
   The Change Foundation, 2012, LOUD CLEAR SEN CAR S, P1
NR 33
TC 1
Z9 1
U1 0
U2 14
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1471-2318
J9 BMC GERIATR
JI BMC Geriatr.
PD JUN 30
PY 2014
VL 14
AR 81
DI 10.1186/1471-2318-14-81
PG 9
WC Geriatrics & Gerontology; Gerontology
SC Geriatrics & Gerontology
GA AK9KZ
UT WOS:000338747300001
PM 24975375
OA DOAJ Gold, Green Published
DA 2019-08-06
ER

PT J
AU McCarthy, M
AF McCarthy, Michael
TI US website is launched to share cancer trial data
SO BMJ-BRITISH MEDICAL JOURNAL
LA English
DT News Item
NR 0
TC 1
Z9 1
U1 0
U2 0
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
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SN 1756-1833
J9 BMJ-BRIT MED J
JI BMJ-British Medical Journal
PD APR 11
PY 2014
VL 348
AR g2742
DI 10.1136/bmj.g2742
PG 1
WC Medicine, General & Internal
SC General & Internal Medicine
GA AE9SI
UT WOS:000334349200005
PM 24727302
DA 2019-08-06
ER

PT B
AU Goudar, V
   Potkonjak, M
AF Goudar, Vishwa
   Potkonjak, Miodrag
GP IEEE
TI On Admitting Sensor Fault Tolerance while Achieving Secure Biosignal
   Data Sharing
SO 2014 IEEE INTERNATIONAL CONFERENCE ON HEALTHCARE INFORMATICS (ICHI)
LA English
DT Proceedings Paper
CT IEEE International Conference on Healthcare Informatics (ICHI)
CY SEP 15-17, 2014
CL Verona, ITALY
SP IEEE, IEEE Comp Soc
DE Body Area Networks; Watermarking; Fault Tolerance; Medical Data Sharing;
   Medical Data Security
AB Remote health monitoring BASNs promise substantive improvements in the
quality of healthcare by providing access to diagnostically rich patient data in
real-time. However, adoption is hindered by the threat of compromise of the
diagnostic quality of the data by faults. Simultaneously, unresolved issues
exist with the secure sharing of the sensitive medical data measured by
automated BASNs, stemming from the need to provide the data owner (BASN user /
patient) and the data consumers (healthcare providers, insurance companies,
medical research facilities) secure control over the medical data as it is
shared. We address these issues with a robust watermarking approach constrained
to leave primary data semantic metrics unaffected and secondary metrics affected
minimally. Further, the approach is coordinated with a fault tolerant sensor
partitioning technique to afford high semantic accuracy together with recovery
of biosignal semantics in the presence of sensor faults, while preserving the
robustness of the watermark so that it is not easily corrupted, recovered or
spoofed by malicious data consumers. Based on experimentally collected datasets
from a gait-stability monitoring BASN, we show that our watermarking technique
can robustly and effectively embed up to 1000 bit watermarks under these
constraints.
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Angeles, CA 90024 USA.
CR Anemaet WK, 1999, TOP GERIATR REHABIL, V15, P66
   Cox I T., 2008, DIGITAL WATERMARKING
```

```
   Goudar V., 2014, IEEE INT C SENS COMM
   Goudar V, 2013, INT WORKS POW TIM, P75, DOI 10.1109/PATMOS.2013.6662158
   Goudar V, 2013, IEEE J EM SEL TOP C, V3, P86, DOI 10.1109/JETCAS.2013.2243634
   Karypis G, 1998, SIAM J SCI COMPUT, V20, P359, DOI 10.1137/S1064827595287997
   Kong X, 2001, IEEE T INF TECHNOL B, V5, P195, DOI 10.1109/4233.945290
   Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
   Li M, 2010, IEEE WIREL COMMUN, V17, P51, DOI 10.1109/MWC.2010.5416350
   Noshadi H, 2010, BIOSIGNALS 2010: PROCEEDINGS OF THE THIRD INTERNATIONAL
CONFERENCE ON BIO-INSPIRED SYSTEMS AND SIGNAL PROCESSING, P264
   Pawar P, 2012, J BIOMED INFORM, V45, P544, DOI 10.1016/j.jbi.2012.02.007
NR 11
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-4799-5701-9
PY 2014
BP 266
EP 275
DI 10.1109/ICHI.2014.44
PG 10
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications
SC Computer Science
GA BF1ML
UT WOS:000380410000034
DA 2019-08-06
ER

PT S
AU Craswell, A
   Moxham, L
   Broadbent, M
AF Craswell, Alison
   Moxham, Lorna
   Broadbent, Marc
BE Grain, H
   MartinSanchez, F
   Schaper, LK
TI Shared responsibility for electronic records: Governance in perinatal
   data entry
SO INVESTING IN E-HEALTH: PEOPLE, KNOWLEDGE AND TECHNOLOGY FOR A HEALTHY
   FUTURE
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 22nd Australian Health Informatics Conference (HIC) on Investing in
   E-Health - People, Knowledge and Technology for a Healthy Future
CY AUG 11-14, 2014
CL Melbourne, AUSTRALIA
DE Data quality; attitude to computers; midwifery; collaborative
   documentation; e-health; qualitative research
ID HEALTH-CARE; INFORMATION; NURSES
AB This paper presents research undertaken as part of a larger research project
to examine the factors that influence midwives when entering perinatal data. A
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grounded theory methodology was used to undertake qualitative interviews with 15 participants from 12 different hospitals across Queensland, Australia using three different systems for perinatal data collection. The findings surrounding accountability are presented revealing that a shift in governance relating to responsibility and accountability is not occurring in midwifery units across Queensland. Without assignation of responsibility for entries and accountability for mistakes or omissions, perinatal data records can be left incomplete or inaccurate. Increasing use of electronic health records and creation of digital hospitals indicates these issues are highly relevant in planning for these services.
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CR Australian Government, 2007, NAT STAT ETH COND HU
Baskaran V, 2013, INFORM HEALTH SOC CA, V38, P196, DOI 10.3109/17538157.2012.735732
Craswell A, 2013, HEALTH INF MANAG J, V42, P11, DOI 10.1177/183335831304200102
Creswell J.W., 2007, QUALITATIVE INQUIRY
Darbyshire P, 2004, J CLIN NURS, V13, P17, DOI 10.1046/j.1365-2702.2003.00823.x
[Deloitte Deloitte], 2008, NAT E HLTH INF PRINC
Dwyer J., 2008, OPTIONS REFORM COMMO
Eley R, 2008, AUST J ADV NURS, V25, P23
Fawdry R., 2011, MIDERS MIDWIFERY DIG, V21, P440
Gajanayake R, 2011, IEEE INTERNET COMPUT, V15, P31, DOI 10.1109/MIC.2011.51
Glaser BG, 1978, THEORETICAL SENSITIV
GRUDIN J, 1994, COMMUN ACM, V37, P92, DOI 10.1145/175222.175230
Hanson RM, 2011, AUST HEALTH REV, V35, P9, DOI 10.1071/AH09865
Healy J, 2006, HLTH SYST TRANSIT, V8, P1
Hegney D, 2007, NURSES INFORM TECHNO
Lapao L, 2011, ELECT J INFORM SYSTE, V14, P37
Lluch M, 2011, INT J MED INFORM, V80, P849, DOI 10.1016/j.ijmedinf.2011.09.005
National eHealth Transition Authority (NEHTA), 2013, NEHTA STRAT PLAN REF
Pope C, 2000, BMJ-BRIT MED J, V320, P114, DOI 10.1136/bmj.320.7227.114
Riley K., 2011, DOES LINE LEARNING C
Vimarlund V., 2012, INTELLIGENT INFORM M, V4, P296, DOI DOI 10.4236/IIM.2012.225042
Zhou X., 2012, CSCW 12
NR 22
TC 1
Z9 1
U1 0
U2 1
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
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J9 STUD HEALTH TECHNOL
PY 2014
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DI 10.3233/978-1-61499-427-5-19
PG 6
WC Computer Science, Information Systems; Computer Science,
   Interdisciplinary Applications; Health Care Sciences & Services
SC Computer Science; Health Care Sciences & Services
GA BL5QY
UT WOS:000452509200004
PM 25087522
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ER

PT J
AU Portwood, SG
   Nelson, EB
AF Portwood, Sharon G.
   Nelson, Elissa B.
TI Data Sharing to Inform School-Based Asthma Services
SO JOURNAL OF SCHOOL HEALTH
LA English
DT Article
DE asthma; data systems; university-community partnerships
ID MANAGEMENT; PROGRAM; HEALTH; EDUCATION; OUTCOMES; CHILDREN
AB BACKGROUNDThis article examines results and lessons learned from a
collaborative project involving a large urban school district, its county health
department, multiple community partners, and the local university to establish
an effective system for data sharing to inform monitoring and evaluation of the
Charlotte Mecklenburg Schools (CMS) Asthma Education Program (AEP).
   METHODSDatabases maintained by nurses, program staff, and school personnel
were integrated into a single AEP Evaluation Database.
   RESULTSThere were a number of positive findings, including evidence that
students with an elevated level of need received priority from AEP. A series of
dependent group t tests analyzing changes across time in students' grade-point
averages and absences, as well as their implications, also demonstrated some
improvements. Additional outcome analyses for the 296 students who received case
management services demonstrated further program benefits in the areas of
attendance, academic performance, behavior, and quality of life.
   CONCLUSIONSEnhancing the ability of school-based programs to merge data
across project partners will facilitate efforts not only to evaluate services
but also to demonstrate program impact on a wide variety of health and academic
outcomes for students.
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   Services, Centers for Disease Control and Prevention to
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CR Bloom Barbara, 2003, Vital Health Stat 10, P1
```

```
   Bonaiuto Maria M, 2007, J Sch Nurs, V23, P202, DOI
10.1177/10598405070230040401
   Bruzzese JM, 2009, J ALLERGY CLIN IMMUN, V124, P195, DOI
10.1016/j.jaci.2009.05.040
   Clark NM, 2004, CHEST, V125, P1674, DOI 10.1378/chest.125.5.1674
   Crickmore Kim, 2002, Health Forum J, V45, P24
   Engelke MK, 2008, J SCH NURS, V24, P205, DOI 10.1177/1059840508319929
   EVANS D, 1987, HEALTH EDUC QUART, V14, P267, DOI 10.1177/109019818701400302
   Gerald LB, 2006, J SCHOOL HEALTH, V76, P291, DOI 10.1111/j.1746-
1561.2006.00114.x
   Jones SE, 2004, AM J PUBLIC HEALTH, V94, P1102, DOI 10.2105/AJPH.94.7.1102
   Moonie S, 2008, J SCHOOL HEALTH, V78, P140, DOI 10.1111/j.1746-
1561.2007.00276.x
   Murray NG, 2007, J SCHOOL HEALTH, V77, P589, DOI 10.1111/j.1746-
1561.2007.00238.x
   National Association of School Nurses, 2012, POS STAT SCH NURS MA
   Taras H, 2004, J SCHOOL HEALTH, V74, P213, DOI 10.1111/j.1746-
1561.2004.tb07935.x
   Texas Department of State Health Services School Health Program, 2008, TEX
DEP STAT HLTH SE, VE05-12889
NR 14
TC 1
Z9 1
U1 0
U2 0
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0022-4391
EI 1746-1561
J9 J SCHOOL HEALTH
JI J. Sch. Health
PD DEC
PY 2013
VL 83
IS 12
BP 851
EP 858
DI 10.1111/josh.12103
PG 8
WC Education & Educational Research; Education, Scientific Disciplines;
   Health Care Sciences & Services; Public, Environmental & Occupational
   Health
SC Education & Educational Research; Health Care Sciences & Services;
   Public, Environmental & Occupational Health
GA 255PD
UT WOS:000327251400003
PM 24261519
DA 2019-08-06
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PT J
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TI Concordance measures in shared frailty models: application to clustered data in cancer prognosis
SO STATISTICS IN MEDICINE
LA English
DT Article
DE prognostic model; concordance; frailty model; clustered data; cancer
ID BREAST-CONSERVING THERAPY; SURVIVAL-DATA; NO BOOST; LIKELIHOOD; TRIAL; EVENTS; RISK

AB Frailty models are gaining interest in prognostic studies, especially because of the spread of multicenter studies. However, little research has been performed to extend prognostic tools to frailty models, including discrimination measures. As previously performed for the Harrell's c-index, we extended two different discrimination measures (the model-based concordance probability estimation of Gonen and Heller and the nonparametric Uno's c-index) to take into account cluster membership. We calculate measures at three levels: between-group, where only patients with different frailties are compared, within-group, where only patients sharing the same frailty are compared, and overall. We performed simulations to study the impact of group size and the number of groups on these measures. Results showed that the two measures can be extended to frailty models while remaining independent from censoring distribution, provided that the group size is sufficient. We apply the extended measures to two real datasets, a meta-analysis and a large multicenter trial. Copyright (c) 2013 John Wiley & Sons, Ltd.

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FX We thank the Institut National du Cancer for funding this research. We thank the European Organisation for Research and Treatment of Cancer for sharing the data of the boost versus no boost trial and especially Laurence Collette for her insightful comments. We thank the meta-analysis of chemotherapy in head and neck cancer (MACH-NC) trialists who agreed to share and update their data and the following institutions for funding the investigators' meeting or the meta-analysis project: Association pour la Recherche sur le Cancer, Programme Hospitalier de Recherche Clinique, Ligue Nationale Contre le Cancer, and Sanofi-Aventis (unrestricted grants).

CR Altman DG, 2000, STAT MED, V19, P453, DOI 10.1002/(SICI)1097-0258(20000229)19:4<453::AID-SIM350>3.0.CO;2-5
Bartelink H, 2007, J CLIN ONCOL, V25, P3259, DOI 10.1200/JCO.2007.11.4991
Bender R, 2005, STAT MED, V24, P1713, DOI 10.1002/sim.2059
Box-Steffensmeier JM, 2006, STAT MED, V25, P3518, DOI 10.1002/sim.2434
Collette S, 2008, EUR J CANCER, V44, P2587, DOI 10.1016/j.ejca.2008.07.032
Cook RJ, 2007, STAT BIOL HEALTH, P1, DOI 10.1007/978-0-387-69810-6

Debray TP, 2013, STAT MED
Duchateau L, 2008, STAT BIOL HEALTH, P1
Field CA, 2007, J ROY STAT SOC B, V69, P369, DOI 10.1111/j.1467-9868.2007.00593.x
Gerds TA, 2012, STAT MED
Gonen M, 2005, BIOMETRIKA, V92, P965, DOI 10.1093/biomet/92.4.965
HARRELL FE, 1982, JAMA-J AM MED ASSOC, V247, P2543, DOI 10.1001/jama.247.18.2543
Harrell FE, 1996, STAT MED, V15, P361, DOI 10.1002/(SICI)1097-0258(19960229)15:4<361::AID-SIM168>3.0.CO;2-4
KORN EL, 1990, STAT MED, V9, P487, DOI 10.1002/sim.4780090503
Legrand C, 2009, LIFETIME DATA ANAL, V15, P59, DOI 10.1007/s10985-008-9092-2
LOUIS TA, 1991, STAT MED, V10, P811, DOI 10.1002/sim.4780100604
Moons KGM, 2009, BRIT MED J, V338, DOI 10.1136/bmj.b375
Pencina MJ, 2008, STAT MED, V27, P157, DOI 10.1002/sim.2929
Pencina MJ, 2012, STAT MED, V31, P1543, DOI 10.1002/sim.4508
Pignon JP, 2009, RADIOTHER ONCOL, V92, P4, DOI 10.1016/j.radonc.2009.04.014
Ramsay J. O., 1988, STAT SCI, V3, P425, DOI DOI 10.1214/SS/1177012761
Ripatti S, 2000, BIOMETRICS, V56, P1016, DOI 10.1111/j.0006-341X.2000.01016.x
Rondeau V, 2008, STAT MED, V27, P1894, DOI 10.1002/sim.3161
Rondeau V, 2003, LIFETIME DATA ANAL, V9, P139, DOI 10.1023/A:1022978802021
Rondeau V, 2010, MATH COMPUT MODEL, V52, P949, DOI 10.1016/j.mcm.2010.02.002
Rondeau V, 2011, STAT METHOD IN PRESS, DOI 10.1177/0962280211425578
Rondeau V., J STAT SOFT IN PRESS
SIMON R, 1994, BRIT J CANCER, V69, P979, DOI 10.1038/bjc.1994.192
Stare J, 2012, 33 ANN C INT SOC CLI
Stare J, 2011, BIOMETRICS, V67, P750, DOI 10.1111/j.1541-0420.2010.01526.x
Steyerberg EW, 2010, EPIDEMIOLOGY, V21, P128, DOI 10.1097/EDE.0b013e3181c30fb2
Uno H, 2011, STAT MED, V30, P1105, DOI 10.1002/sim.4154
Van Oirbeek R, 2010, STAT MED, V29, P3160, DOI 10.1002/sim.4058
Wienke A, 2003, 2003032 MPIDR WP
Yan GF, 2008, STAT MED, V27, P4190, DOI 10.1002/sim.3257

NR 35
TC 1
Z9 1
U1 0
U2 7
PU WILEY-BLACKWELL
PI HOBOKEN
PA 111 RIVER ST, HOBOKEN 07030-5774, NJ USA
SN 0277-6715
EI 1097-0258
J9 STAT MED
JI Stat. Med.
PD NOV 30
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VL 32
IS 27
BP 4803
EP 4820
DI 10.1002/sim.5852
PG 18
WC Mathematical & Computational Biology; Public, Environmental & Occupational Health; Medical Informatics; Medicine, Research & Experimental; Statistics & Probability
SC Mathematical & Computational Biology; Public, Environmental & Occupational Health; Medical Informatics; Research & Experimental

```
   Medicine; Mathematics
GA 238QT
UT WOS:000325963300009
PM 23729305
DA 2019-08-06
ER

PT J
AU Cole, A
AF Cole, Andrew
TI Public has fewer worries about sharing health information than other
   personal data
SO BMJ-BRITISH MEDICAL JOURNAL
LA English
DT News Item
CR Wellcome Trust, 2013, SUMM REP QUAL RES PU
NR 1
TC 1
Z9 1
U1 0
U2 0
PU BMJ PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 1756-1833
J9 BMJ-BRIT MED J
JI BMJ-British Medical Journal
PD JUL 25
PY 2013
VL 347
AR f4753
DI 10.1136/bmj.f4753
PG 1
WC Medicine, General & Internal
SC General & Internal Medicine
GA 193BO
UT WOS:000322532000008
PM 23887051
DA 2019-08-06
ER

PT J
AU Keyes, GR
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TI Evidence-based Medicine and Data Sharing in Outpatient Plastic Surgery
SO CLINICS IN PLASTIC SURGERY
LA English
DT Article
DE Evidence-based medicine; Data sharing; Outpatient surgery; Plastic
   surgery; Patient outcomes; EBM implementation
ID RANDOMIZED CONTROLLED-TRIALS; AESTHETIC SURGERY; RECONSTRUCTIVE-SURGERY;
   PUBLICATION BIAS; QUALITY; RECOMMENDATIONS; IMPROVEMENT; HEALTH; LEVEL
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AB The Authors discuss the importance of evidence based medicine (EBM) as related particularly to outpatient surgery. They discuss the five core steps in current EBM and take the reader through each of the steps, listing methods the surgeon can follow to achieve a thorough and relevant evidence based plan. Challenges of EBM such as reporting bias and evidence grading are discussed along with solutions and tools to meet those challenges. The article concludes with a look at data sharing as a means of enabling surgeons to access outcomes and specific aspects of care for a surgical procedure.

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CR Ahmed I, 2012, BMJ-BRIT MED J, V344, DOI 10.1136/bmj.d7762
American Medical Association, 2012, COR TOP EV BAS MED 2
American Society of Plastic Surgeons, EV BAS CLIN PRACT GU
Balshem H, 2011, J CLIN EPIDEMIOL, V64, P401, DOI 10.1016/j.jclinepi.2010.07.015
Bill and Melinda Gates Foundation, GLOB HLTH DAT ACC PR
Booth A, 2006, J MED LIBR ASSOC, V94, P421
*CAN TASK FORC PER, 1979, CAN MED ASSOC J, V121, P1193
Cano SJ, 2012, PLAST RECONSTR SURG, V129, P293, DOI 10.1097/PRS.0b013e31823aec6b
Centers for Disease Control, 2012, SURG SIT INF SSI EV
Chang EY, 2009, AESTHET SURG J, V29, P144, DOI 10.1016/j.asj.2008.12.007
Chung KC, 2009, PLAST RECONSTR SURG, V123, P1385, DOI 10.1097/PRS.0b013e31819f25ff
Claridge JA, 2005, WORLD J SURG, V29, P547, DOI 10.1007/s00268-005-7910-1
Doherty Steven, 2005, Emerg Med Australas, V17, P314, DOI 10.1111/j.1742-6723.2005.00752.x
Eaves FF, 2011, AESTHET SURG J, V31, P718, DOI 10.1177/1090820X11416921
Eaves FF, 2011, AESTHET SURG J, V31, P137, DOI 10.1177/1090820X10396033
Eaves F, 2012, AESTHET SURG J, V32, P117, DOI 10.1177/1090820X11430215
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
ELLIS J, 1995, LANCET, V346, P407, DOI 10.1016/S0140-6736(95)92781-6
*EQUATOR NETW, INTR REP GUID
*EV BAS MED WORK G, 2002, US GUID MED LIT ESS
Evans I., 2006, TESTING TREATMENTS B
Farrokhyar F, 2010, ANN SURG, V251, P409, DOI 10.1097/SLA.0b013e3181cf863d
Federal Coordinating Council for Comparative Effectiveness Research, 2009, REP PRES C
Gliklich R, 2010, REGISTRIES EVALUATIN
GUYATT G, 1992, JAMA-J AM MED ASSOC, V268, P2420, DOI 10.1001/jama.1992.03490170092032
Guyatt G., 1991, ACP J CLUB, V114, pA, DOI DOI 10.7326/ACPJC-1991-114-2-A16
Guyatt GH, 2008, BRIT MED J, V336, P924, DOI 10.1136/bmj.39489.470347.AD
Hart B, 2011, BMJ-BRIT MED J, V344, pd7202
Hasenboehler EA, 2007, PATIENT SAF SURG, V1, DOI 10.1186/1754-9493-1-4
Higgins J, 2011, COCHRANE HDB SYSTEMA

```
   Howes N, 1997, BRIT J SURG, V84, P1220
   Hrynaszkiewicz I, 2009, TRIALS, V10, DOI 10.1186/1745-6215-10-17
   Joober R, 2012, J PSYCHIATR NEUROSCI, V37, P149, DOI 10.1503/jpn.120065
   Keyes GR, 2008, PLAST RECONSTR SURG, V122, P245, DOI
10.1097/PRS.0b013e31817747fd
   Keyes GR, 2004, PLAST RECONSTR SURG, V113, P1760, DOI
10.1097/01.PRS.0000124743.75839.11
   Kingston R, 2001, EUR J SURG, V167, P324
   Loiselle F, 2008, PLAST RECONSTR SURG, V121, p207E, DOI
10.1097/01.prs.0000304600.23129.d3
   McCarthy CM, 2008, PLAST RECONSTR SURG, V122, P1942, DOI
10.1097/PRS.0b013e31818d2098
   McGauran N, 2010, TRIALS, V11, DOI 10.1186/1745-6215-11-37
   Nahai F, 2011, AESTHET SURG J, V31, P135, DOI 10.1177/1090820X10390924
   National Institutes of Health, 2009, REV POL ENH PUBL ACC
   *OCEBM LEV EVID WO, 2011, OXF 2011 LEV EV
   Pasternak LR, 2008, HDB AMBULATORY ANEST, P1
   Patient-Centered Outcomes Research Institute, 2014, MISS VIS
   SACKETT DL, 1989, CHEST, V95, pS2, DOI 10.1378/chest.95.2.2S
   Sackett DL, 1996, BRIT MED J, V312, P71
   SOLOMON MJ, 1995, SURGERY, V118, P459, DOI 10.1016/S0039-6060(05)80359-9
   Song F., 2010, HLTH TECHNOL ASSESS, V14
   Sullivan D, 2011, PLAST RECONSTR SURG, V128, P311, DOI
10.1097/PRS.0b013e3182195826
   Swanson JA, 2010, PLAST RECONSTR SURG, V126, P286, DOI
10.1097/PRS.0b013e3181dc54ee
   The Congress of the United States Congressional Budget Office, 2007, RES COMP
EFF MED TRE
   United States Department of Health and Human Services, SUMM HIPAA PRIV RUL
   United States Food and Drug Administration, PATHW GLOB PROD SAF
   Weitzman ER, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-39
   Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
NR 55
TC 1
Z9 1
U1 0
U2 2
PU W B SAUNDERS CO-ELSEVIER INC
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SN 0094-1298
J9 CLIN PLAST SURG
JI Clin. Plast. Surg.
PD JUL
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IS 3
BP 453
EP +
DI 10.1016/j.cps.2013.04.008
PG 12
WC Surgery
SC Surgery
GA 197JK
UT WOS:000322847300012
PM 23830754
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ER
```

PT S
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   Kaniovskyi, Yuriy
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   Wood, Steven
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   DAmbra, P
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   DiMartino, B
   Gerndt, M
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   Namyst, R
   Roman, J
   Scott, SL
   Traff, JL
   Vallee, G
   Weidendorfer, J
TI Towards Collaborative Data Management in the VPH-Share Project
SO EURO-PAR 2011: PARALLEL PROCESSING WORKSHOPS, PT I
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
CT 17th International Euro-Par Conference on Parallel Processing
CY AUG 29-SEP 02, 2011
CL Bordeaux, FRANCE
SP French Natl Inst Res Comp Sci & Control, Bordeaux Sud Ouest Ctr, Comp Sci Lab Bordeaux
DE virtual physiological human; healthcare infrastructure
ID INFRASTRUCTURE; SERVICES; IMPLEMENTATION
AB The goal of the Virtual Physiological Human Initiative is to provide a systematic framework for understanding physiological processes in the human body in terms of anatomical structure and biophysical mechanisms across multiple length and time scales. In the long term it will transform the delivery of European healthcare into a more personalised, predictive, and integrative process, with significant impact on healthcare and on disease prevention. This paper outlines how the recently funded project VPH-Share contributes to this vision. The project is motivated by the needs of the whole VPH community to harness ICT technology to improve health services for the individual. VPH-Share will provide the organisational fabric (the infostructure), realised as a series of services, offered in an integrated framework, to expose and to manage data, information and tools, to enable the composition and operation of new VPH

workflows and to facilitate collaborations between the members of the VPH community.
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OI Benkner, Siegfried/0000-0002-6520-2047
CR Alpdemir MN, 2004, LECT NOTES COMPUT SC, V2992, P858
Antonioletti M, 2005, CONCURR COMP-PRACT E, V17, P357, DOI 10.1002/cpe.939
ARGOS, 2011, TRANS OBS M GLOB HLT
Benkner S., 2009, CYBERINFRASTRUCTURE
Benkner S, 2010, IEEE T INF TECHNOL B, V14, P1365, DOI 10.1109/TITB.2010.2049268
Bizer C., 2009, INT J SEMANTIC WEB I
Branson A., 2008, P HEALTHGR
Buetow KH, 2009, HEALTH AFFAIR, V28, P923, DOI 10.1377/hlthaff.28.3.923-a
Dunlop R., 2008, P HEALTHGR
Franklin M., 2005, ACM SIGMOD
Hunter P., 2010, PHILOS T R SOC A, P2595
Koehler M., 2011, 7 INT C AUT AUT SYST
Komatsoulis GA, 2008, J BIOMED INFORM, V41, P106, DOI 10.1016/j.jbi.2007.03.009
Oster S, 2008, J AM MED INFORM ASSN, V15, P138, DOI 10.1197/jamia.M2522
Pedrinaci C, 2010, J UNIVERS COMPUT SCI, V16, P1694
Testi D, 2010, PHILOS T R SOC A, V368, P2853, DOI 10.1098/rsta.2010.0023
NR 16
TC 1
Z9 1
U1 0
U2 3
PU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 0302-9743
BN 978-3-642-29737-3; 978-3-642-29736-6
J9 LECT NOTES COMPUT SC
PY 2012
VL 7155
BP 54
EP 63
PG 10
WC Computer Science, Hardware & Architecture; Computer Science, Information Systems; Computer Science, Software Engineering; Computer Science, Theory & Methods
SC Computer Science
GA BE3WA
UT WOS:000371303500007
DA 2019-08-06
ER

```
PT S
AU Zvarova, J
   Lhotska, L
   Seidl, L
   Zvara, K
AF Zvarova, Jana
   Lhotska, Lenka
   Seidl, Libor
   Zvara, Karel
BE Mantas, J
   Andersen, SK
   Mazzoleni, MC
   Blobel, B
   Quaglini, S
   Moen, A
TI Health Data Collecting and Sharing: Case Studies of Czech e-Health
   Applications
SO QUALITY OF LIFE THROUGH QUALITY OF INFORMATION
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 24th Medical Informatics in Europe Conference (MIE)
CY AUG 26-29, 2012
CL Pisa, ITALY
SP European Federat Med Informat, Italian Med Informat Assoc, Italian E Hlth
Community
DE e-hhealth; electronic health record; home care; health documentation
ID RECORD
AB The paper shows the importance of e-health applications for electronic
healthcare development. It describes several e-health applications for health
data collecting and sharing that are running in the Czech Republic. These are
IZIP system, electronic health record MUDR and K4CARE project applications. The
e3-health concept is considered as a tool for judging e-health applications in
different healthcare settings.
C1 [Zvarova, Jana; Seidl, Libor; Zvara, Karel] Charles Univ Prague, Fac Med 1,
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RP Zvarova, J (reprint author), Charles Univ Prague, Fac Med 1, EuroMISE Ctr,
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RI Zvarova, Jana/B-5196-2014
OI Zvarova, Jana/0000-0001-9485-8822
FU Charles University in Prague and the research [264513]; MSM
   [6840770012]; CTU in Prague; Czech Republic
FX The work was supported by the specific research project no. 264513 of
   Charles University in Prague and the research program MSM 6840770012 of
   the CTU in Prague, Czech Republic.
CR Andersen S.K., 2008, HLTH TECHNOLOGY INFO, V136
   Aubrecht P, 2008, HEALTHINF 2008: PROCEEDINGS OF THE FIRST INTERNATIONAL
CONFERENCE ON HEALTH INFORMATICS, VOL 2, P280
   Blobel B., 2008, HLTH TECHNOLOGY INFO, V134
   Demiris G., 2004, HLTH TECHNOLOGY INFO, P106
   Dostalova T., 2008, COMPUTER SUPPORTED T, P171
   Hanzlicek P, 2005, INT J MED INFORM, V74, P221, DOI
10.1016/j.ijmedinf.2004.06.003
   Hayrinen K, 2008, INT J MED INFORM, V77, P291, DOI
10.1016/j.ijmedinf.2007.09.001
```

```
   Healy JC, 2007, METHOD INFORM MED, V46, P2
   Hippmann R, 2010, METHOD INFORM MED, V49, P168, DOI 10.3414/ME9301
   Iakovidis I., 2004, HLTH TECHNOLOGY INFO, P100
   Lhotska L., 2010, P 20 EUR M CYB SYST
   LHOTSKA L, 2011, AMBIENT ASSISTED LIV, V6693, P151
   Menachemi N, 2011, RISK MANAG HEALTHC P, V4, P47, DOI 10.2147/RMHP.S12985
   Nagy M, 2010, METHOD INFORM MED, V49, P186, DOI 10.3414/ME09-02-0018
   Novotny P., 2004, E HLTH CENTRAL E EUR
   Nykanen P, 2011, INT J MED INFORM, V80, P815, DOI
10.1016/j.ijmedinf.2011.08.004
   Spidlen J, 2006, INT J MED INFORM, V75, P201, DOI
10.1016/j.ijmedinf.2005.07.044
   van Ginneken AM, 1999, METHOD INFORM MED, V38, P332
   VANBEMMEL JH, 1984, MED INFORM, V9, P175, DOI 10.3109/14639238409015187
   Zvarova J, 2008, METHOD INFORM MED, V47, P8, DOI 10.3414/ME0426
   Zvarova J, 2004, LECT NOTES COMPUT SC, V3039, P1133
   Zvarova J., 2009, DATA MINING MED KNOW, P1
   Zvarova J, 2011, E-HEALTH SYSTEMS QUALITY AND RELIABILITY: MODELS AND
STANDARDS, P18, DOI 10.4018/978-1-61692-843-8.ch002
NR 23
TC 1
Z9 1
U1 2
U2 5
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-61499-101-4
J9 STUD HEALTH TECHNOL
PY 2012
VL 180
BP 672
EP 676
DI 10.3233/978-1-61499-101-4-672
PG 5
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BA3ZL
UT WOS:000335219500131
PM 22874276
DA 2019-08-06
ER

PT J
AU Boyle, AA
   Snelling, K
AF Boyle, Adrian A.
   Snelling, Katrina
TI Data sharing to reduce violence Incentives are needed to facilitate data
   sharing and reduce violence
SO BRITISH MEDICAL JOURNAL
LA English
DT Letter
ID PREVENTING VIOLENCE; HEALTH
EM adrian.boyle@addenbrookes.nhs.uk
OI Boyle, Adrian/0000-0002-9009-5423
CR Butchart A, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d2882
```

```
   Florence C, 2011, BRIT MED J, V342, DOI 10.1136/bmj.d3313
NR 2
TC 1
Z9 1
U1 0
U2 0
PU B M J PUBLISHING GROUP
PI LONDON
PA BRITISH MED ASSOC HOUSE, TAVISTOCK SQUARE, LONDON WC1H 9JR, ENGLAND
SN 0959-535X
J9 BRIT MED J
JI Br. Med. J.
PD JUL 19
PY 2011
VL 343
AR d4452
DI 10.1136/bmj.d4452
PG 2
WC Medicine, General & Internal
SC General & Internal Medicine
GA 797ZG
UT WOS:000293168500020
PM 21771838
DA 2019-08-06
ER

PT J
AU Moser, RP
   Hesse, BW
   Shaikh, AR
   Courtney, P
   Morgan, G
   Auguston, E
   Levin, K
   Helba, C
   Garner, D
   Dunn, M
AF Moser, Richard P.
   Hesse, Bradford W.
   Shaikh, Abdul R.
   Courtney, Paul
   Morgan, Glen
   Auguston, Erik
   Levin, Kerry
   Helba, Cynthia
   Garner, David
   Dunn, Marsha
TI PROMOTING THE USE OF HARMONIZED MEASURES AND SHARING DATA TO CATALYZE
   PROGRESS IN BEHAVIORAL SCIENCE: THE NATIONAL CANCER INSTITUTE'S
   GRID-ENABLED MEASURES (GEM) PORTAL
SO ANNALS OF BEHAVIORAL MEDICINE
LA English
DT Meeting Abstract
C1 [Moser, Richard P.; Hesse, Bradford W.; Shaikh, Abdul R.; Morgan, Glen;
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NR 0
TC 1
Z9 1
U1 0
U2 0
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0883-6612
J9 ANN BEHAV MED
JI Ann. Behav. Med.
PD APR
PY 2011
VL 41
SU 1
BP S145
EP S145
PG 1
WC Psychology, Multidisciplinary
SC Psychology
GA 747CK
UT WOS:000289297701054
DA 2019-08-06
ER

PT B
AU Benzschawel, S
   Da Silveira, M
AF Benzschawel, Stefan
   Da Silveira, Marcos
BE VanGemertPijnen, L
   Ossebaard, HC
   Hamalainen, P
TI Protecting Patient Privacy when Sharing Medical Data
SO PROCEEDINGS OF THE THIRD INTERNATIONAL CONFERENCE ON EHEALTH,
   TELEMEDICINE, AND SOCIAL MEDICINE (ETELEMED 2011)
LA English
DT Proceedings Paper
CT 3rd International Conference on eHealth, Telemedicine, and Social
   Medicine (eTELEMED)
CY FEB 23-28, 2011
CL Gosier, FRANCE
SP IARIA
DE eHealth; Patient Privacy; Electronic Health Records; Secure Patient Data
   Storage
AB This paper describes a national eHealth platform concept with a multi-level
privacy protection in order to improve the security and privacy of medical
information on their storage locations as well as during the exchanging/sharing
processes. The key idea is to classify and split-up data into different servers.
A Trusted Third Party server manages personal identifying data together with the
related pseudonyms while the medical information server manages the related
medical data assigned to pseudonyms. The well known IHE-XDS profiles are
enriched by Public Key Infrastructure, symmetric and asymmetric encryption
together with pseudonymization methods. IHE-XDS promote the interoperability
level and the extensions increase the security level.
C1 [Benzschawel, Stefan; Da Silveira, Marcos] CR SANTEC Publ Res Ctr Henri Tudor,
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CR [Anonymous], 2007, TECHNICAL REPORT
   Au R., 2008, P 41 ANN HAW INT C S, P234
   Bansal G, 2010, DECIS SUPPORT SYST, V49, P138, DOI 10.1016/j.dss.2010.01.010
   Benzschawel S., 2010, GLOBAL TELEMEDICINE, V3, P141
   Galindo D, 2010, ADV INFORM KNOWL PRO, P157, DOI 10.1007/978-1-84996-238-4_8
   Neubauer T, 2011, INT J MED INFORM, V80, P190, DOI
10.1016/j.ijmedinf.2010.10.016
   Pruski C, 2010, SECOND INTERNATIONAL CONFERENCE ON EHEALTH, TELEMEDICINE, AND
SOCIAL MEDICINE: ETELEMED 2010, PROCEEDINGS, P141, DOI 10.1109/eTELEMED.2010.27
   Slamanig D., 2008, ECIFMBE 2008, P974
NR 8
TC 1
Z9 1
U1 0
U2 0
PU IARIA XPS PRESS
PI WILMINGTON
PA PO BOX 7827, WILMINGTON, DE 19803 USA
BN 978-1-61208-119-9
PY 2011
BP 108
EP 113
PG 6
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BH0GK
UT WOS:000394896700017
DA 2019-08-06
ER

PT S
AU Germanus, D
   Dionysiou, I
   Gjermundrod, H
   Khelil, A
   Suri, N
   Bakken, DE
   Hauser, C
AF Germanus, Daniel
   Dionysiou, Ioanna
   Gjermundrod, Harald
   Khelil, Abdelmajid
   Suri, Neeraj
   Bakken, David E.
   Hauser, Carl
GP IEEE
TI Leveraging the Next-Generation Power Grid: Data Sharing and Associated
   Partnerships
SO 2010 IEEE PES CONFERENCE ON INNOVATIVE SMART GRID TECHNOLOGIES EUROPE
   (ISGT EUROPE)
SE IEEE PES Innovative Smart Grid Technologies Conference Europe
LA English
DT Proceedings Paper
CT IEEE-PES Conference on Innovative Smart Grid Technologies Europe (ISGT
   Europe)
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CY OCT 11-13, 2010
CL Gothenburg, SWEDEN
SP IEEE Power & Energy Soc, IEEE, Chalmers Univ Technol
DE power grid; communication models; trusted partnerships
AB Data delivery in the power grid today is, for the most part, hard-coded, tedious to implement and change, and does not provide any real end-to-end guarantees. Applications have started to emerge that require real-time data delivery in order to provide a wide-area assessment of the health of the power grid. This paper presents two novel communication infrastructures that facilitate the delivery of power data to intended recipients, each based on a different communication paradigm. The necessity of forming and managing trusted partnerships in either framework is further discussed.
C1 [Dionysiou, Ioanna; Gjermundrod, Harald] Univ Nicosia, Dept Comp Sci, Nicosia, Cyprus.
[Germanus, Daniel; Khelil, Abdelmajid; Suri, Neeraj] Tech Univ Darmstadt, Dept Comp Sci, Darmstadt, Germany.
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RP Germanus, D (reprint author), Tech Univ Darmstadt, Dept Comp Sci, Darmstadt, Germany.
FU CT-CS: Trustworthy Cyber Infrastructure for the Power Grid(TCIP) [CNS 05-24695]; US NSF [CCR-0326006]; EU INSPIRE, CASED; EU CoMiFin
FX The GridStat research has been supported in part by Grants CNS 05-24695 (CT-CS: Trustworthy Cyber Infrastructure for the Power Grid(TCIP)) and CCR-0326006 from the US NSF. The INSPIRE research is supported in part by EU INSPIRE, CASED (www.cased.de), and EU CoMiFin.
CR Abelsen SF, 2009, 2009 COMPUTATION WORLD: FUTURE COMPUTING, SERVICE COMPUTATION, COGNITIVE, ADAPTIVE, CONTENT, PATTERNS, P86, DOI 10.1109/ComputationWorld.2009.17
[Anonymous], 2008, SCI RES DEV APPR CYB
[Anonymous], 2006, PROT CRIT INFR INF P
[Anonymous], 2004, INT EN COMM SYST ARC
Bakken D. E., 2010, TRGS015 WASH STAT U
*CSI FBI, 2005, COMP CRIM SEC SURV
D'Antonio Salvatore, 2009, International Journal of Systems of Systems Engineering, V1, P401, DOI 10.1504/IJSSE.2009.031348
DAntonio S., 2008, P 3 INT WORKSH CRIT
Germanus D, 2010, LECT NOTES COMPUT SC, V6150, P161, DOI 10.1007/978-3-642-13556-9_10
Giani Annarita, 2009, 2009 2nd International Symposium on Resillient Control Systems (ISRCS 2009), P31, DOI 10.1109/ISRCS.2009.5251361
Gjermundrod H, 2009, 2009 COMPUTATION WORLD: FUTURE COMPUTING, SERVICE COMPUTATION, COGNITIVE, ADAPTIVE, CONTENT, PATTERNS, P259, DOI 10.1109/ComputationWorld.2009.18
Gjermundrod H, 2009, IEEE T POWER DELIVER, V24, P136, DOI 10.1109/TPWRD.2008.917693
Gjermundrod K. H., 2006, THESIS
Hauser C. H., 2005, IEEE Power & Energy Magazine, V3, P47, DOI 10.1109/MPAE.2005.1405870
Johnston R. A., 2006, P 39 ANN HAW INT C S
Khelil A., 2010, P 2 INT C MOB LIGHTW
Maymounkov P, 2002, LECT NOTES COMPUT SC, V2429, P53
Phadke A. G., 1993, IEEE Computer Applications in Power, V6, P10, DOI 10.1109/67.207465
Solum E., 2009, DEBS 09, P1
Stoica I, 2001, ACM SIGCOMM COMP COM, V31, P149, DOI 10.1145/964723.383071
U. C. P. S. O. T. Force, 2003, FIN REP AUG 14 2003

```
   Viddal ES, 2010, PROCEEDINGS OF THE INTERNATIONAL CONFERENCE ON COMPLEX,
INTELLIGENT AND SOFTWARE INTENSIVE SYSTEMS (CISIS 2010), P17, DOI
10.1109/CISIS.2010.60
NR 22
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2165-4816
BN 978-1-4244-8510-9
J9 IEEE PES INNOV SMART
PY 2010
PG 8
WC Energy & Fuels; Engineering, Electrical & Electronic
SC Energy & Fuels; Engineering
GA BI2RS
UT WOS:000409970400135
DA 2019-08-06
ER

PT B
AU Uthmani, O
   Buchanan, W
   Lawson, A
   Thuemmler, C
   Fan, L
   Scott, R
   Lavery, A
   Mooney, C
AF Uthmani, Omair
   Buchanan, William
   Lawson, Alistair
   Thuemmler, Christoph
   Fan, Lu
   Scott, Russell
   Lavery, Anne
   Mooney, Chris
BE Demergis, J
TI Novel Information Sharing Syntax for Data Sharing Between Police and
   Community Partners, Using Role-Based Security
SO PROCEEDINGS OF THE 9TH EUROPEAN CONFERENCE ON INFORMATION WARFARE AND
   SECURITY
LA English
DT Proceedings Paper
CT 9th European Conference on Information Warfare and Security
CY JUL 01-02, 2010
CL Univ Macedonia, Thessaloniki, GREECE
HO Univ Macedonia
DE information sharing syntax; intelligence model; security policy
   implementation; role-based security; police and public services;
   community risks
AB The exchange of information between the police and community partners forms a
central aspect of effective community service provision. In the context of
policing, a robust and timely communications mechanism is required between
police agencies and community partner domains, including: Primary healthcare
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(such as a Family Physician or a General Practitioner); Secondary healthcare (such as hospitals); Social Services; Education; and Fire and Rescue services. Analyses of numerous criminal investigations have frequently highlighted the requirement for a robust information-sharing framework. This paper presents a novel syntax that supports information-sharing requests, within strict data-sharing policy definitions. Such requests may form the basis for any information-sharing agreement that can exist between the police and their community partners. It defines a role-based architecture, with partner domains, with a syntax for the effective and efficient information sharing, using SPoC (Single Point-of-Contact) agents to control information exchange. The application of policy definitions using rules within these SPoCs is inspired by network firewall rules and thus define information exchange permissions. These rules can be implemented by software filtering agents that act as information gateways between partner domains. Roles are exposed from each domain to give the rights to exchange information as defined within the policy definition. This work involves collaboration with the Scottish Police, as part of the Scottish Institute for Policing Research (SIPR), and aims to improve the safety of individuals by reducing risks to the community using enhanced information-sharing mechanisms.

C1 [Uthmani, Omair; Buchanan, William; Lawson, Alistair; Thuemmler, Christoph; Fan, Lu] Edinburgh Napier Univ, Edinburgh, Midlothian, Scotland.
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cthuemmler@napier.ac.uk; russell.scott@spsa.pnn.police.uk;
anne.lavery@spsa.pnn.police.uk; chris.mooney@strathclyde.pnn.police.uk
RI Buchanan, William/F-2240-2015
OI Buchanan, William/0000-0003-0809-3523

CR Association of Chief Police Officers in Scotland (ACPOS), 2008, ACPOS GUID MAN POL I
Bichard M., 2004, BICHARD INQUIRY REPO
Cabinet Office, 2005, EGOV INT FRAM VERS 6
Clarence E., 1998, PUBLIC POLICY ADM, V13, P8
Daley DM, 2009, J PUBL ADM RES THEOR, V19, P477, DOI 10.1093/jopart/mun020
Federal Ministry of the Interior, 2003, SAGA STAND ARCH EGOV, V59
Feinberg LE, 2002, GOV INFORM Q, V19, P265, DOI 10.1016/S0740-624X(02)00106-5
HUDSON B, 1999, PUBLIC MANAGEMENT, V1, P235, DOI DOI 10.1080/14719039900000005
KOENIG DJ, 2001, INT POLICE COOPERATI
Laming Lord, 2009, PROTECTION CHILDREN
Lord Laming, 2003, V CLIMBIE INQUIREY
NIEM Program Management Office, 2007, NAT INF EXCH MOD NIE
Police and Crime Standards Directorate (PCSD) and Home Office, 2007, DEL SAF COMM GUID EF
Walport M., 2008, DATA SHARING REV REP
Willem A, 2007, J PUBL ADM RES THEOR, V17, P581, DOI 10.1093/jopart/mul021

NR 15
TC 1
Z9 1
U1 0
U2 0
PU ACAD CONFERENCES LTD
PI NR READING
PA CURTIS FARM, KIDMORE END, NR READING, RG4 9AY, ENGLAND
BN 978-1-906638-66-5
PY 2010

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BP 394
EP 402
PG 9
WC Computer Science, Information Systems; Political Science
SC Computer Science; Government & Law
GA BSE07
UT WOS:000284258200048
DA 2019-08-06
ER

PT B
AU Russell, D
   Power, D
   Slaymaker, M
   Mostefaoui, GK
   Ma, XQ
   Simpson, A
AF Russell, Douglas
   Power, David
   Slaymaker, Mark
   Mostefaoui, Ghita Kouadri
   Ma, Xiaoqi
   Simpson, Andrew
GP IEEE Computer Society
TI On the secure sharing of legacy data
SO PROCEEDINGS OF THE 2009 SIXTH INTERNATIONAL CONFERENCE ON INFORMATION
   TECHNOLOGY: NEW GENERATIONS, VOLS 1-3
LA English
DT Proceedings Paper
CT 6th International Conference on Information Technology - New Generations
   (ITNG 2009)
CY APR 27-29, 2009
CL Las Vegas, NV
SP IEEE Comp Soc
ID HEALTH-CARE
AB We describe a framework for the secure sharing and aggregation of legacy data.
The framework, sif (for service-oriented interoperability framework), has two
key principles at its core: that it should be possible to expose data from any
legacy data source, irrespective of the underlying technologies or data models,
and that data owners should be afforded the opportunity for expressive access
control policies. sif abstracts issues such as secure transport and
heterogeneous federation from application developers via a Java API. Our
particular focus in this paper is sif's plug-in mechanism, which gives rise to a
simple and elegant means of facilitating interoperability.
C1 [Russell, Douglas; Power, David; Slaymaker, Mark; Mostefaoui, Ghita Kouadri;
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EM douglas.russell@comlab.ox.ac.uk; david.power@comlab.ox.ac.uk;
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   xiaoqi.ma@comlab.ox.ac.uk; andrew.simpson@comlab.ox.ac.uk
CR Power DJ, 2005, SOFTWARE PRACT EXPER, V35, P857, DOI 10.1002/spe.692
   Simpson A, 2005, COMP MED SY, P564, DOI 10.1109/CBMS.2005.59
   SIMPSON AC, 2008, P HLTH GRID 2008
   SLAYMAKER MA, 2008, P SAC 2008, P1317, DOI DOI 10.1145/1363686.1363994
   Slaymaker M, 2008, LECT NOTES COMPUT SC, V5159, P169, DOI 10.1007/978-3-540-
85259-9_11
   Tromans C., 2008, P MICCAI GRID 2008
```

```
NR 6
TC 1
Z9 1
U1 0
U2 0
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
BN 978-1-4244-3770-2
PY 2009
BP 1676
EP 1679
DI 10.1109/ITNG.2009.21
PG 4
WC Computer Science, Artificial Intelligence; Computer Science, Information
   Systems; Computer Science, Software Engineering; Computer Science,
   Theory & Methods
SC Computer Science
GA BLQ66
UT WOS:000270815100316
DA 2019-08-06
ER

PT J
AU Yoshida, A
   Kim, YS
AF Yoshida, Atsushi
   Kim, Young-Sook
TI Sharing health risk and income risk within households: evidence from
   Japanese data
SO APPLIED ECONOMICS
LA English
DT Article
ID DECISION-MAKING; DEMAND
AB The question of which household members should consume medical services, and
in what quantities, is examined by using Japanese household-level data. Two key
concepts are employed, health risk and income risk, and whether family heads or
dependants bear these risks investigated. Health risk is the risk that a
household member falls ill, while income risk is the risk that future household
income decreases. It is found that both heads and dependants make fewer visits
to doctors as household size increases. It is also found that only dependants
visited doctors less frequently following the reform of the public health
insurance system, which raised the co-payment rate of family heads from 10% to
20%. These findings imply that heads and dependants share health risk but
dependants bear income risk.
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EM ayoshida@sk.tsukuba.ac.jp
CR BECKER GS, 1974, J POLIT ECON, V82, P1063, DOI 10.1086/260265
   BOURGUIGNON F, 1992, EUR ECON REV, V36, P355, DOI 10.1016/0014-2921(92)90091-
A
   Cameron A. C., 1998, REGRESSION ANAL COUN
   CHIAPPORI PA, 1988, ECONOMETRICA, V56, P63, DOI 10.2307/1911842
   Dercon S, 2000, J POLIT ECON, V108, P688, DOI 10.1086/316098
   MANSER M, 1980, INT ECON REV, V21, P31, DOI 10.2307/2526238
   MCELROY MB, 1981, INT ECON REV, V22, P333, DOI 10.2307/2526280
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   Pezzin LE, 1999, J HUM RESOUR, V34, P475, DOI 10.2307/146377
   POHLMEIER W, 1995, J HUM RESOUR, V30, P339, DOI 10.2307/146123
   Yoshida A, 2002, JPN ECON REV, V53, P444, DOI 10.1111/1468-5876.00238
NR 10
TC 1
Z9 1
U1 0
U2 0
PU ROUTLEDGE JOURNALS, TAYLOR & FRANCIS LTD
PI ABINGDON
PA 4 PARK SQUARE, MILTON PARK, ABINGDON OX14 4RN, OXFORDSHIRE, ENGLAND
SN 0003-6846
J9 APPL ECON
JI Appl. Econ.
PY 2008
VL 40
IS 13
BP 1723
EP 1735
DI 10.1080/00036840600895798
PG 13
WC Economics
SC Business & Economics
GA 323IA
UT WOS:000257438600008
DA 2019-08-06
ER

PT S
AU Devlies, J
   De Moor, G
   De Clercq, E
   Vandenberghe, A
AF Devlies, Jos
   De Moor, Georges
   De Clercq, Etienne
   Vandenberghe, Andre
BA Bellon, J
   Foulon, M
   VanDerLei, J
BF Bellon, J
   Foulon, M
   VanDerLei, J
BE DeClercq, E
   DeMoor, G
TI Health Data Exchange, Health Data Sharing and Decentralised Clinical
   Data Collections - Recommendations from a Belgian expert group
SO COLLABORATIVE PATIENT CENTRED EHEALTH
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT HIT at HealthCare Congress 2008
CY OCT 10, 2008
CL Brussels, BELGIUM
DE Health information policy; eHealth
AB The Belgian Federal Health Authorities are willing to redefine their eHealth
vision and to reformulate their strategy in consensus with healthcare
professionals and other domain experts. The National Health Insurance Institute
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ordered end 2007 a study to a group of experts(1), representing the majority of the eHealth stakeholders. The aim of the study was to define the strategy to be followed regarding health data exchange, data sharing, decentralised clinical data collections and Electronic Health Records. The experts issued, June 2008, a description of the current standing regarding nationally available (or to be made available) services as well as a set of priorities (structural and technological ones) for the coming years. This paper presents the experts' recommandations and some translated excerpts of their report.
C1 [Devlies, Jos] EuroRec Inst, Ghent, Belgium.
[De Moor, Georges] Univ Ghent, Dept Med Informat & Stat, Ghent, Turkey.
[De Clercq, Etienne] Catholic Univ Louvain, Hlty Syst Res, Brussels, Belgium.
[Vandenberghe, Andre] CHU Charleroi, Charleroi, Belgium.
RP Devlies, J (reprint author), EuroRec Inst, Ghent, Belgium.
CR *GROEP EXP MIM ADV, 2008, ZIEK BETR MED BER DE
NR 1
TC 1
Z9 1
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-58603-922-6
J9 STUD HEALTH TECHNOL
PY 2008
VL 141
BP 162
EP +
DI 10.3233/978-1-58603-922-6-162
PG 2
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BMR84
UT WOS:000273427800018
PM 18953136
DA 2019-08-06
ER

PT S
AU Passell, HD
Solodukhin, V
Khazekhber, S
Pozniak, VL
Vasiliev, IA
Alekhina, V
Djuraev, A
Salikhbaev, US
Radyuk, RI
Suozzi, D
Barber, DS
AF Passell, H. D.
Solodukhin, V.
Khazekhber, S.
Pozniak, V. L.
Vasiliev, I. A.
Alekhina, V.
Djuraev, A.

```
   Salikhbaev, U. S.
   Radyuk, R. I.
   Suozzi, D.
   Barber, D. S.
BE Salbu, B
   Skipperud, L
TI The Navruz Project: Cooperative, transboundary monitoring, data sharing
   and modeling of water resources in Central Asia
SO NUCLEAR RISKS IN CENTRAL ASIA
SE NATO Science for Peace and Security Series C-Environmental Security
LA English
DT Proceedings Paper
CT NATO Advanced Research Workshop on Nuclear Risk in Central Asia
CY JUN 20-22, 2006
CL Almaty, KAZAKHSTAN
SP NATO
DE sustainable water resources management; radionuclides and metals; Syr
   Darya and Amu Darya River
ID RIVERS
AB The Navruz Project engages scientists from nuclear physics research
institutes and water science institutions in the Central Asia Republics of
Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan, and Sandia National
Laboratories. The project uses standardized methods to monitor basic water
quality parameters, radionuclides, and metals in the Syr Darya and Amu Darya
rivers. Phase I of the project was initiated in 2000 with 15 sampling points in
each of the four countries with sample analysis performed for over 100
parameters. Phase 11 of the project began in 2003 and expanded sampling to
include at least 30 points in each country in an effort to characterize "hot
spots" and to identify sources. Phase III of the project began in 2006 and will
integrate decision support modeling with the existing monitoring. Overall, the
project addresses four main goals: to create collaboration among Central Asian
scientists and countries; to help increase capabilities in Central Asian nations
for sustainable water resources management; to provide a scientific basis for
supporting nuclear transparency and nonproliferation in the region; and to help
reduce the threat of conflict in Central Asia over water resources.
Contamination of these rivers is a result of growing population, urbanization,
and agricultural activities, as well as radioactive contamination from a legacy
of uranium mining and related activities of the former Soviet Union. The project
focuses on waterbome radionuclides and metals because of the importance of these
contaminants to public health and political stability in Central Asia.
C1 [Passell, H. D.; Suozzi, D.] Sandia Natl Labs, Geosci & Environm Ctr,
Monitoring Ctr, POB 5800, Albuquerque, NM 87185 USA.
   [Solodukhin, V.; Khazekhber, S.; Pozniak, V. L.] NNC RK, Inst Phys Nucl, Alma
Ata 050032, Kazakhstan.
   [Vasiliev, I. A.; Alekhina, V.] Chui Prospect, Inst Phys, Bishkek 720071,
Kyrgyzstan.
   [Djuraev, A.] Tajik Acad Sci, Atomic Energy Agcy, Dushanbe, Tajikistan.
   [Salikhbaev, U. S.; Radyuk, R. I.] Inst Nucl Phys, AS RU, Novosibirsk, Russia.
RP Passell, HD (reprint author), Sandia Natl Labs, Geosci & Environm Ctr,
Monitoring Ctr, POB 5800, Albuquerque, NM 87185 USA.
FU Sandia National Laboratories; U.S. Department of Energy National Nuclear
   Security Agency's Office of Nonproliferation Policy; International
   Science and Technology Center (ISTC); Science and Technology Center of
   the Ukraine (STCU); home institutions and governments of all the Navruz
   Project partners; NATO Science for Peace Subprogramme; United States
   Department of Energy [DE-AC04-94AL85000]
FX We gratefully acknowledge the support and assistance from Sandia
   National Laboratories, the U.S. Department of Energy National Nuclear
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   Security Agencys Office of Nonproliferation Policy, the International
   Science and Technology Center (ISTC), and the Science and Technology
   Center of the Ukraine (STCU), the home institutions and governments of
   all the Navruz Project partners, and the NATO Science for Peace
   Subprogramme. Sandia National Laboratories is a multiprogram laboratory
   operated by Sandia Corporation, a Lockheed-Martin Company, for the
   United States Department of Energy under contract DE-AC04-94AL85000.
CR Barber DS, 2005, J RADIOANAL NUCL CH, V263, P213, DOI 10.1007/s10967-005-
0039-8
   Barber DS, 2003, NATO SCI S SS IV EAR, V33, P39
   Kadyrzhanov KK, 2005, J RADIOANAL NUCL CH, V263, P197, DOI 10.1007/s10967-
005-0037-x
   PASSELL H, 2002, 20020484 SAND SAND N
   PASSELL H, 2003, 20031149 SAND SAND N
   PASSELL H, 2002, SW HYDROLOGY, V1, P26
   Tidwell VC, 2004, AQUAT SCI, V66, P357, DOI 10.1007/s00027-004-0722-9
   Vasiliev IA, 2005, J RADIOANAL NUCL CH, V263, P207
   Yuldashev BS, 2005, J RADIOANAL NUCL CH, V263, P219, DOI 10.1007/s10967-005-
0040-2
NR 9
TC 1
Z9 2
U1 1
U2 9
PU SPRINGER
PI DORDRECHT
PA PO BOX 17, 3300 AA DORDRECHT, NETHERLANDS
SN 1871-4668
BN 978-1-4020-8315-0
J9 NATO SCI PEACE SECUR
JI NATO Sci. Peace Secur. Ser. C- Environ. Secur.
PY 2008
BP 191
EP +
DI 10.1007/978-1-4020-8317-4_18
PG 4
WC Ecology; Environmental Sciences; Geosciences, Multidisciplinary;
   Physics, Nuclear
SC Environmental Sciences & Ecology; Geology; Physics
GA BHQ21
UT WOS:000255383400018
DA 2019-08-06
ER

PT S
AU Fan, XU
   Yu, P
AF Fan, Xiue
   Yu, Ping
BE Kuhn, KA
   Warren, JR
   Leong, TY
TI A Discussion about the Importance of Laws and Policies for Data Sharing
   for Public Health in the People's Republic of China
SO MEDINFO 2007: PROCEEDINGS OF THE 12TH WORLD CONGRESS ON HEALTH (MEDICAL)
   INFORMATICS, PTS 1 AND 2: BUILDING SUSTAINABLE HEALTH SYSTEMS
SE Studies in Health Technology and Informatics
LA English
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DT Proceedings Paper
CT 12th World Congress on Health (Medical) Informatics
CY AUG 20-24, 2007
CL Brisbane, AUSTRALIA
SP Hlth Informat Soc Australia
DE data; data sharing; public health; law; policy; implementation
ID STATE
AB This paper introduces the current status of data sharing in the People Republic of China. It discusses barriers to data sharing and proposes three key solutions to overcome these barriers in China. The establishment of national laws and policies for data sharing is considered the key prerequisite to ensuring the successful implementation of resource sharing activities in public health. Driven by established laws and policies, the relevant operational models should be developed. It is also important to have strategies in place to ensure the established films and policies are implemented by various organizations in different jurisdictions. These discussions are supported by relevant local and international evidence.
C1 [Fan, Xiue] Chinese Ctr Dis Control & Prevent, Dept Hlth, Beijing 100050, Peoples R China.
   [Yu, Ping] Univ Wollongong, Fac Informat, Sch Informat Syst & Technol, Wollongong, NSW 2522, Australia.
RP Yu, P (reprint author), Univ Wollongong, Sch Informat Syst & Technol, Wollongong, NSW 2522, Australia.
EM ping@uow.edu.au
RI Yu, Ping/B-1205-2008
OI Yu, Ping/0000-0002-7910-9396
CR BAKER TA, 2002, GLOBE, V53, P23
   Canada Health Infoway, CANADA HLTH INFOWAY
   CHAPMAN R, 2003, PUBLIC HLTH INFORM I, P408
   *DCA JUST RIGHTS D, PUBL SECT DAT SHAR G
   Department of Health, NAT PROGR IT NHS KEY
   *GEN CAN, 2005, DAT REL RES SHAR POL
   Hill K, 2001, Aust Health Rev, V24, P163
   Hodge JG, 2006, J LAW MED ETHICS, V34, P77, DOI 10.1111/j.1748-720X.2006.00010.x
   HUANG D, 2002, DISCUSSION MANAGE SH, P40
   Lee LM, 2004, ANNU REV PUBL HEALTH, V25, P327, DOI 10.1146/annurev.publhealth.25.101802.123116
   LUMPKIN JR, 2003, PUBLIC HLTH INFORM I, P16
   Parris TM, 2005, ENVIRONMENT, V47, P3, DOI 10.3200/ENVT.47.5.3-7
   *STAT CAN, DAT SHAR AGR
   WANG H, 2004, XINGHUA DIGEST, V11, P114
   Wilson K, 2004, CAN MED ASSOC J, V170, P222
   XIAO XM, 1997, J LIB
   XUE G, 2003, FUNDAMENTAL SCI CHIN, V1, P5
   HEALTHCONNECT
NR 18
TC 1
Z9 1
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-58603-774-1
J9 STUD HEALTH TECHNOL
PY 2007

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VL 129
BP 316
EP +
PG 2
WC Computer Science, Interdisciplinary Applications; Health Care Sciences &
   Services; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA BMF03
UT WOS:000272064000064
PM 17911730
DA 2019-08-06
ER

PT S
AU Grandison, T
   Ganta, SR
   Braun, U
   Kaufman, J
AF Grandison, Tyrone
   Ganta, Srivatsava Ranjit
   Braun, Uri
   Kaufman, James
BE Kuhn, KA
   Warren, JR
   Leong, TY
TI Protecting Privacy while Sharing Medical Data Between Regional
   Healthcare Entities
SO MEDINFO 2007: PROCEEDINGS OF THE 12TH WORLD CONGRESS ON HEALTH (MEDICAL)
   INFORMATICS, PTS 1 AND 2: BUILDING SUSTAINABLE HEALTH SYSTEMS
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 12th World Congress on Health (Medical) Informatics
CY AUG 20-24, 2007
CL Brisbane, AUSTRALIA
SP Hlth Informat Soc Australia
DE privacy; healthcare systems; collaboration
AB Economics of scale, corporate partnerships and a need to increase the
efficiency of Information Technology in the Healthcare sector are leading to the
construction of Regional Health Information Organizations (RHIOs) across the
United States. RHIOs are normally aligned by service provision given by
particular healthcare payers (e.g. Blue Cross-Blue Shield, PacifiCare etc.) in
particular geographies. Globalization has created a transient workforce that may
require their healthcare provider access their patient data across several
sovereign RHIOs. The harrier to enabling RHIO to RHIO collaboration lies in the
need to respect the data disclosure policy of each RHIO, to adhere to the
geography-specific healthcare legislation and also to not violate the express
privacy wishes of the patient(s) involved In this paper, we propose a data-level
control called Stick), Policy Enforcement which allows sharing to occur across
RHIOs, while adhering to the concerns mentioned.
C1 [Grandison, Tyrone; Kaufman, James] IBM Almaden Res, 650 Harry Rd, San Jose,
CA 95120 USA.
   [Ganta, Srivatsava Ranjit] Penn State Univ, University Pk, PA 16802 USA.
   [Braun, Uri] Harvard Univ, Cambridge, MA 02138 USA.
RP Grandison, T (reprint author), IBM Almaden Res, 650 Harry Rd, San Jose, CA
95120 USA.
OI Kaufman, James/0000-0002-7049-7134
CR DOLIN RH, 2006, J AM MED INF ASS JAM
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```
   GANTA SR, 2006, 5 INT C HEALTHC TECH
   He Q., 2004, P 2004 ACM WORKSH PR
   *IBM ALM RES, HIPP DAT ACT ENF US
   LEFEVRE K, 2004, P 30 INT C VER LARG
   RIVEST RL, SDSI SIMPLE DISTRIBU
   *TCG, TCG SPEC ARCH OV REV
   GOALS STRATEGIC NETW
NR 8
TC 1
Z9 1
U1 1
U2 3
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-58603-774-1
J9 STUD HEALTH TECHNOL
PY 2007
VL 129
BP 483
EP +
PG 2
WC Computer Science, Interdisciplinary Applications; Health Care Sciences &
   Services; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA BMF03
UT WOS:000272064000098
PM 17911764
DA 2019-08-06
ER

PT S
AU Stut, W
   Wartena, F
   van Steen, M
AF Stut, Wim
   Wartena, Frank
   van Steen, Maarten
BE Hasman, A
   Haux, R
   VanderLei, J
   DeClercq, E
   France, FHR
TI A distributed shared data space for personal health systems
SO UBIQUITY: TECHNOLOGIES FOR BETTER HEALTH IN AGING SOCIETIES
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 20th International Congress of the
   European-Federation-for-Medical-Informatics
CY AUG 27-30, 2006
CL Univ Hamburg, Maastricht, NETHERLANDS
SP European Federat Med Informat
HO Univ Hamburg
DE Medical Informatics; Ubiquitous Computing; Sensor Networks; Body Area
   Networks; Intermittent Connectivity; Middleware
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AB Ubiquitous computing is a promising paradigm to support health care outside
traditional care institutes. Sensor-based systems may continuously collect data
on a person's health status and context, and provide immediate feedback or
contact a remote physician. This paper presents a novel programming model to
facilitate the development of such systems. The model, which has been inspired
by tuple spaces, offers robustness for ad hoc mobile environments and explicit
support for data streams
C1 [Stut, Wim; Wartena, Frank] Philips Res, High Tech Campus 31, NL-5656 AE
Eindhoven, Netherlands.
   [van Steen, Maarten] Vrije Univ Amsterdam, Amsterdam, Netherlands.
RP Stut, W (reprint author), Philips Res, High Tech Campus 31, NL-5656 AE
Eindhoven, Netherlands.
EM wim.stut@philips.com
CR GELERNTER D, 1985, ACM T PROGR LANG SYS, V7, P80, DOI 10.1145/2363.2433
   GRAF M, 2003, ERCIM NEWS       JUL, P21
   Heinzelman WB, 2004, IEEE NETWORK, V18, P6, DOI 10.1109/MNET.2004.1265828
   KEINANEN K, 2005, ERCIM NEWS       OCT, P25
   Picco G. P., 2000, Proceedings of the 2000 International Conference on
Software Engineering. ICSE 2000 the New Millennium, P766, DOI
10.1109/ICSE.2000.870491
NR 5
TC 1
Z9 1
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
BN 978-1-58603-647-8
J9 STUD HEALTH TECHNOL
PY 2006
VL 124
BP 57
EP +
PG 2
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BQJ13
UT WOS:000281143200007
PM 17108504
DA 2019-08-06
ER

PT S
AU Wozak, F
   Ammenwerth, E
   Breu, M
   Penz, R
   Schabetsberger, T
   Vogl, R
   Wurz, M
AF Wozak, Florian
   Ammenwerth, Elske
   Breu, Micheal
   Penz, Robert
   Schabetsberger, Thomas
   Vogl, Raimund
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   Wurz, Manfred
BE Hasman, A
   Haux, R
   VanderLei, J
   DeClercq, E
   France, FHR
TI Medical Data GRIDs as Approach towards Secure Cross Enterprise Document
   Sharing (Based on IHE XDS)
SO UBIQUITY: TECHNOLOGIES FOR BETTER HEALTH IN AGING SOCIETIES
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 20th International Congress of the
   European-Federation-for-Medical-Informatics
CY AUG 27-30, 2006
CL Univ Hamburg, Maastricht, NETHERLANDS
SP European Federat Med Informat
HO Univ Hamburg
AB Quality and efficiency of health care services is expected to be improved by
the electronic processing and trans-institutional availability of medical data.
A prototype architecture based on the IHE-XDS profile is currently being
developed. Due to legal and organizational requirements specific adaptations to
the IHE-XDS profile have been made. In this work the services of the health@net
reference architecture are described in details, which have been developed with
focus on compliance to both, the IHE-XDS profile and the legal situation in
Austria. We expect to gain knowledge about the development of a shared
electronic health record using Medical Data Grids as an Open Source reference
implementation and how proprietary Hospital Information systems can be
integrated in this environment.
C1 [Wozak, Florian; Ammenwerth, Elske; Schabetsberger, Thomas] Univ Hlth Sci Med
Informat & Technol, Hall In Tirol, Austria.
   [Breu, Micheal] Leopold Franzens Univ Innsbruck, Innsbruck, Austria.
   [Penz, Robert; Vogl, Raimund] Hlth Informat Technol Tyrol, Innsbruck, Austria.
   [Wurz, Manfred] Icoserve Informat Technol, Innsbruck, Austria.
RP Wozak, F (reprint author), Univ Hlth Sci Med Informat & Technol, Eduard
Wallnofer Ctr 1, A-6060 Hall Tyrol, Austria.
EM florian.wozak@umit.at
CR *ADV, 2005, AUSTR E HLTH STRAT T
   *BGBI, 2005, 1792004 BGBI
   Foster I., 2001, INT J SUPERCOMPUTER
   Hafner M, 2005, 2005 IEEE INTERNATIONAL CONFERENCE ON WEB SERVICES, VOLS 1
AND 2, PROCEEDINGS, P533
   Haux R, 2002, INT J MED INFORM, V66, P3, DOI 10.1016/S1386-5056(02)00030-8
   *IHE NET, 2005, IHE RAD TECHN FRAM S
   LEONI L, 2004, EUROPACS MIR 2004, V1, P475
   Maglaveras N, 2002, METHOD INFORM MED, V41, P393
   *OASIS OP, 2005, OASIS WEB SERV SEC
   SCHABETSBERGER T, 2005, EUROPEAN NOTES MED I, V1, P1861
   SCHABETSBERGER T, IJMI IN PRESS
NR 11
TC 1
Z9 1
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
```

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BN 978-1-58603-647-8
J9 STUD HEALTH TECHNOL
PY 2006
VL 124
BP 377
EP +
PG 3
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BQJ13
UT WOS:000281143200053
PM 17108551
DA 2019-08-06
ER

PT B
AU Lopez-Alonso, V
   Sanchez, JP
   Liebana, L
   Hermosilla, I
   Martin-Sanchez, F
AF Lopez-Alonso, V
   Sanchez, JP
   Liebana, L
   Hermosilla, I
   Martin-Sanchez, F
GP IEEE Comp Soc
TI INBIOMED: a platform for the integration and sharing of genetic,
   clinical and epidemiological data oriented to biomedical research
SO BIBE 2004: FOURTH IEEE SYMPOSIUM ON BIOINFORMATICS AND BIOENGINEERING,
   PROCEEDINGS
LA English
DT Proceedings Paper
CT 4TH IEEE Symposium on Bioinformatics and Bioengineering (BIBE 2004)
CY MAY 19-21, 2004
CL Tai Chung, TAIWAN
SP IEEE Comp Soc, IEEE Neural Networks Soc, Taichung Healthcare & Management
Univ, Minist Educ, Natl Sci Council, Inst Informat Ind
AB INBIOMED is a Biomedical Informatics Network that coordinates biomedical
informatics and biomedical research groups working on diverse approaches
(pharmacogenetics, genetic epidemiology and image-based diagnosis). The INBIOMED
informatics platform is designed to facilitate the integration and sharing of
clinical, genetic and epidemiological data, as well as to provide tools to
analyze experimental data, predict and simulate biomedical knowledge.
   The INBIOMED platform integrates information from heterogeneous data sources,
based on the available standards, facilitating the application of information
analysis to study a concrete pathology.
   The integration of biomedical data will allow to obtain significant results
to use in clinical and biomedical research as, for example in the development of
diagnostic systems based on molecular and genetic classifications that could be
applied in the study of tumors, the development of pharmacogenetics treatments,
and the development of applications to improve public health research by means
of the development of genomic epidemiology.
   This paper also presents the motivation for, and the initial stages in
planning the application of grid technology for the INBIOMED Network.
C1 Inst Hlth Carlos III, Med Bioinformat Unit, Ctra Majadahonda Pozuelo, Madrid,
Spain.
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Ctra Majadahonda Pozuelo, Km 2, Madrid, Spain.
EM victorialopez@isciii.es
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   Fernando/A-7587-2008
OI Martin-Sanchez, Fernando/0000-0002-7312-5707
CR Ashburner M, 2000, NAT GENET, V25, P25, DOI 10.1038/75556
   *BIRN, BIOM INF RES NETW
   Brazma A, 2001, NAT GENET, V29, P365, DOI 10.1038/ng1201-365
   Davidson S B, 1995, J Comput Biol, V2, P557, DOI 10.1089/cmb.1995.2.557
   Friedman CP, 2001, J AM MED INFORM ASSN, V8, P189, DOI
10.1136/jamia.2001.0080189
   *INBIOMED, RED TEM INV COOP INF
   *INFOGENMED, VIRT LAB ACC INT GEN
   Karp P D, 1995, J Comput Biol, V2, P573, DOI 10.1089/cmb.1995.2.573
   LINDBERG C, 1990, J AM MED REC ASS
   MARTINSANCHEZ, J BIOMED INFORM, V37, P30
NR 10
TC 1
Z9 1
U1 0
U2 0
PU IEEE COMPUTER SOC
PI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1264 USA
BN 0-7695-2173-8
PY 2004
BP 222
EP 226
DI 10.1109/BIBE.2004.1317346
PG 5
WC Biochemistry & Molecular Biology; Computer Science, Interdisciplinary
   Applications; Medicine, Research & Experimental
SC Biochemistry & Molecular Biology; Computer Science; Research &
   Experimental Medicine
GA BAH58
UT WOS:000222238200030
DA 2019-08-06
ER

PT J
AU Pugazhenthi, A
   Chitra, D
AF Pugazhenthi, A.
   Chitra, D.
TI Data Access Control and Secured Data Sharing Approach for Health Care
   Data in Cloud Environment
SO JOURNAL OF MEDICAL SYSTEMS
LA English
DT Article
DE Cloud security; Access control; Encryption; Secured key sharing; Access
   policy limitation
AB One of the vital hitches in today's world of research is ensuring the
security of the Cloud. This security can be ensured by inventing new techniques
that may possibly help in safeguarding and assuring the optimal status of
information in the cloud. Contents that are stored in the Cloud are majorly
affected by the attempts made by illegitimate sources that are trying to access
it. The security level of the contents that are stored in the cloud can be
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guaranteed by focusing on a task that helps in both securing and verifying the data. In order to manage the security level, (SE-KAC) which is also known as Scalable and Enhanced Key-Aggregate Cryptosystem was initiated in current research method. But this method of securing and sharing secret keys cannot be used in the stage of decryption. However this problem can be resolved in proposed method since it introduces sharing of the data securely using a method called Improved Diffie Hellman Key Exchange Algorithm (IDHKE). By introducing the Improved Diffie Hellman Key Exchange Algorithm, securely sharing the secret keys to the receivers of the data has been achieved. The secret key details can be exchanged securely using this method. By this means it makes sure its affirmations. Here the key is safely generated using one random prime number, a master secret key and parameter value. Intended for the secured and consistent access control limitation, an encryption which is attribute-based is used. The proposed method thus ensures the protected data transmission with exact and trustworthy validation.

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CR Ali M, 2017, IEEE SYST J, V11, P395, DOI 10.1109/JSYST.2014.2379646
Dong X, 2014, COMPUT SECUR, V42, P151, DOI 10.1016/j.cose.2013.12.002
Ghosh R. K., 2017, WIRELESS NETWORKING, P3
Hampton SE, 2017, BIOSCIENCE, V67, P546, DOI 10.1093/biosci/bix025
Huang QL, 2015, CHINESE J ELECTRON, V24, P862, DOI 10.1049/cje.2015.10.033
Huang XY, 2015, IEEE T COMPUT, V64, P971, DOI 10.1109/TC.2014.2315619
Hur J, 2013, IEEE T KNOWL DATA EN, V25, P2271, DOI 10.1109/TKDE.2011.78
Jain N., 2017, COMP COMM WORKSH C C, P1
Lanc D., 2017, U. S. Patent Application, Patent No. [15/383,540, 15383540]
Li M., 2012, IEEE T PARALL DISTR, V12, P743
Liu H, 2015, IEEE T PARALL DISTR, V26, P241, DOI 10.1109/TPDS.2014.2308218
Moscicki JT, 2018, FUTURE GENER COMP SY, V78, P1052, DOI 10.1016/j.future.2017.09.019
Mushtaq MO, 2017, ARXIV170207140
Nikkhah H. R., 2017, INT C INF SYST ICIS
Patel AK, 2017, INT J ENG SCI, V7, P6603
Pugazhenthi A., 2018, CLUST COMPUT
Sethi S, 2017, ADV SYST ANAL SOFTW, P89, DOI 10.4018/978-1-5225-1721-4.ch004
Syed S. M. A., 2017, APPL BIG DATA ANAL B, P99
Tang Q, 2014, IEEE T INF FOREN SEC, V9, P1943, DOI 10.1109/TIFS.2014.2359389
Veletsianos G, 2018, LEARN MEDIA TECHNOL, V43, P17, DOI 10.1080/17439884.2017.1305966
Wang L, 2017, COMPUT MATH METHOD M, DOI 10.1155/2017/7294761
Xue KP, 2014, IEEE TRANS CLOUD COM, V2, P459, DOI 10.1109/TCC.2014.2366152

NR 22
TC 0
Z9 0
U1 0
U2 0
PU SPRINGER
PI NEW YORK
PA 233 SPRING ST, NEW YORK, NY 10013 USA
SN 0148-5598
EI 1573-689X
J9 J MED SYST
JI J. Med. Syst.
PD AUG
PY 2019

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VL 43
IS 8
AR 258
DI 10.1007/s10916-019-1381-7
PG 9
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA IH4DM
UT WOS:000474441900001
PM 31264005
DA 2019-08-06
ER

PT J
AU Courbier, S
   Dimond, R
   Bros-Facer, V
AF Courbier, Sandra
   Dimond, Rebecca
   Bros-Facer, Virginie
TI Share and protect our health data: an evidence based approach to rare
   disease patients' perspectives on data sharing and data protection -
   quantitative survey and recommendations
SO ORPHANET JOURNAL OF RARE DISEASES
LA English
DT Article
DE Rare diseases; quantitative survey; Data sharing; Data protection;
   Patient engagement; Recommendations; Evidence-based approach; Patient
   organisation; Public trust; Healthcare; Research
ID RD-CONNECT
AB BackgroundThe needs and benefits of sharing health data to advance scientific
research and improve clinical benefits have been well documented in recent years,
specifically in the field of rare diseases where knowledge and expertise are
limited and patient populations are geographically dispersed. Understanding what
patients want and need from rare disease research and data sharing is important
to ensure their participation and engagement in the process, and to ensure that
these wishes and needs are embedded within research design. EURORDIS-Rare
Diseases Europe regularly surveys the rare disease community to identify its
perspectives and needs on a number of issues in order to represent rare disease
patients and be their voice within European and International initiatives and
policy developments.Here, we present key findings from a large quantitative
survey conducted with patients with rare diseases and family members as part of
a continuous evidence-based advocacy process developed at EURORDIS. The aim of
this survey was to explore patient and family perspectives on data sharing and
data protection in research and healthcare settings and develop relevant
recommendations to support shaping of future data sharing initiatives in rare
disease research.This survey, translated into 23 languages, was carried out via
the Rare Barometer Programme and was designed to be accessible to a diverse
population with a wide range of education backgrounds. It was widely
disseminated via patient organisations worldwide to ensure that a wide range of
voices and experiences were represented.Main findingsRare disease patients,
regardless of the severity of their disease and their socio-demographic profile,
are clearly supportive of data sharing to foster research and improve healthcare.
However, rare disease patients' willingness to share their data does come with
specific requirements in order to respect their privacy, choices and needs for
information regarding the use of their data.ConclusionsTo ensure sustainability
and success of international data sharing initiatives in health and research for
rare diseases, appropriate legislations need to be implemented and multi-
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stakeholder efforts need to be pursued to foster cultural and technological changes enabling the systematic integration of patients' preferences regarding sharing of their own health data.

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FX European Commission grants: the Operating grant from the European Health programme (2014-2020), the European Union Seventh Framework Programme (FP7/2007-2013) under Grant Agreement Nos. 305444 RD-Connect.

CR Allsop J, 2004, SOCIOL HEALTH ILL, V26, P737, DOI 10.1111/j.0141-9889.2004.00416.x
[Anonymous], 2015, 431 EUR COMM, V431
[Anonymous], 2017, TRANSF HLTH CAR DIG
[Anonymous], 2017, PUBL PAT PERC CLIN R
Brownson RC, 2009, AM J PUBLIC HEALTH, V99, P1576, DOI 10.2105/AJPH.2008.156224
Budin-Ljosne I, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-016-0162-9
Burke K, 2016, ARCH DIS CHILD, V101, P1048, DOI 10.1136/archdischild-2013-304109
Contreras JL, 2015, SCIENCE, V350, P1312, DOI 10.1126/science.aaa7485
Contreras JL, 2015, TRENDS GENET, V31, P55, DOI 10.1016/j.tig.2014.12.006
Court J, 2006, POLICY ENGAGEMENT CI
Darquy S, 2016, EUR J HUM GENET, V24, P338, DOI 10.1038/ejhg.2015.115
El Emam K, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h1139
European Commission, 2010, SPEC EUR, V359
EURORDIS-Rare, 2017, DIS EUR JUGGL CAR DA
EURORDIS-Rare, 2018, DIS EUR RAR DIS PAT
Evangelista T, 2016, ORPHANET J RARE DIS, V11, DOI 10.1186/s13023-016-0398-y
Figueiredo AS, 2017, FRONT PUBLIC HEALTH, V5, DOI 10.3389/fpubh.2017.00327
Gainotti S, 2016, EUR J HUM GENET, V24, P1248, DOI 10.1038/ejhg.2016.2
Genetic Alliance UK, 2015, GEN SEQ WHAT DO PAT
Griggs RC, 2009, MOL GENET METAB, V96, P20, DOI 10.1016/j.ymgme.2008.10.003
Haeusermann Tobias, 2018, AJOB Empir Bioeth, V9, P207, DOI 10.1080/23294515.2018.1550123
Hallowell N, 2019, GENET MED, V21, P272, DOI 10.1038/s41436-018-0067-8
Kaare S, 2007, POWER EVIDENCE ADVOC
Lochmuller H, 2018, EUR J HUM GENET, V26, P778, DOI 10.1038/s41431-018-0115-5
Mathers N, 2017, BRIT J GEN PRACT, V67, P56, DOI 10.3399/bjgp17X688933
McCormack P, 2016, EUR J HUM GENET, V24, P1403, DOI 10.1038/ejhg.2016.30
McHugh ML, 2013, BIOCHEM MEDICA, V23, P143, DOI 10.11613/BM.2013.018
Merkel PA, 2016, ORPHANET J RARE DIS, V11, DOI 10.1186/s13023-016-0445-8
Minion JT, 2018, PLOS ONE, V13, DOI 10.1371/journal.pone.0202502
Odierna DH, 2014, SAGE OPEN, V4, DOI 10.1177/2158244014554391
Rainie L., AM COMPLICATED FEELI
Rehm HL, 2017, NAT REV GENET, V18, P259, DOI 10.1038/nrg.2016.162
Sirchia F, 2018, EUR J HUM GENET, V26, P946, DOI 10.1038/s41431-018-0131-5
Spencer K, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5011
Takashima K, 2018, BMC MED ETHICS, V19, DOI 10.1186/s12910-018-0310-5
Thompson R, 2014, J GEN INTERN MED, V29, pS780, DOI 10.1007/s11606-014-2908-8
Watson MS, 2017, GENET MED, V19, P721, DOI 10.1038/gim.2016.196
Zyskind G, 2015, J INFORM SECURITY CR
NR 38
TC 0
Z9 0

U1 0
U2 0
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1750-1172
J9 ORPHANET J RARE DIS
JI Orphanet J. Rare Dis.
PD JUL 12
PY 2019
VL 14
AR 175
DI 10.1186/s13023-019-1123-4
PG 15
WC Genetics & Heredity; Medicine, Research & Experimental
SC Genetics & Heredity; Research & Experimental Medicine
GA IJ1UL
UT WOS:000475684000004
PM 31300010
OA DOAJ Gold
DA 2019-08-06
ER

PT J
AU Hurtado-Navarro, I
Garcia-Sempere, A
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Sanfelix-Genoves, J
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AF Hurtado-Navarro, Isabel
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TI Impact of Drug Safety Warnings and Cost-Sharing Policies on Osteoporosis Drug Utilization in Spain: A Major Reduction But With the Persistence of Over and Underuse. Data From the ESOSVAL Cohort From 2009 to 2015
SO FRONTIERS IN PHARMACOLOGY
LA English
DT Article
DE osteoporosis; bisphosphonates; drug labeling; cost-sharing; appropriateness; utilization
ID HIP FRACTURE; MANAGEMENT; TRENDS; BISPHOSPHONATES; WOMEN; RECOMMENDATIONS; PROBABILITY; MEDICATIONS; POPULATION; PREVALENCE
AB Background: Recent studies in several countries show a significant decrease in the consumption of osteoporosis drugs from a peak around 2009, mainly attributed to bisphosphonate safety warnings issued by regulatory agencies on jaw osteonecrosis, atypical fractures, and esophageal cancer, but no studies have assessed the impact of these warnings by risk of fracture strata.

Aim: The aim of this work is to assess changes in the utilization of osteoporosis drugs in the region of Valencia (Spain) after safety warnings from regulatory agencies and cost-sharing changes, according to patient socio-demographic and risk of fracture characteristics.

Patients and Methods: We constructed a monthly series of osteoporosis drug consumption for 2009-2015 from the ESOSVAL cohort (n = 11,035; women: 48%; mean age: 65 years old) and used interrupted time series and segmented linear regression models to assess changes in osteoporosis drug utilization while controlling for previous levels and trends after three natural intervention dates: the issue of the Spanish Agency for Drugs and Medical Products (AEMPS) Osteonecrosis Jaw Warning (Sept 2009), the AEMPS Atypical femur Fracture Warning (Apr 2011), and the modification of the cost-sharing scheme (Jul 2012).

Results: The AEMPS Osteonecrosis Jaw Warning was not associated with a decline in the consumption of osteoporosis drugs, while the warning on atypical fracture (a downward trend of 0.11% fewer people treated each month) and the increase in the cost-sharing scheme (immediate change level of -1.07% in the proportion of people treated) were associated with a strong decline in the proportion of patients treated, so that by the end of 2015 osteoporosis drug consumption was around half that of 2009. The relative decline was similar in people with both a high and low risk of fracture.

Conclusion: The AEMPS Atypical femur Fracture Warning of Apr 2010 was associated with a significant decrease in the number of people treated, reinforced by the increase in the pharmaceutical cost-sharing in 2012. Decreases in treatment affected patients both at a low and higher risk of fracture.

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FU Instituto de Salud Carlos III from the Spanish Ministry of Health [PS09/02500, PI11/00238, PI13/01721]; European Regional Development Fund; FISABIO; MSD Spain; AMGEN S.A.; Valencia Department of Health

FX The ESOSVAL research program is co-funded by the Instituto de Salud Carlos III (grants PS09/02500, PI11/00238, and PI13/01721) from the Spanish Ministry of Health and the European Regional Development Fund, and by collaboration agreements established by FISABIO and the Valencia Department of Health with MSD Spain (2009-2012) and AMGEN S.A. (2010-2013), to conduct training and real-world research into musculoskeletal disorders and osteoporosis. None of the sponsors played any role in the design of the ESOSVAL studies, the collection, analysis or interpretation of data, the writing of the manuscript, or in the decision to submit it for publication.

CR Allen S., 2017, DIAGNOSIS TREATMENT
Balkhi B, 2018, SAUDI PHARM J, V26, P238, DOI 10.1016/j.jsps.2017.12.005
Bolland MJ, 2010, J CLIN ENDOCR METAB, V95, P1856, DOI 10.1210/jc.2009-2157
Compston J, 2017, ARCH OSTEOPOROS, V12, DOI 10.1007/s11657-017-0324-5
Cosman F, 2014, OSTEOPOROSIS INT, V25, P2359, DOI 10.1007/s00198-014-2794-2
Desai RJ, 2018, JAMA NETW OPEN, V1, DOI 10.1001/jamanetworkopen.2018.0826
Salgueiro ME, 2013, MATURITAS, V74, P74, DOI 10.1016/j.maturitas.2012.10.002
Fenton JJ, 2016, JAMA INTERN MED, V176, P391, DOI 10.1001/jamainternmed.2015.6020
Lopez-Valcarcel BG, 2017, HEART, V103, P1082, DOI 10.1136/heartjnl-2016-310610
Hanley DA, 2017, AM J MED, V130, DOI 10.1016/j.amjmed.2017.03.002
Hernlund E, 2013, ARCH OSTEOPOROS, V8, DOI 10.1007/s11657-013-0136-1
Hurtado I, 2014, J CLIN ENDOCR METAB, V99, P142, DOI 10.1210/jc.2013-3448
Jarvinen TLN, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2088
Jha S, 2015, J BONE MINER RES, V30, P2179, DOI 10.1002/jbmr.2565
Kanis JA, 2008, OSTEOPOROSIS INT, V19, P385, DOI 10.1007/s00198-007-0543-5
Kanis JA, 2012, OSTEOPOROSIS INT, V23, P2239, DOI 10.1007/s00198-012-1964-3

```
   Kim SC, 2016, J BONE MINER RES, V31, P1536, DOI 10.1002/jbmr.2832
   Kim SC, 2015, AM J MED, V128, P519, DOI 10.1016/j.amjmed.2015.01.014
   Kyriakos G, 2016, EXP CLIN ENDOCR DIAB, V124, P466, DOI 10.1055/s-0042-107671
   Maraka S, 2015, BMJ-BRIT MED J, V351, DOI 10.1136/bmj.h3783
   Martin-Merino E, 2017, BONE, V105, P292, DOI 10.1016/j.bone.2017.08.031
   Papaioannou A, 2010, CAN MED ASSOC J, V182, P1864, DOI 10.1503/cmaj.100771
   Peeters G, 2014, PHARMACOEPIDEM DR S, V23, P1303, DOI 10.1002/pds.3703
   Richards M., 2010, EXTENT CAUSES INT VA
   Ruggiero SL, 2004, J ORAL MAXIL SURG, V62, P527, DOI
10.1016/j.joms.2004.02.004
   Sanfelix-Genoves J, 2013, OSTEOPOROSIS INT, V24, P1045, DOI 10.1007/s00198-
012-2018-6
   Sanfelix-Genoves J, 2014, MED CLIN-BARCELONA, V142, P15, DOI
10.1016/j.medcli.2012.10.025
   Sanfelix-Genoves J, 2010, BMC PUBLIC HEALTH, V10, DOI 10.1186/1471-2458-10-
153
   Sanfelix-Gimeno G, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135475
   Sanfelix-Gimeno G, 2013, J BONE MINER RES, V28, P2286, DOI 10.1002/jbmr.1977
   Schilcher J, 2011, NEW ENGL J MED, V364, P1728, DOI 10.1056/NEJMoa1010650
   Svedbom A, 2013, ARCH OSTEOPOROS, V8, DOI 10.1007/s11657-013-0137-0
   van der Velde RY, 2017, BONE, V94, P50, DOI 10.1016/j.bone.2016.10.013
   Wang M, 2016, CLIN ENDOCRINOL, V84, P687, DOI 10.1111/cen.13000
   Whitaker M, 2012, NEW ENGL J MED, V366, P2048, DOI 10.1056/NEJMp1202619
   Wysowski DK, 2013, BONE, V57, P423, DOI 10.1016/j.bone.2013.09.008
   Wysowski DK, 2009, NEW ENGL J MED, V360, P89, DOI 10.1056/NEJMc0808738
NR 37
TC 0
Z9 0
U1 0
U2 0
PU FRONTIERS MEDIA SA
PI LAUSANNE
PA AVENUE DU TRIBUNAL FEDERAL 34, LAUSANNE, CH-1015, SWITZERLAND
SN 1663-9812
J9 FRONT PHARMACOL
JI Front. Pharmacol.
PD JUL 10
PY 2019
VL 10
AR PMID 768
DI 10.3389/fphar.2019.00768
PG 10
WC Pharmacology & Pharmacy
SC Pharmacology & Pharmacy
GA IH8LG
UT WOS:000474756100001
PM 31354484
OA DOAJ Gold
DA 2019-08-06
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PT J
AU Berger, B
   Cho, H
AF Berger, Bonnie
   Cho, Hyunghoon
TI Emerging technologies towards enhancing privacy in genomic data sharing
SO GENOME BIOLOGY
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LA English
DT Editorial Material
AB As the scale of genomic and health-related data explodes and our
understanding of these data matures, the privacy of the individuals behind the
data is increasingly at stake. Traditional approaches to protect privacy have
fundamental limitations. Here we discuss emerging privacy-enhancing technologies
that can enable broader data sharing and collaboration in genomics research.
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FU US NIH [R01GM01108348]
FX Both authors are partially supported by the US NIH grant R01GM01108348
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CR Cho H, 2018, NAT BIOTECHNOL, V36, P547, DOI 10.1038/nbt.4108
   Cramer Ronald, 2015, SECURE MULTIPARTY CO
   Dwork C, 2013, FOUND TRENDS THEOR C, V9, P211, DOI 10.1561/0400000042
   Erlich Y, 2018, SCIENCE, V362, P690, DOI 10.1126/science.aau4832
   Gentry Craig, 2009, FULLY HOMOMORPHIC EN, V20
   Harmanci A, 2018, NAT COMMUN, V9, DOI 10.1038/s41467-018-04875-5
   Hie B, 2018, SCIENCE, V362, P347, DOI 10.1126/science.aat4807
   Homer N, 2008, PLOS GENET, V4, DOI 10.1371/journal.pgen.1000167
   Sankar PL, 2017, GENET MED, V19, P743, DOI 10.1038/gim.2016.183
   Sudlow C, 2015, PLOS MED, V12, DOI 10.1371/journal.pmed.1001779
   Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI
10.1142/S0218488502001648
   Wang XF, 2018, BMC MED GENOMICS, V11, DOI 10.1186/s12920-018-0396-0
NR 12
TC 0
Z9 0
U1 0
U2 0
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1474-760X
J9 GENOME BIOL
JI Genome Biol.
PD JUL 2
PY 2019
VL 20
AR 128
DI 10.1186/s13059-019-1741-0
PG 3
WC Biotechnology & Applied Microbiology; Genetics & Heredity
SC Biotechnology & Applied Microbiology; Genetics & Heredity
GA IG0QK
UT WOS:000473495000001
PM 31262363
OA DOAJ Gold
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AF Perez, Andres M.
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Sanhueza, Juan M.
Torrison, Jerry
Torremorell, Montserrat
Corzo, Cesar A.
TI Individual or Common Good? Voluntary Data Sharing to Inform Disease Surveillance Systems in Food Animals
SO FRONTIERS IN VETERINARY SCIENCE
LA English
DT Article
DE porcine reproductive and respiratory syndrome; epidemiology; surveillance; data sharing; US
ID RESPIRATORY SYNDROME VIRUS; PRODUCTION LOSSES; ECONOMIC-IMPACT; HERDS; TIME; STABILITY

AB Livestock producers have traditionally been reluctant to share information related to their business, including data on health status of their animals, which, sometimes, has impaired the ability to implement surveillance programs. However, during the last decade, swine producers in the United States (US) and other countries have voluntarily begun to share data for the control and elimination of specific infectious diseases, such as the porcine reproductive and respiratory syndrome virus (PRRSv). Those surveillance programs have played a pivotal role in bringing producers and veterinarians together for the benefit of the industry. Examples of situations in which producers have decided to voluntarily share data for extended periods of time to support applied research and, ultimately, disease control in the absence of a regulatory framework have rarely been documented in the peer-reviewed literature. Here, we provide evidence of a national program for voluntary sharing of disease status data that has helped the implementation of surveillance activities that, ultimately, allowed the generation of critically important scientific information to better support disease control activities. Altogether, this effort has supported, and is supporting, the design and implementation of prevention and control approaches for the most economically devastating swine disease affecting the US. The program, which has been voluntarily sustained and supported over an extended period of time by the swine industry in the absence of any regulatory framework and that includes data on approximately 50% of the sow population in the US, represents a unique example of a livestock industry self-organized surveillance program to generate scientific-driven solutions for emerging swine health issues in North America.

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FU Swine Health Information Center (SHIC); National Pork Board (NPB)
FX The MSHMP, and the coordination activities that led to the paper here, have been funded by the Swine Health Information Center (SHIC) and the National Pork Board (NPB). This paper is dedicated to the memory of Dr. Robert Morrison who initiated and led the program and whose vision is helping emerging disease preparedness.

CR Alkhamis MA, 2018, PREV VET MED, V150, P135, DOI 10.1016/j.prevetmed.2017.11.011
Alkhamis MA, 2016, FRONT MICROBIOL, V7, DOI 10.3389/fmicb.2016.00067
Arruda AG, 2017, FRONT VET SCI, V4, DOI 10.3389/fvets.2017.00046
Arruda AG, 2018, PLOS ONE, V13, DOI 10.1371/journal.pone.0195282
Arruda AG, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0172638
Corzo CA, 2010, VIRUS RES, V154, P185, DOI 10.1016/j.virusres.2010.08.016
Holtkamp DJ, 2013, J SWINE HEALTH PROD, V21, P72
Holtkamp DJ, 2011, J SWINE HEALTH PROD, V19, P44
Jackson M. O., 2010, SOCIAL EC NETWORKS
Kinsley AC, 2019, PREV VET MED, V164, P1, DOI 10.1016/j.prevetmed.2019.01.001
LePotier MF, 1997, VET MICROBIOL, V55, P355, DOI 10.1016/S0378-1135(96)01318-1
Linhares DCL, 2017, PREV VET MED, V144, P112, DOI 10.1016/j.prevetmed.2017.05.024
Linhares DCL, 2014, PREV VET MED, V116, P111, DOI 10.1016/j.prevetmed.2014.05.010
Machado G, 2019, SCI REP-UK, V9, DOI 10.1038/s41598-018-36934-8
Murtaugh MP, 2010, VIRUS RES, V154, P18, DOI 10.1016/j.virusres.2010.08.015
National Pork Board, 2018, ANN PRRS COSTS FALL
Neumann EJ, 2005, JAVMA-J AM VET MED A, V227, P385, DOI 10.2460/javma.2005.227.385
Perez AM, 2016, FRONT VET SCI, V3, DOI 10.3389/fvets.2016.00018
Perez AM, 2015, JAVMA-J AM VET MED A, V246, P1304, DOI 10.2460/javma.246.12.1304
Rasmusen E., 2010, GAMES INFORM INTRO G
Sanhueza JM, 2018, EMERG DIS, P823, DOI [10.1111/tbed.13091, DOI 10.1111/TBED.13091]
Schelling TC, 1978, MICROMOTIVES MACROBE
Stevenson GW, 2013, J VET DIAGN INVEST, V25, P649, DOI 10.1177/1040638713501675
Tousignant SJP, 2015, CAN VET J, V56, P1087
Tousignant SJP, 2015, AM J VET RES, V76, P70, DOI 10.2460/ajvr.76.1.70
USDA, 2015, OV US HOG IND
VanderWaal K, 2018, EPIDEMICS-NETH, V24, P67, DOI 10.1016/j.epidem.2018.04.001
Wang LY, 2014, EMERG INFECT DIS, V20, P1227, DOI 10.3201/eid2007.140296
Wright DJ, 2017, 48 ANN M AM ASS SWIN, P385

NR 29
TC 0
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U1 0
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PU FRONTIERS MEDIA SA
PI LAUSANNE
PA AVENUE DU TRIBUNAL FEDERAL 34, LAUSANNE, CH-1015, SWITZERLAND
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J9 FRONT VET SCI

JI Front. Vet. Sci.
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DI 10.3389/fvets.2019.00194
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WC Veterinary Sciences
SC Veterinary Sciences
GA IE8OI
UT WOS:000472632600001
PM 31294036
OA DOAJ Gold
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ER

PT J
AU Andrea, M
   David, S
   Simone, EB
AF Andrea, Martani
   David, Shaw
   Simone, Elger Bernice
TI Stay fit or get bit - ethical issues in sharing health data with insurers' apps
SO SWISS MEDICAL WEEKLY
LA English
DT Review
DE digital health; health data; ethics; app; insurance
ID CASUISTRY; CARE; RESPONSIBILITY; SOLIDARITY; BEHAVIORS; INSURANCE
AB In the framework of digital health, mobile applications with health-related content are increasing in number and importance. Many of these apps are targeted at the general public and, although they differ in features and purposes, their functions are often based on the promotion of health and the monitoring of customers' lifestyle data. Apps of this type have also recently been developed by health insurance companies. In many cases, insurers' apps do not simply offer health-related recommendations to the users, but also provide economic incentives to those customers who agree to share their behavioural data through the applications. Although such apps may contribute to the adoption of a health-conscious lifestyle, the fact that they require the sharing of dense individual data with the companies responsible for insurance coverage raises some relevant ethical issues.

   This paper investigates the phenomenon of insurers' apps permitting customers to share their data in exchange for monetary rewards currently available in Switzerland. After describing the features and functioning of the apps, we present some ethically relevant aspects related to their use. More specifically, we discuss the issues of transparency of data-sharing purposes, potential discrimination amongst insured people, "quantification" of the users and, finally, the potential tension generated between solidarity and responsibility. We conclude by emphasising that these apps are becoming a new paradigm for insurers in many countries and that a thorough assessment of their ethical and societal implications is required.

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CR Albrecht UV, 2016, CHANCEN RISIKEN GESU, P62
Angerer A, 2017, DIGITAL HLTH ZUKUNFT
[Anonymous], TERMS OF USE OF HEAL
[Anonymous], 2016, EUR INS FIG
[Anonymous], SANAHEALTH DIE APP F
[Anonymous], GESCHAFTSBEDINGUNGEN
[Anonymous], 2018, VERZEICHNIS DER ZUGE
[Anonymous], MAXYOURHEALTH
[Anonymous], TIME FOR NEW HABITS
[Anonymous], IGNILIFE DER MOBILE
[Anonymous], NUTZUNGSBEDINGUNGEN
[Anonymous], DATA PRIVACY POLICY
[Anonymous], SWICA BENEVITA BONUS
[Anonymous], MYSTEP EVERY STEP CO
[Anonymous], HELSANA APP YOUR PLU
[Anonymous], PRESS GEN VIT
[Anonymous], PRIV HLTH INS REW YO
[Anonymous], 2016, MYSTEP TEILNAHMEBEDI
[Anonymous], FITN TRACK APPS
[Anonymous], SANITAS ACTIVE APP F
[Anonymous], TERMS OF USE AND DAT
[Anonymous], DISC VIT MAK S AFR H
ARRAS JD, 1991, J MED PHILOS, V16, P29, DOI 10.1093/jmp/16.1.29
Aumann I, 2016, CHANCEN RISIKEN GESU, P244
Bakos Y, 2014, J LEGAL STUD, V43, P1, DOI 10.1086/674424
Becker U, 2010, SECURITY GEN PRINCIP, P1
Biller-Andorno N, 2015, NEW ENGL J MED, V373, P2193, DOI 10.1056/NEJMp1508256
Bloss CS, 2016, PEERJ, V4, DOI 10.7717/peerj.1554
Bonoli G, 2014, ANALYTICAL SUPPORT O
Boulos Maged N Kamel, 2014, Online J Public Health Inform, V5, P229, DOI 10.5210/ojphi.v5i3.4814
Bram C, 2016, PUBLIC HEALTH GENOM, V19, P251, DOI 10.1159/000448276
Brouwer ER, 2011, ECLIPSE LEGALITY PRI, P273
Brown RCH, 2013, J MED ETHICS, V39, P695, DOI 10.1136/medethics-2012-100774
Buijink Arthur Willem Gerard, 2013, Evid Based Med, V18, P90, DOI 10.1136/eb-2012-100885
Burgstein WE, 2015, EIGENVERANTWORTUNG S
Crossley Mary, 2005, KAN L REV, V54, P73, DOI DOI 10.1377/HLTHAFF.2009.1074
Cudney P, 2014, THEOR MED BIOETH, V35, P205, DOI 10.1007/s11017-014-9295-3
De Pietro Carlo, 2015, Health Syst Transit, V17, P1
DEGRAZIA D, 1992, J MED PHILOS, V17, P511, DOI 10.1093/jmp/17.5.511
Empfehlung zum Bonusprogramm, EMPFEHLUNG ZUM BONUS
Forgo N, 2017, PERSPECT LAW BUS INN, P17, DOI 10.1007/978-981-10-5038-1_2
Hamine S, 2015, J MED INTERNET RES, V17, P2, DOI DOI 10.2196/JMIR.3951.PUBMED
Herberz C, 2018, BUNDESGESUNDHEITSBLA, V61, P298, DOI 10.1007/s00103-018-2693-3
Huber Machteld, 2011, BMJ, V343, pd4163, DOI 10.1136/bmj.d4163
JONSEN AR, 1995, KENNEDY INST ETHIC J, V5, P237

```
   Karhula T, 2015, J MED INTERNET RES, V17, DOI 10.2196/jmir.4059
   KPT, DIE KRANKENKASSE MIT
   Liukko J, 2010, NEW GENET SOC, V29, P457, DOI 10.1080/14636778.2010.528197
   Loef M, 2012, PREV MED, V55, P163, DOI 10.1016/j.ypmed.2012.06.017
   Lucht M, 2015, GESUNDHEITS UND VERS
   Lupton D, 2013, SOC THEOR HEALTH, V11, P256, DOI 10.1057/sth.2013.10
   Lupton D, 2012, SOC THEOR HEALTH, V10, P229, DOI 10.1057/sth.2012.6
   Lynch JW, 1997, SOC SCI MED, V44, P809, DOI 10.1016/S0277-9536(96)00191-8
   MCCARTNEY M, 2013, BMJ-BRIT MED J, V346, DOI DOI 10.1136/BMJ.F1811
   Mesko B, 2017, MHEALTH, V3, P38, DOI DOI 10.21037/MHEALTH.2017.08.07
   ONeill O, 1997, PHILOS T ROY SOC B, V352, P1087, DOI 10.1098/rstb.1997.0089
   Payne HE, 2015, JMIR MHEALTH UHEALTH, V3, DOI 10.2196/mhealth.3335
   Pieters D, 2015, RES HANDB EUR LAW, P534
   Plaut VC, 2012, LAW HUMAN BEHAV, V36, P293, DOI 10.1037/h0093969
   Sax A, 2017, SCHWEIZ ARZTEZTG, V98, P174, DOI [10.4414/saez.2017.05360, DOI
10.4414/SAEZ.2017.05360]
   Schmidt H, 2010, NEW ENGL J MED, V362, DOI 10.1056/NEJMp0911552
   Schmidt H, 2009, BRIT MED J, V339, DOI 10.1136/bmj.b3504
   Sharon T, 2017, PHILOS TECHNOLOGY, V30, P93, DOI DOI 10.1007/S13347-016-0215-
5
   Sharon T, 2017, NEW MEDIA SOC, V19, P1695, DOI 10.1177/1461444816636090
   Steinhubl SR, 2015, SCI TRANSL MED, V7, DOI 10.1126/scitranslmed.aaa3487
   Swan M, 2013, BIG DATA, V1, P85, DOI 10.1089/big.2012.0002
   Swiss Federal Government, BUND VERS
   Thaler R., 2008, NUDGE IMPROVING DECI
   van Baal PHM, 2008, PLOS MED, V5, P242, DOI 10.1371/journal.pmed.0050029
   Van Hoyweghen I, 2007, HEALTH CARE ANAL, V15, P179, DOI 10.1007/s10728-006-
0041-5
   Zhao J, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5692
NR 71
TC 0
Z9 0
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U2 0
PU E M H SWISS MEDICAL PUBLISHERS LTD
PI MUTTENZ
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JI Swiss Med. Wkly.
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WC Medicine, General & Internal
SC General & Internal Medicine
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UT WOS:000474214400005
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PT J
AU Zheng, XC
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Sun, SJ
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AF Zheng, Xiaochen
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TI Accelerating Health Data Sharing: A Solution Based on the Internet of Things and Distributed Ledger Technologies

SO JOURNAL OF MEDICAL INTERNET RESEARCH

LA English

DT Article

DE Internet of Things; distributed ledger technologies; data sharing; health information interoperability; IOTA Tangle; masked authenticated messaging; blockchain; intelligent healthcare

ID CARE

AB Background: Huge amounts of health-related data are generated every moment with the rapid development of Internet of Things (IoT) and wearable technologies. These big health data contain great value and can bring benefit to all stakeholders in the health care ecosystem. Currently, most of these data are siloed and fragmented in different health care systems or public and private databases. It prevents the fulfillment of intelligent health care inspired by these big data. Security and privacy concerns and the lack of ensured authenticity trails of data bring even more obstacles to health data sharing. With a decentralized and consensus-driven nature, distributed ledger technologies (DLTs) provide reliable solutions such as blockchain, Ethereum, and IOTA Tangle to facilitate the health care data sharing.

Objective: This study aimed to develop a health-related data sharing system by integrating IoT and DLT to enable secure, fee-less, tamper-resistant, highly-scalable, and granularly-controllable health data exchange, as well as build a prototype and conduct experiments to verify the feasibility of the proposed solution.

Methods: The health-related data are generated by 2 types of IoT devices: wearable devices and stationary air quality sensors. The data sharing mechanism is enabled by IOTA's distributed ledger, the Tangle, which is a directed acyclic graph. Masked Authenticated Messaging (MAM) is adopted to facilitate data communications among different parties. Merkle Hash Tree is used for data encryption and verification.

Results: A prototype system was built according to the proposed solution. It uses a smartwatch and multiple air sensors as the sensing layer; a smartphone and a single-board computer (Raspberry Pi) as the gateway; and a local server for data publishing. The prototype was applied to the remote diagnosis of tremor disease. The results proved that the solution could enable costless data integrity and flexible access management during data sharing.

Conclusions: DLT integrated with IoT technologies could greatly improve the health-related data sharing. The proposed solution based on IOTA Tangle and MAM could overcome many challenges faced by other traditional blockchain-based solutions in terms of cost, efficiency, scalability, and flexibility in data access management. This study also showed the possibility of fully decentralized health data sharing by replacing the local server with edge computing devices.

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CR Adam L., 2013, HASH BASED SIGNATURE
   Ali ST, 2015, LECT NOTES COMPUT SC, V9379, P283, DOI 10.1007/978-3-319-26096-
9_29
   Blockchain, 2019, T RAT
   Bohme R, 2015, J ECON PERSPECT, V29, P213, DOI 10.1257/jep.29.2.213
   Brassard G, 1998, LAT AM S THEOR INF S, DOI [10.1007/BFb0054319, DOI
10.1007/BFB0054319]
   Brogan J, 2018, COMPUT STRUCT BIOTEC, V16, P257, DOI
10.1016/j.csbj.2018.06.004
   Callegati F, 2009, IEEE SECUR PRIV, V7, P78, DOI 10.1109/MSP.2009.12
   Emerson T, 2016, 2016 8TH WORKSHOP ON HYPERSPECTRAL IMAGE AND SIGNAL
PROCESSING: EVOLUTION IN REMOTE SENSING (WHISPERS)
   FitBit, 2016, OR UNC PEBBL CLASS
   Gao YW, 2015, IND MANAGE DATA SYST, V115, P1704, DOI 10.1108/IMDS-03-2015-
0087
   Gubbi J, 2013, FUTURE GENER COMP SY, V29, P1645, DOI
10.1016/j.future.2013.01.010
   Handy P., 2017, IOTA BLOG
   Harlev M, 2018, P 51 HAW INT C SYST, P3497
   IOTA Blog, 2018, IOTA BLOG
   Mamoshina Polina, 2018, Oncotarget, V9, P5665, DOI 10.18632/oncotarget.22345
   Manyika JM, 2025 INTERNET THINGS
   Merkle R., 1989, P CRYPTO, DOI 10.1007/0-387-34805-0_21
   Nakamoto S., 2008, BITCOA PEER TO PEER
   Ni Q, 2016, J SENSORS, DOI 10.1155/2016/9493047
   Popov S., 2018, TANGLE
   Ralph C. Merkle, 1987, C THEOR APPL CRYPT T, P369, DOI DOI 10.1007/3-540-
48184-2_32
   Son D, 2014, NAT NANOTECHNOL, V9, P397, DOI [10.1038/nnano.2014.38,
10.1038/NNANO.2014.38]
   Statista, 2017, AV CONF TIM BITC T J
   Stojkoska BLR, 2017, J CLEAN PROD, V140, P1454, DOI
10.1016/j.jclepro.2016.10.006
   Sun S., 2019, INDOOR AIR QUALITY P
   Varshney U, 2007, MOBILE NETW APPL, V12, P113, DOI 10.1007/s11036-007-0017-1
   Zhang J, 2016, IEEE ACCESS, V4, P9239, DOI 10.1109/ACCESS.2016.2645904
   Zheng X., 2019, IOTA MAM DATA SHARIN
   Zheng XC, 2019, PARKINSONISM RELAT D, V58, P17, DOI
10.1016/j.parkreldis.2018.08.001
   Zheng XC, 2017, FRONT NEUROL, V8, DOI 10.3389/fneur.2017.00096
   Zheng XC, 2015, TELEMED E-HEALTH, V21, P443, DOI 10.1089/tmj.2014.0102
NR 31
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U1 8
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PI TORONTO
PA 59 WINNERS CIRCLE, TORONTO, ON M4L 3Y7, CANADA
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J9 J MED INTERNET RES
JI J. Med. Internet Res.
PD JUN 6
PY 2019
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IS 6
AR e13583
DI 10.2196/13583
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WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA IC0SQ
UT WOS:000470670600001
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ER

PT J
AU Schmit, C
   Kelly, K
   Bernstein, J
AF Schmit, Cason
   Kelly, Kathleen
   Bernstein, Jennifer
TI Cross Sector Data Sharing: Necessity, Challenge, and Hope
SO JOURNAL OF LAW MEDICINE & ETHICS
LA English
DT Article; Proceedings Paper
CT National Public Health Law Conference on Health Justice - Empowering
   Public Health and Advancing Health Equity
CY OCT, 2018
CL Phoenix, AZ
SP Network Publ Hlth Law, Ammer Soc Law, Med & Eth, Robert Wood Johnson Fdn
AB Existing data sources have tremendous potential to inform public health
activities. However, a patchwork of data protection laws impede data sharing
efforts. Nevertheless, a data-sharing initiative in Peoria, IL was able to
overcome challenges to set up a cross-sectoral data system to coordinate mental
health, law enforcement, and healthcare services.
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CR Munetz MR, 2006, PSYCHIAT SERV, V57, P544, DOI 10.1176/appi.ps.57.4.544
   Schmit C, 2017, PUBLIC HEALTH REP, V132, P585, DOI 10.1177/0033354917722994
   World Health Organization, 2017, WHO GUID ETH ISS PUB
NR 3
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Z9 0
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PI THOUSAND OAKS
PA 2455 TELLER RD, THOUSAND OAKS, CA 91320 USA
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JI J. Law Med. Ethics
PD JUN
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VL 47
SU 2
SI SI
BP 83
EP 86
DI 10.1177/1073110519857325
PG 4
WC Ethics; Law; Medical Ethics; Medicine, Legal
SC Social Sciences - Other Topics; Government & Law; Medical Ethics; Legal
   Medicine
GA II8RE
UT WOS:000475458400021
PM 31298141
OA Bronze
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PT J
AU Colombo, C
   Roberto, A
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AF Colombo, Cinzia
   Roberto, Anna
   Krleza-Jeric, Karmela
   Parmelli, Elena
   Banzi, Rita
TI Sharing individual participant data from clinical studies: a
   cross-sectional online survey among Italian patient and citizen groups
SO BMJ OPEN
LA English
DT Article
ID PERSPECTIVES; BENEFITS
AB Objectives To gather knowledge on the current debate, opinions and attitudes
of Italian patient and citizen groups on individual participant data (IPD)
sharing from clinical studies.
   Design Cross-sectional online survey.
   Setting and participants A 22-item online questionnaire was sent by email to
2003 contacts of patient and citizen groups in Italy. We received 311 responses,
checked for duplicate respondents (16); 295 single groups responded, 280
providing questionnaires eligible for analysis (response rate 15%). Ninety
(32.1%) dealt with oncology and palliative care, 175 (46.2%) operated locally or
regionally and 136 (48.6%) were involved in clinical research.
   Outcome measure Data on Italian patient and citizen groups' self-reported
knowledge, attitudes and opinions on IPD sharing, mechanisms for IPD access,
advantages and risks.
   Results Half the respondents (144 out of 280, 51%) had some knowledge about
the IPD sharing debate, and 60 (42%) stated they had an official position (35 in
favour, 19 in favour with restrictions, 2 against, 1 neither for nor against, 3
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missing). Nineteen discussed the topic encouraged by this survey; 39% approved broad access by researchers and other professions and identified information to participants, data de-identification, secure archives, access agreements and sanctions for misuse as important aspects of IPD sharing models. Respondents highlighted re-identification, privacy and re-use of data for purposes that participants do not agree on, as main risks, advancement of innovation and reducing waste in research as main advantages. Around half believed IPD sharing would not discourage study participation.

Conclusions Half the respondents were aware of the debate. Those who had an official position were mainly in favour of IPD sharing. Many supported broad access, asking for conditions important for building trust in entities that handle IPD sharing. Although limited by the low response rate, these findings reinforce the demand for reliable and transparent processes where accountabilities are clear.

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CR Aitken M, 2016, BMC MED ETHICS, V17, DOI 10.1186/s12910-016-0153-x
Antman EM, 2015, J AM HEART ASSOC, V4, DOI 10.1161/JAHA.115.002810
Bisol GD, 2014, J ANTHROPOL SCI, V92, P179, DOI 10.4436/JASS.92006
Bradley Meaghan, 2016, Res Involv Engagem, V2, P33, DOI 10.1186/s40900-016-0047-6
Chan AW, 2014, LANCET, V383, P257, DOI 10.1016/S0140-6736(13)62296-5
Colombo C, 2012, INTERN EMERG MED, V7, P183, DOI 10.1007/s11739-012-0757-1
Devereaux PJ, 2016, NEW ENGL J MED, V375, P405, DOI 10.1056/NEJMp1605654
Domecq JP, 2014, BMC HEALTH SERV RES, V14, DOI 10.1186/1472-6963-14-89
Dresser R, 2001, SCI OFFERS SALVATION
El Emam K, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h1139
European Medicines Agency, 2012, ACC CLIN TRIAL DAT T
European Medicines Agency, 2017, DAT AN KEY EN CLIN D
European Medicines Agency, 2014, FIN EMA POL PUBL ACC
Haug CJ, 2017, NEW ENGL J MED, V376, P2203, DOI 10.1056/NEJMp1704485
International Organization for Migration, 2015, SHAR CLIN TRIAL DAT
Jones CW, 2016, ANN INTERN MED, V165, P748, DOI 10.7326/L16-0089
Kiley R, 2017, NEW ENGL J MED, V377, P1990, DOI 10.1056/NEJMsb1708278
Kim KK, 2017, BMC MED ETHICS, V18, DOI 10.1186/s12910-017-0185-x
Kostkova P, 2016, FRONT PUBLIC HEALTH, V4, DOI 10.3389/fpubh.2016.00007
Krleza-Jeric K, 2017, COCHRANE DATABASE S1, V9
Krleza-Jeric K, 2016, BIOCHEM MEDICA, V26, P308, DOI 10.11613/BM.2016.035
Krleza-Jeric K, 2014, PERIOD BIOL, V116, P337
Krleza-Jeric Karmela, 2008, Croat Med J, V49, P267

```
   Liabo K, 2018, BMJ-BRIT MED J, V361, DOI 10.1136/bmj.k1463
   Mello MM, 2018, NEW ENGL J MED, V378, P2202, DOI 10.1056/NEJMsa1713258
   Mosconi P, 2007, HEALTH EXPECT, V10, P194, DOI 10.1111/j.1369-
7625.2007.00444.x
   Mosconi P, 2012, HEALTH RES POLICY SY, V10, DOI 10.1186/1478-4505-10-27
   Naudet F, 2018, BMJ-BRIT MED J, V360, P1, DOI 10.1136/bmj.k400
   NHS, 2017, PAT PUBL PART POL HE
   Ohmann C, 2017, BMJ OPEN, V7, DOI 10.1136/bmjopen-2017-018647
   Olson L, 2010, B WORLD HEALTH ORGAN, V88, P568, DOI 10.2471/BLT.10.030810
   PHRMA EFPIA, 2014, PRINC RESP CLIN TRIA
   Rockhold F, 2016, NEW ENGL J MED, V375, P1115, DOI 10.1056/NEJMp1608086
   Rowhani-Farid A, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2016-011784
   Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
   Smith CT, 2015, BMC MED, V13, DOI 10.1186/s12916-015-0532-z
   Spencer K, 2016, J MED INTERNET RES, V18, DOI 10.2196/jmir.5011
   Streuli JC, 2015, EPILEPTOLOGIE
   Taichman DB, 2017, BMJ-BRIT MED J, V357, DOI 10.1136/bmj.j2372
   Tallacchini M., 2015, SCI PHILOS SUSTAINAB, P98
   TNS-BMRB, 2012, OP DAT DIAL FIN REP
   Tully MP, 2018, J MED INTERNET RES, V20, DOI 10.2196/jmir.7763
   Vayena E, 2016, J MED ETHICS, V42, P216, DOI 10.1136/medethics-2015-102663
   Vickers AJ, 2006, TRIALS, V7, DOI 10.1186/1745-6215-7-15
   World Med Assoc, 2013, JAMA-J AM MED ASSOC, V310, P2191, DOI
10.1001/jama.2013.281053
   Zakarija-Grkovic I, 2018, COCHRANE DATABASE SY, V303
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TC 0
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PT J
AU Hernandez, N
   Arnrich, B
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   Demiray, B
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Fontecha, J
AF Hernandez, N.
Arnrich, B.
Favela, J.
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Demiray, B.
Fontecha, J.
TI A multi-site study on walkability, data sharing and privacy perception using mobile sensing data gathered from the m(k)-sense platform
SO JOURNAL OF AMBIENT INTELLIGENCE AND HUMANIZED COMPUTING
LA English
DT Article
DE Smartphone; Sensing campaign; Data sharing; Privacy concern; Completeness data
ID HEALTH
AB Walking is a fundamental part of a physically active lifestyle, it is one of everyday activities that positively impacts health and wellbeing. In this paper we describe the challenges and experiences of conducting a sensing campaign in the wild. We make use of m(k)-sense; a software platform to facilitate the deployment of collaborative sensing campaigns. We elaborate on two cross-cultural studies conducted in four different countries (Mexico, Turkey, Spain, and Switzerland) with a total of 77 participants. We present a detailed description of the data collected from one of the studies aimed at measuring walkability around three different university campuses. The analysis of the data shows that walkability can be assessed using information from the sensors in the smartphones and results from surveys answered by participants. In addition, we analyze issues about data sharing and privacy awareness.
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FX We thank the participants of the two sensing campaigns described in the paper for contributing their time and effort in making them successful. This work was partially funded by (1) the Co-Funded Brain Circulation Scheme Project "Pervasive Healthcare: Towards Computational Networked Life Science" (TuBITAK Co-Circ 2236, Grant agreement number: 112C005) supported by TuBTAK and EC FP7 Marie Curie Action COFUND and (2) the EC FP7 Marie Curie Action "UBIHEALTH-Exchange of Excellence in Ubiquitous Computing Technologies to Address Healthcare Challenges" (Project number 316337).
CR Abdelzaher T, 2007, IEEE PERVAS COMPUT, V6, P20, DOI 10.1109/MPRV.2007.38
Bengtsson L, 2011, PLOS MED, V8, DOI 10.1371/journal.pmed.1001083
Berke EM, 2011, ANN FAM MED, V9, P344, DOI 10.1370/afm.1266
Berkeley J, 2015, ECONOMICS
Brownstein JS, 2009, NEW ENGL J MED, V360, P2153, DOI 10.1056/NEJMp0904012
Campbell AT, 2008, IEEE INTERNET COMPUT, V12, P12, DOI 10.1109/MIC.2008.90

```
   Chen PY, 2015, IEEE COMMUN MAG, V53, P157, DOI 10.1109/MCOM.2015.7295478
   Christian HE, 2011, INT J BEHAV NUTR PHY, V8, DOI 10.1186/1479-5868-8-55
   Cornelius C, 2008, MOBISYS'08: PROCEEDINGS OF THE SIXTH INTERNATIONAL
CONFERENCE ON MOBILE SYSTEMS, APPLICATIONS, AND SERVICES, P211
   Corno F, 2016, IEEE SYS MAN CYBERN, P3039, DOI 10.1109/SMC.2016.7844703
   Moraes ALD, 2014, INT C COMP SUPP COOP, P429, DOI 10.1109/CSCWD.2014.6846883
   Eagle N, 2006, PERS UBIQUIT COMPUT, V10, P255, DOI 10.1007/s00779-005-0046-3
   Froehlich J, 2007, MOBISYS '07: PROCEEDINGS OF THE FIFTH INTERNATIONAL
CONFERENCE ON MOBILE SYSTEMS, APPLICATIONS, AND SERVICES, P57
   Harari GM, 2016, PERSPECT PSYCHOL SCI, V11, P838, DOI
10.1177/1745691616650285
   Hernandez N, 2015, LECT NOTES COMPUT SC, V9454, P26, DOI 10.1007/978-3-319-
26401-1_3
   Kanhere SS, 2013, DISTRIB COMPUT, P19, DOI DOI 10.1007/978-3-642-36071-8
   Lu H, 2010, PERVASIVE MOB COMPUT, V6, P58, DOI 10.1016/j.pmcj.2009.10.005
   Macias E, 2013, SENSORS-BASEL, V13, P17292, DOI 10.3390/s131217292
   MOHAN P., 2010, P 8 INT C MOB SYST A, P63, DOI DOI 10.1145/1814433.1814442
   Nandugudi A., 2013, P 1 INT WORKSH SENS, P1, DOI DOI 10.1145/2536714.2536718
   Pasupathi M, 2003, PSYCHOL AGING, V18, P430, DOI 10.1037/0882-7974.18.3.430
   Perdue WC, 2003, AM J PUBLIC HEALTH, V93, P1390, DOI 10.2105/AJPH.93.9.1390
   Quercia D, 2015, DIGITAL LIFE WALKABL, DOI [10.1145/2736277.2741631, DOI
10.1145/2736277.2741631]
   Satyanarayanan M, 2001, IEEE PERS COMMUN, V8, P10, DOI 10.1109/98.943998
   Silva TH, 2014, ACM T INTERNET TECHN, V14, DOI 10.1145/2677208
   Suddendorf T, 2007, BEHAV BRAIN SCI
   Sunyoung Kim, 2013, P 2013 C COMP SUPP C, P1453, DOI DOI
10.1145/2441776.2441940
   Tentori M, 2006, J UNIVERS COMPUT SCI, V12, P252
   Villanueva K, 2013, BMJ OPEN, V3, DOI 10.1136/bmjopen-2012-002482
NR 29
TC 0
Z9 0
U1 1
U2 1
PU SPRINGER HEIDELBERG
PI HEIDELBERG
PA TIERGARTENSTRASSE 17, D-69121 HEIDELBERG, GERMANY
SN 1868-5137
EI 1868-5145
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JI J. Ambient Intell. Humaniz. Comput.
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SI SI
BP 2199
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WC Computer Science, Artificial Intelligence; Computer Science, Information
   Systems; Telecommunications
SC Computer Science; Telecommunications
GA HX6CG
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PT J
AU Oliveira, JL
Trifan, A
Silva, LAB
AF Oliveira, Jose Luis
Trifan, Alina
Bastiao Silva, Luis A.
TI EMIF Catalogue: A collaborative platform for sharing and reusing biomedical data
SO INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS
LA English
DT Article
DE Biomedical data integration; Data discovery; Data sharing; Data catalogue; Research study; Data reuse
ID INTEGRATION; QUALITY

AB Objective: The collaboration and knowledge exchange between researchers are often hindered by the nonexistence of accurate information about which databases may support research studies. Even though a considerable amount of patient health information does exist, it is usually distributed and hidden in many institutions. The goal of this project is to provide, for any research community, a holistic view of biomedical datasets of interests, from which researchers can explore several distinct levels of granularity.

Methods: We developed a community-centered approach to facilitate data sharing while ensuring privacy. A dynamic schema allows exposing any metadata model about existing repositories. The framework was developed following a modular plugin-based architecture that facilitates the integration of internal and external tools.

Results: The EMIF Catalogue, a web platform for sharing and reusing biomedical data. Through this system, data custodians can publish and share different levels of information, while the researchers can search for databases that fulfill research requirements.

Conclusions: The EMIF Catalogue currently fosters several distinct research communities, with different levels of data governance, combining, for instance, data available in pan-European EHR and Alzheimer cohorts.

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FX This work has received support from the EU/EFPIA Innovative Medicines Initiative Joint Undertaking (EMIF grant n. 115372) and from the Integrated Programme of SR&TD SOCA (Ref. CENTRO-01-0145-FEDER-000010).

CR Ball R, 2016, CLIN PHARMACOL THER, V99, P265, DOI 10.1002/cpt.320
Bianchi S, 2009, IEEE ENG MED BIO, P4654, DOI 10.1109/IEMBS.2009.5332650
Chen Xiaoling, 2018, J AM MED INFORM ASS
Cimino JJ, 2014, J BIOMED INFORM, V52, P11, DOI 10.1016/j.jbi.2013.11.004
Danciu I, 2014, J BIOMED INFORM, V52, P28, DOI 10.1016/j.jbi.2014.02.003
Geissbuhler A, 2013, INT J MED INFORM, V82, P1, DOI 10.1016/j.ijmedinf.2012.11.003
Gini Rosa, 2016, EGEMS, V4
Goble C, 2008, J BIOMED INFORM, V41, P687, DOI 10.1016/j.jbi.2008.01.008
Harris PA, 2009, J BIOMED INFORM, V42, P377, DOI 10.1016/j.jbi.2008.08.010
HCU.P, 2014, HCU P DAT
Horvath MM, 2011, J BIOMED INFORM, V44, P266, DOI 10.1016/j.jbi.2010.11.008
Johnson SG, 2016, APPL CLIN INFORM, V7, P69, DOI 10.4338/ACI-2015-08-RA-0107

```
   Liyanage Harshana, 2018, Stud Health Technol Inform, V247, P61
   Liyanage H, 2017, STUD HEALTH TECHNOL, V244, P8, DOI 10.3233/978-1-61499-824-
2-8
   Loukides G, 2014, J BIOMED INFORM, V50, P46, DOI 10.1016/j.jbi.2014.05.009
   McMurry  J., 2015, REPORT SCALABILITY S
   Monaco L, 2014, PATHOBIOLOGY, V81, P231, DOI 10.1159/000358492
   Murphy Shawn N, 2006, AMIA Annu Symp Proc, P1040
   Oliveira  Olga, 2018, 11 INT C HLTH INF HE, P465
   Perez-Riverol Y, 2017, NAT BIOTECHNOL, V35, P406, DOI 10.1038/nbt.3790
   Phan John H, 2012, IEEE Rev Biomed Eng, V5, P74, DOI
10.1109/RBME.2012.2212427
   Savonnet M, 2016, IEEE J BIOMED HEALTH, V20, P1640, DOI
10.1109/JBHI.2015.2464353
   Silva Luis Basti ao, 2018, COMPUTER METHODS PRO
   Trifan  Alina, 2018, 31 IEEE CBMS INT S C, P465
   Visser Pieter Jelle, 2015, ALZHEIMERS DEMENT, V11, pP120
   Wang Fusheng, 2014, Int J Metadata Semant Ontol, V9, P42, DOI
10.1504/IJMSO.2014.059126
   2013, J AM MED INFORM ASSN, V20, P144, DOI DOI 10.1136/AMIAJNL-2011-000681
NR 27
TC 0
Z9 0
U1 4
U2 4
PU ELSEVIER IRELAND LTD
PI CLARE
PA ELSEVIER HOUSE, BROOKVALE PLAZA, EAST PARK SHANNON, CO, CLARE, 00000,
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   Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA HU6TU
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PT J
AU Weng, CH
   Friedman, C
   Rommel, CA
   Hurdle, JF
AF Weng, Chunhua
   Friedman, Carol
   Rommel, Casey A.
   Hurdle, John F.
TI A two-site survey of medical center personnel's willingness to share
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clinical data for research: implications for reproducible health NLP research

SO BMC MEDICAL INFORMATICS AND DECISION MAKING

LA English

DT Article

ID DE-IDENTIFICATION; SCIENCE; PRIVACY

AB BackgroundA shareable repository of clinical notes is critical for advancing natural language processing (NLP) research, and therefore a goal of many NLP researchers is to create a shareable repository of clinical notes, that has breadth (from multiple institutions) as well as depth (as much individual data as possible).MethodsWe aimed to assess the degree to which individuals would be willing to contribute their health data to such a repository. A compact e-survey probed willingness to share demographic and clinical data categories. Participants were faculty, staff, and students in two geographically diverse major medical centers (Utah and New York). Such a sample could be expected to respond like a typical potential participant from the general public who is given complete and fully informed consent about the pros and cons of participating in a research study.ResultsTwo thousand one hundred forty respondents completed the surveys. 56% of respondents were somewhat/definitely willing to share clinical data with identifiers, while 89% of respondents were somewhat (17%)/definitely willing (72%) to share without identifiers. Results were consistent across gender, age, and education, but there were some differences by geographical region. Individuals were most reluctant (50-74%) sharing mental health, substance abuse, and domestic violence data.ConclusionsWe conclude that a substantial fraction of potential patient participants, once educated about risks and benefits, would be willing to donate de-identified clinical data to a shared research repository. A slight majority even would be willing to share absent de-identification, suggesting that perceptions about data misuse are not a major concern. Such a repository of clinical notes should be invaluable for clinical NLP research and advancement.

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FU National Institutes of Health [R01LM010981, R01LM008635, R01LM009886, 5UL1TR001873-02, UL1 TR000040]
FX This work was supported by National Institutes of Health grants R01LM010981 (JFH), R01LM008635 (CF), R01LM009886 (CW), 5UL1TR001873-02 (MPR), and UL1 TR000040 (HG). The publication costs for this article were funded by the corresponding author's Departmental funds.

CR Amazon, AM MECH TURK SEC AM
[Anonymous], 2007, P WORKSH BIONLP 2007
CHCF, NAT CONS HLTH PRIV S
Corn M, 2009, J AM MED INFORM ASSN, V16, P1, DOI 10.1197/jamia.M2925
Darr DA, 2006, METHOD INFORM MED, V45, P246
Deleger L, 2014, J BIOMED INFORM, V50, P173, DOI 10.1016/j.jbi.2014.01.014
Ferrandez O, 2012, BMC MED RES METHODOL, V12, DOI 10.1186/1471-2288-12-109
Grande D, 2013, JAMA INTERN MED, V173, P1798, DOI 10.1001/jamainternmed.2013.9166
Huser V, 2014, J AM MED INFORM ASSN, V21, P8, DOI 10.1136/amiajnl-2013-002061
Malin B, 2010, J INVEST MED, V58, P11, DOI 10.2310/JIM.0b013e3181c9b2ea
NCVHS, REC PRIV CONF 2006 2
Ness RB, 2007, JAMA-J AM MED ASSOC, V298, P2164, DOI 10.1001/jama.298.18.2164
Ross JS, 2013, JAMA-J AM MED ASSOC, V309, P1355, DOI 10.1001/jama.2013.1299
Saeed M, 2002, COMPUT CARDIOL, V29, P641, DOI 10.1109/CIC.2002.1166854

```
   Stubbs Amber, 2015, J Biomed Inform, V58 Suppl, pS11, DOI
10.1016/j.jbi.2015.06.007
   Sullivan LM, 1996, STAT MED, V15, P477, DOI 10.1002/(SICI)1097-
0258(19960315)15:5<477::AID-SIM217>3.0.CO;2-R
   USDE, NEW RAC ETHN GUID CO
   Weitzman ER, 2012, BMC MED INFORM DECIS, V12, DOI 10.1186/1472-6947-12-39
   Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356
   Zulman DM, 2011, ANN INTERN MED, V155, P805, DOI 10.7326/0003-4819-155-12-
201112200-00002
NR 20
TC 0
Z9 0
U1 1
U2 1
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
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PT J
AU Chawinga, WD
   Zinn, S
AF Chawinga, Winner Dominic
   Zinn, Sandy
TI Global perspectives of research data sharing: A systematic literature
   review
SO LIBRARY & INFORMATION SCIENCE RESEARCH
LA English
DT Review
ID RESEARCH DATA-MANAGEMENT; BIODIVERSITY DATA; HEALTH DATA; SCIENCE;
   CHALLENGES; KNOWLEDGE; ACCESS; TRENDS; ETHICS
AB Studies investigating data sharing from a world perspective are seemingly
rare. By employing a quantitative design,this systematic review investigates and
presents a comprehensive account of factors hampering data sharing at three
levels of the global research hierarchy (individual, institutional and
international). The study analyses secondary data extracted from 105
publications (n=105). Journal publishers and research grant organisations are
key players in promoting data sharing activities by formulating, adopting and
implementing policies on data sharing. Despite concerted efforts to promote data
sharing, various factors frustrate these initiatives; they include lack of time
and data misappropriation (individual level); data sharing training, absence of
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compensation and unfavourable internal policies (institutional level); and weak policies, ethical and legal norms, lack of data infrastructure and interoperability issues (international level). To counter these challenges, there is a need for research stakeholders to recognise researchers who share data through data citations, acknowledgement and incentives; invest in infrastructure, conduct training and advocacy programs; formulate stringent and fair policies. Data sharing will only become a success if research stakeholders apply equal efforts in managing data to that of research publications in general. The study offers a unique and comprehensive account of factors hampering data sharing from a global perspective. Solutions suggested could be adopted by research stakeholders in their efforts to enhance data sharing activities at various research levels.

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CR Ahmed YA, 2019, TELEMAT INFORM, V37, P72, DOI 10.1016/j.tele.2018.01.015
Albert H, 2012, SPRINGER HEALTHC NEW, V1, P1, DOI [10.1007/s40014-012-1434-z, DOI 10.1007/S40014-012-1434-Z]
Anane-Sarpong E., 2017, DEV WORLD BIOETH, P1
Anderson James R, 2009, IRB, V31, P17
Bertzky M, 2009, J ENVIRON MANAGE, V90, P8, DOI 10.1016/j.jenvman.2007.11.001
Bezuidenhout L, 2013, SCI ENG ETHICS, V19, P83, DOI 10.1007/s11948-011-9298-7
Bishoff C., 2015, J LIBRARIANSHIP SCHO, V3, DOI 10.7710/2162-3309.1231
Bond-Lamberty B, 2018, J GEOPHYS RES-BIOGEO, V123, P1440, DOI 10.1002/2018JG004502
Borgman CL, 2012, J AM SOC INF SCI TEC, V63, P1059, DOI 10.1002/asi.22634
Brakewood B, 2013, NEUROIMAGE, V82, P671, DOI 10.1016/j.neuroimage.2013.02.040
Brettle A, 2009, EVID BASED LIB INF P, V4, P43, DOI 10.18438/B8N613
Brown S., 2015, DIRECTIONS RES DATA
Bull S, 2015, J EMPIR RES HUM RES, V10, P302, DOI 10.1177/1556264615594606
Burgi PY, 2017, IFLA J-INT FED LIBR, V43, P5, DOI 10.1177/0340035216678238
Cahill JM, 2007, NEAR EAST ARCHAEOL, V70, P194, DOI 10.2307/20361332
Chandramohan D, 2008, PLOS MED, V5, P169, DOI 10.1371/journal.pmed.0050057
Charbonneau Deborah H., 2013, Medical Reference Services Quarterly, V32, P365, DOI 10.1080/02763869.2013.807089
Chen XJ, 2017, J ACAD LIBR, V43, P346, DOI 10.1016/j.acalib.2017.06.006
Chigwada J., 2017, DATA SCI J, V16, P1, DOI [10.5334/dsj-2017-03, DOI 10.5334/DSJ-2017-03]
Chiware E. R. T., 2016, S AFRICAN J LIB INFO, V81, P1
Clement R, 2017, IFLA J-INT FED LIBR, V43, P105, DOI 10.1177/0340035216678239
Coady SA, 2013, TRIALS, V14, DOI 10.1186/1745-6215-14-201
Cohn JP, 2012, BIOSCIENCE, V62, P1004, DOI [10.1525/bio.2012.62.11.16, DOI 10.1525/BI0.2012.62.11.16, DOI 10.1525/BIO.2012.62.11.16]
Cook DJ, 1997, ANN INTERN MED, V126, P376, DOI 10.7326/0003-4819-126-5-199703010-00006
Cooper M, 2007, J EMPIR RES HUM RES, V2, P3, DOI 10.1525/JERHRE.2007.2.1.3
Corti L, 2014, MANAGING SHARING RES
Costello MJ, 2009, BIOSCIENCE, V59, P418, DOI 10.1525/bio.2009.59.5.9
Cragin MH, 2010, PHILOS T R SOC A, V368, P4023, DOI 10.1098/rsta.2010.0165
Curty R. G., 2015, THESIS
Curty RG, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0189288
Dai SQ, 2018, J GEOPHYS RES-BIOGEO, V123, P129, DOI 10.1002/2017JG004277
Davenport TH, 2012, HARVARD BUS REV, V90, P70
Delson E, 2007, EVOL ANTHROPOL, V16, P161, DOI 10.1002/evan.20141

Deng X., 2016, ECOSYST HEALTH SUST, V2, DOI [10.1002/ehs2, DOI 10.1002/EHS2]
Dillo I., 2013, INT J DIGITAL CURATI, V8, P229, DOI [DOI 10.2218/IJDC.V8I1.256, 10.2218/ijdc.v8i1.256]
Dong Rencai, 2016, Ecosystem Health and Sustainability, V2, DOI 10.1002/ehs2.1218
Dube L, 2003, MIS QUART, V27, P597
Elsayed AM, 2018, IFLA J-INT FED LIBR, V44, P281, DOI 10.1177/0340035218785196
Enke N, 2012, ECOL INFORM, V11, P25, DOI 10.1016/j.ecoinf.2012.03.004
European Commission, 2012, SCI DAT OP ACC RES R
Fecher B, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0118053
Fienberg S. E., 1985, SHARING RES DATA
Fisher JB, 2010, INFORM MANAGE-AMSTER, V47, P237, DOI 10.1016/j.im.2010.04.001
Friedlander A., 2006, STAND TEST TIME LONG
Fry J., 2008, IDENTIFYING BENEFITS
Glaeser P. S., 1990, SCI TECHNICAL DATA N
Guedon J. C, 2015, OPEN DATA SCI OPTIMI
Gupta Ashwaria, 2013, Perspect Clin Res, V4, P144, DOI 10.4103/2229-3485.111800
Haddow G, 2011, J EVAL CLIN PRACT, V17, P1140, DOI 10.1111/j.1365-2753.2010.01488.x
Harding A, 2012, ENVIRON HEALTH PERSP, V120, P6, DOI 10.1289/ehp.1103904
He Y., 2016, THESIS, DOI [10.13016/M2Z84M, DOI 10.13016/M2Z84M]
Heidorn PB, 2011, J LIBR ADM, V51, P662, DOI 10.1080/01930826.2011.601269
Heidorn PB, 2008, LIBR TRENDS, V57, P280
HIGGINS S, 2011, INT J DIGITAL CURATI, V2, P78
Housewright R., 2013, ITHAKA S R US FACULT
Houtkoop B. L, 2018, ADV METHODS PRACTICE, V1, P70, DOI DOI 10.1177/2515245917751886
Huang XL, 2013, BIOSCIENCE, V63, P5, DOI 10.1525/bio.2013.63.1.2
Huang XL, 2012, CONSERV LETT, V5, P399, DOI 10.1111/j.1755-263X.2012.00259.x
Jeng W., 2016, P 79 ASIS T ANN M CR
Kambatla K, 2014, J PARALLEL DISTR COM, V74, P2561, DOI 10.1016/j.jpdc.2014.01.003
Kaye J, 2018, HUM GENOMICS, V12, DOI 10.1186/s40246-018-0143-9
Kitchenham B., 2007, GUIDELINES PERFORMIN
Koltay T, 2017, J LIBR INF SCI, V49, P3, DOI 10.1177/0961000615616450
Koopman M. M, 2015, THESIS
Kostkova P, 2018, LIFE SCI SOC POLICY, V14, DOI 10.1186/s40504-018-0078-x
Kowalczyk S, 2011, ANNU REV INFORM SCI, V45, P247, DOI 10.1002/aris.2011.1440450113
Levenson D, 2010, AM J MED GENET A, V152A, pVII, DOI 10.1002/ajmg.a.33287
Matlatse R. L., 2016, THESIS
Matteson ML, 2011, REF USER SERV Q, V51, P172, DOI 10.5860/rusq.51n2.172
Mbuagbaw L, 2017, TRIALS, V18, DOI 10.1186/s13063-017-1816-8
McCullough BD, 2009, ECON ANAL POLICY, V39, P117, DOI 10.1016/S0313-5926(09)50047-1
McKibbon KA, 2006, LIBR TRENDS, V55, P202, DOI 10.1353/lib.2006.0049
Mennes M, 2013, NEUROIMAGE, V82, P683, DOI 10.1016/j.neuroimage.2012.10.064
Milia N, 2012, PLOS ONE, V7, DOI 10.1371/journal.pone.0037552
Moher D, 2009, ANN INTERN MED, V151, P264, DOI 10.7326/0003-4819-151-4-200908180-00135
Mundel T., 2014, KNOWLEDGE IS POWER S
Nelson B, 2009, NATURE, V461, P160, DOI 10.1038/461160a
Ngeno E. J, 2018, THESIS
Okoli C, 2010, SPROUTS WORKING PAPE, V10

Ostell J., 2009, HUM MUTAT, V30, pvii, DOI [10.1002/humu.21013, DOI 10.1002/HUMU.21013]
Parr CS, 2007, BIOSCIENCE, V57, P309, DOI 10.1641/B570402
Pearce N, 2011, ENVIRON HEALTH-GLOB, V10, DOI 10.1186/1476-069X-10-107
Peng Changhui, 2016, Ecosystem Health and Sustainability, V2, DOI 10.1002/ehs2.1225
Perrino T, 2013, PERSPECT PSYCHOL SCI, V8, P433, DOI 10.1177/1745691613491579
Pisani E, 2010, B WORLD HEALTH ORGAN, V88, P462, DOI 10.2471/BLT.09.074393
Pitt MA, 2013, TOP COGN SCI, V5, P214, DOI 10.1111/tops.12006
Piwowar HA, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0018657
Plengsaeng B, 2014, WATER INT, V39, P933, DOI 10.1080/02508060.2015.981783
Pryor G., 2012, MANAGING RES DATA
Rohlfing T, 2012, NEUROIMAGE, V59, P4189, DOI 10.1016/j.neuroimage.2011.09.080
Ross JS, 2016, SYST REV, V5, DOI 10.1186/s13643-016-0334-1
Rowhani-Farid Anisa, 2017, Res Integr Peer Rev, V2, P4, DOI 10.1186/s41073-017-0028-9
Rowhani-Farid A, 2016, BMJ OPEN, V6, DOI 10.1136/bmjopen-2016-011784
Royal Society, 2012, SCI OP ENT OP DAT OP
Sansone SA, 2012, GIGASCIENCE, V1, DOI 10.1186/2047-217X-1-10
Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078
Sayogo DS, 2013, GOV INFORM Q, V30, pS19, DOI 10.1016/j.giq.2012.06.011
Schmidt B, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0146695
Schopfel J, 2018, DATA TECHNOL APPL, V52, P248, DOI 10.1108/DTA-01-2017-0005
Schumacher J, 2015, INT J DIGITAL CURATI, V10, P96
Shakeri S., 2013, THESIS
Sheather J, 2009, BRIT MED J, V338, DOI 10.1136/bmj.b2160
Specht A, 2015, SCI TOTAL ENVIRON, V534, P144, DOI 10.1016/j.scitotenv.2015.03.092
Steen RG, 2011, J MED ETHICS, V37, P249, DOI 10.1136/jme.2010.040923
Takashima K, 2018, BMC MED ETHICS, V19, DOI 10.1186/s12910-018-0310-5
Teeters JL, 2008, NEUROINFORMATICS, V6, P47, DOI 10.1007/s12021-008-9009-y
Tenopir C, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0021101
Tucker J., 2009, THESIS
Ullah A, 2018, LIBR INFORM SCI RES, V40, P53, DOI 10.1016/j.lisr.2018.03.002
Van Horn JD, 2013, NEUROIMAGE, V82, P677, DOI 10.1016/j.neuroimage.2012.11.010
Volk CJ, 2014, ENVIRON MANAGE, V53, P883, DOI 10.1007/s00267-014-0258-2
Wallis JC, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067332
Walters T., 2011, NEW ROLES NEW TIMES
Watson M, 2015, GENOME BIOL, V16, DOI 10.1186/s13059-015-0669-2
Wicherts JM, 2012, INTELLIGENCE, V40, P73, DOI 10.1016/j.intell.2012.01.004
Wiley Christie, 2018, Science & Technology Libraries, V37, P409, DOI 10.1080/0194262X.2018.1516596
Wittenberg J, 2017, IFLA J-INT FED LIBR, V43, P89, DOI 10.1177/0340035216686982
Woolfrey L., 2009, THESIS
Yoon A., 2015, THESIS
Yoon A, 2017, COLL RES LIBR, V78, P920, DOI 10.5860/crl.78.7.920
Zimmerman AS, 2008, SCI TECHNOL HUM VAL, V33, P631, DOI 10.1177/0162243907306704
Zvyagintseva L., 2015, THESIS, DOI [10.7939/R3M66S, DOI 10.7939/R3M66S]
NR 122
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AU Katsanis, SH
   Huang, E
   Young, A
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   Warner, E
   Larson, S
   Wagner, JK
AF Katsanis, Sara H.
   Huang, Elaine
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TI Caring for trafficked and unidentified patients in the EHR shadows:
   Shining a light by sharing the data
SO PLOS ONE
LA English
DT Article
ID HEALTH-CARE; GENOMICS; IDENTIFICATION; INCLUSION; DIVERSITY; MEDICINE
AB Objective
   Healthcare providers have key roles in the prevention of, detection of, and
interventions for human trafficking. Yet caring for trafficked persons is
particularly challenging: patients whose identities are unknown, unreliable, or
false could receive subpar care from providers delivering care in a vacuum of
relevant information. The application of precision medicine principles and
integration of biometric data (including genetic information) could facilitate
patient identification, enable longitudinal medical records, and improve
continuity and quality of care for this vulnerable patient population. Scant
empirical data exist regarding healthcare system preparedness and care for the
needs of this vulnerable population nor data on perspectives on the use and
risks of biometrics or genetic information for trafficked patients.
   Methods
   To address this gap, we conducted mixed-methods research involving semi-
structured interviews with key informants, which informed a subsequent broad
survey of physicians and registered nurses.
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Results

Our findings support the perception that trafficked persons obtain care yet remain unnoticed or undocumented in the electronic health record. Our survey findings further reveal that healthcare providers remain largely unaware of human trafficking issues and are inadequately prepared to provide patient-centered care for trafficked and unidentified patients.

Conclusion

Meaningful efforts to design and implement precision medicine initiatives in an inclusive way that optimizes impacts are unlikely to succeed without concurrent efforts to increase general awareness of and preparedness to care for trafficked persons. Additional research is needed to examine properly the potential utility for biometrics to improve the delivery of care for trafficked patients.

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CR Ahn R, 2013, AM J PREV MED, V44, P283, DOI 10.1016/j.amepre.2012.10.025
American Hospitals Association (AHA), 2018, NCHS APPR 1 ICD 10 C
[Anonymous], 2015, BEST PRACT RESC TRAF
[Anonymous], SOAR HLTH WELLN TRAI
Auffray C, 2010, GENOME MED, V2, DOI 10.1186/gm178
Baldwin SB, 2011, HEALTH HUM RIGHTS, V13, P36
Basavatia A, 2016, CUREUS, V8, DOI 10.7759/cureus.492
Bentley AR, 2017, J COMMUN GENET, V8, P255, DOI 10.1007/s12687-017-0316-6
Bespalova N, 2016, ACAD PSYCHIATR, V40, P124, DOI 10.1007/s40596-014-0245-1
Cheshire William Polk Jr, 2017, AMA J Ethics, V19, P91, DOI 10.1001/journalofethics.2017.19.1.msoc3-1701
Chisolm-Straker M, 2016, J HEALTH CARE POOR U, V27, P1220, DOI 10.1353/hpu.2016.0131
Cornel MC, 2017, J COMMUN GENET, V8, P249, DOI 10.1007/s12687-017-0333-5
Ferris S., 2015, STREET SEX WORK CANA
Grace AM, 2014, PEDIATR EMERG CARE, V30, P856, DOI 10.1097/PEC.0000000000000287
Hemmings S, 2016, BMC HEALTH SERV RES, V16, DOI 10.1186/s12913-016-1538-8
Hindorff LA, 2018, NAT REV GENET, V19, P175, DOI 10.1038/nrg.2017.89
Hood LA, 2008, PHYS BIOL ATOMS MED, P337
Hood L, 2012, NEW BIOTECHNOL, V29, P613, DOI 10.1016/j.nbt.2012.03.004
Hood L, 2011, NAT REV CLIN ONCOL, V8, P184, DOI 10.1038/nrclinonc.2010.227
Huang E, 2017, J LAW BIOSCI, V4, P159, DOI 10.1093/jlb/lsw064
Judge AM, 2018, ANN INTERN MED, V168, P658, DOI 10.7326/M17-2605
Karan A, 2017, HUMAN TRAFFICKING MU
Katsanis SH, 2017, INT J CRIM JUSTICE S, V12, P111, DOI 10.5281/zenodo.345720
Katsanis Sara H, 2014, Recent Adv DNA Gene Seq, V8, P78
Khoury MJ, 2012, AM J PREV MED, V42, P639, DOI 10.1016/j.amepre.2012.02.012

Lederer L, 2014, ANN HLTH LAW, V23, P61
Macias-Konstantopoulos Wendy L, 2017, AMA J Ethics, V19, P80, DOI 10.1001/journalofethics.2017.19.1.msoc2-1701
Makary MA, 2016, BMJ-BRIT MED J, V353, DOI 10.1136/bmj.i2139
Michele Gilman, 2018, NYU REV L SOC CHANGE, V42, P255
Michele Gilman, 2018, NYU REV L SOC CHANGE, V42, P253
National Human Trafficking Resource Center, 2015, 11201512312015 NHTRC
National Human Trafficking Resource Center (NHTRC), 2010, WHAT LOOK HEALTHC SE
Pato J. N., 2010, BIOMETRIC RECOGNITIO
Popejoy AB, 2016, NATURE, V538, P161, DOI 10.1038/538161a
Powell C, 2017, MED EDUC ONLINE, V22, DOI 10.1080/10872981.2017.1267980
Sinha R, 2018, J HUMAN TRAFFICKING, P1
United Nations Office on Drugs and Crime, 2000, PROT PREV SUPPR PUN
US Department of State Office to Monitor and Combat Trafficking in Persons, 2016, OFF MON COMB TRAFF P
US Department of State Office to Monitor and Combat Trafficking in Persons, 2017, OFF MON COMB TRAFF P
US Department of State Office to Monitor and Combat Trafficking in Persons, 2014, OFF MON COMB TRAFF P
Wagner JK, 2017, GENET MED, V19, P620, DOI 10.1038/gim.2016.165
Wang L., 2012, International Journal of Information Technology and Management, V11, P72, DOI 10.1504/IJITM.2012.044065
Weston AD, 2004, J PROTEOME RES, V3, P179, DOI 10.1021/pr0499693
Williamson E, 2009, NAT S HLTH NEEDS HUM
Zimmerman C, 2011, SOC SCI MED, V73, P327, DOI 10.1016/j.socscimed.2011.05.028
NR 45
TC 0
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AU Chiauzzi, E
AF Chiauzzi, Emil
TI DEMOCRATIZING DATA: WHAT HAPPENS WHEN MEMBERS OF AN ONLINE NETWORK SHARE

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   THEIR MENTAL HEALTH DATA WITH EACH OTHER?
SO ANNALS OF BEHAVIORAL MEDICINE
LA English
DT Meeting Abstract
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PT J
AU Holleman, MS
   Uyl-de Groot, CA
   Goodall, S
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AF Holleman, Marscha S.
   Uyl-de Groot, Carin A.
   Goodall, Stephen
   van der Linden, Naomi
TI Determining the Comparative Value of Pharmaceutical Risk-Sharing
   Policies in Non-Small Cell Lung Cancer Using Real-World Data
SO VALUE IN HEALTH
LA English
DT Article
ID PERFORMANCE; ARRANGEMENTS; UNCERTAINTY; FRAMEWORK; SCHEMES
AB Background: Risk-sharing arrangements (RSAs) can be used to mitigate
uncertainty about the value of a drug by sharing the financial risk between
payer and pharmaceutical company. We evaluated the projected impact of
alternative RSAs for non-small cell lung cancer (NSCLC) therapies based on real-
world data. Methods: Data on treatment patterns of Dutch NSCLC patients from
four different hospitals were used to perform "what-if" analyses, evaluating the
costs and benefits likely associated with various RSAs. In the scenarios, drug
costs or refunds were based on response evaluation criteria in solid tumors
(RECIST) response, survival compared to the pivotal trial, treatment duration,
or a fixed cost per patient. Analyses were done for erlotinib,
gemcitabine/cisplatin, and pemetrexed/platinum for metastatic NSCLC, and
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gemcitabine/cisplatin, pemetrexed/cisplatin, and vinorelbine/cisplatin for nonmetastatic NSCLC. Results: Money-back guarantees led to moderate cost reductions to the payer. For conditional treatment continuation schemes, costs and outcomes associated with the different treatments were dispersed. When price was linked to the outcome, the payer's drug costs reduced by 2.5% to 26.7%. Discounted treatment initiation schemes yielded large cost reductions. Utilization caps mainly reduced the costs of erlotinib treatment (by 16%). Given a fixed cost per patient based on projected average use of the drug, risk sharing was unfavorable to the payer because of the lower than projected use. The impact of RSAs on a national scale was dispersed. Conclusions: For erlotinib and pemetrexed/platinum, large cost reductions were observed with risk sharing. RSAs can mitigate uncertainty around the incremental cost-effectiveness or budget impact of drugs, but only when the type of arrangement matches the setting and type of uncertainty. Copyright (c) 2019, ISPOR-The Professional Society for Health Economics and Outcomes Research. Published by Elsevier Inc.

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CR Adamski J, 2010, BMC HEALTH SERV RES, V10, DOI 10.1186/1472-6963-10-153
[Anonymous], 2007, LANCET ONCOL, V8, P561
Cardenal F, 1999, J CLIN ONCOL, V17, P12, DOI 10.1200/JCO.1999.17.1.12
Carlson JJ, 2010, HEALTH POLICY, V96, P179, DOI 10.1016/j.healthpol.2010.02.005
Chouaid C, 2013, J THORAC ONCOL, V8, P997, DOI 10.1097/JTO.0b013e318299243b
Dutch National Health Care Institute (ZIN), 2006, ERL TARC BIJ LOK GEV, V2017
Dutch National Health Care Institute (ZIN), 2006, VIN NAV NAV BIJ GEM, V2017
Dutch National Health Care Institute (ZIN), 2016, PEM AL BIJ LOK GEV G, V2017
Dutch National Health Care Institute (ZIN), 2009, PEM AL BIJ NIETKL LO, V2017
Garrison LP, 2013, VALUE HEALTH, V16, P703, DOI 10.1016/j.jval.2013.04.011
Green C, 2009, HEALTH TECHNOL ASSES, V13, P29, DOI 10.3310/hta13suppl1/05
Gregson N, 2005, NAT REV DRUG DISCOV, V4, P121, DOI 10.1038/nrd1633
Kim Hansoo, 2018, J Pharm Policy Pract, V11, P4, DOI 10.1186/s40545-018-0131-4
Mullins CD, 2010, ONCOLOGIST, V15, P58, DOI 10.1634/theoncologist.2010-S1-58
National Institute for Health and Clinical Excellence, 2017, BORT MON REL MULT MY, V2007
National Institute for Health and Clinical Excellence, 2017, SUN 1 LIN TREATM ADV, V2009
National Institute for Health and Clinical Excellence, 2008, RAN PEG TREATM AG RE, V2017
National Institute for Health and Clinical Excellence, 2017, LEN TREAT MYEL SYNDR, V2014
National Institute for Health and Clinical Excellence, 2010, FIN APPR DET GEF 1 L, V2017
Navarria A, 2015, VALUE HEALTH, V18, P131, DOI 10.1016/j.jval.2014.09.007
Paris V, 2014, VALUE PHARM PRICING
Pharmaceutical Benefits Scheme (PBS), 2013, PUBL SUMM DOC IV, V2018
Towse A, 2010, PHARMACOECONOMICS, V28, P93, DOI 10.2165/11314080-000000000-00000
van den Hout WB, 2006, J NATL CANCER I, V98, P1786, DOI 10.1093/jnci/djj496
van der Linden N, 2016, LUNG CANCER, V91, P79, DOI 10.1016/j.lungcan.2015.10.015
van der Linden N, 2017, CLIN LUNG CANCER, V18, pE341, DOI 10.1016/j.cllc.2015.11.011

```
   Walker S, 2012, VALUE HEALTH, V15, P570, DOI 10.1016/j.jval.2011.12.013
   Wlodarczyk JH, 2006, PHARMACOECONOMICS, V24, P903, DOI 10.2165/00019053-
200624090-00007
   Yeung K, 2017, J MANAG CARE SPEC PH, V23, P1010, DOI
10.18553/jmcp.2017.23.10.1010
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