Public-private share in maternal health care services utilization in India: A multinomial logistic regression analysis from three consecutive survey data

Background: The Antenatal care and institutional delivery to improve maternal and child health is the prime focus of the time. India, with its large economic diversity, the health care utilization may depend on type of service provider i.e. public or private. The present study estimates the trends in the utilization of public and private maternal health care services and the associated socio-demographic factors, the major focus being Antenatal care and skilled delivery.

Methodology: The present population based cross-sectional analysis is performed on the secondary data of India from three rounds of District Level Household Survey (DLHS) conducted in 1998-99, 2002-04 and 2007-08. Indicators for maternal health care utilization are based on full antenatal check up (FANC) as defined by RCH program and skilled institutional delivery attendance (SID) as defined by WHO by the mode of service provider (Public vs Private). Multinomial logistic regression was used for statistical analysis by considering these indicators as the outcome variables treating various socio-demographic factors as independent variables.

Result: The urban area, other than SC/ST caste, higher wealth index and more than 10 years of mother's & father's education have high proportion of maternal health care utilization. Lower parent's education have shown lower relative risk ratio of FANC and SID accessibility throughout the survey periods. Wealth indices as a factor of FANC and SID are observed higher in private sectors as compared to public sectors during second and third survey. Women with more pregnancy related problem have chosen private sector for their institutional delivery during all the survey periods. Maternal health programme related initiatives such as when health worker visit for antenatal care and women counselled to go for institutional delivery have shown improvement in terms of accessibility.

Conclusion: This study used multinomial logistic regression which attempts to integrate the different socio-economic and demographic factors as well as maternal health related program initiatives by mode of service provider. The analysis strongly brings out the preference for public sector and private sector for seeking maternal services mainly depends on the various socio-economic characterises. Program initiatives clearly demonstrate that accessibility is higher for public sector. However, the improvement in the public sector is stagnating beyond a point across India. Public-private partnership needs to be
explored by keeping in mind that the efforts are to be directed more for deprived section of the society. (C) 2017 Published by Elsevier, a division of RELX India, Pvt. Ltd on behalf of INDIACLLEN.

Chatterjee M., 1990, INDIAN WOMEN THEIR H

Das NP, 2001, NATL FAMILY HLTH SUR


Chatterjee M., 1990, INDIAN WOMEN THEIR H

Das NP, 2001, NATL FAMILY HLTH SUR

Funding agencies encourage and sometimes require data sharing. However, there is limited empirical research on participant perspectives on sharing de-identified data from research on sensitive topics (e.g., HIV, sexual health) with other researchers, and virtually none from adolescents or sexual and gender minority (SGM) participants. SGM teens (N=197) ages 14-17 completed an online survey with multiple-choice and open-ended items assessing perspectives toward sharing survey responses and blood samples from sexual health and HIV testing studies with other researchers. SGM youth were willing to share data but frequently cited confidentiality and privacy concerns, including fears about parents finding out about their identities even after de-identification was explained. Researchers need to ensure youth understand explanations of data security protections in order to make well-informed decisions about participating in research.
Health under award R01MD009561 (PIs: Mustanski & Fisher). The content is solely the responsibility of the authors and does not necessarily represent the views of the funding agencies.

CR [Anonymous], 2003, FIN NIH STAT SHAR RE
Braun V., 2006, QUALITATIVE RES PSYC, V3, P77, DOI DOI 10.1191/1478088706QP0630A
De Vries RG, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0159113
Diclemente RJ, 2010, JAIDS - J ACQ IMM DEF, V54, pS12, DOI 10.1097/QAI.0b013e3181e1e2c0
Fisher CB, 2003, ETHICS BEHAV, V13, P303, DOI 10.1207/s15327019eb1304_1
Fisher CB, 2018, PLOS ONE, V13, DOI 10.1371/journal.pone.0200560
Fisher CB, 2010, J EMPIR RES HUM RES, V5, P65, DOI 10.1525/jer.2010.5.2.65
Fisher Celia B, 2008, IRB, V30, P1
Freimuth VS, 2001, SOC SCI MED, V52, P797, DOI 10.1016/S0277-9536(00)00178-7
Gonsiorek J. C., 1991, HOMOSEXUALITY RES IM, P115
HALDEMAN DC, 1994, J CONSULT CLIN PSYCH, V62, P221, DOI 10.1037/01.mlr.01.mlr.0022-006X.62.2.221
Hall MA, 2006, MED CARE, V44, P1048, DOI 10.1097/01.mlr.0000228023.37087.cb
Herek G. M., 1998, STIGMA SEXUAL ORIENT, V4, P223
Jones J. H., 1981, BAD BLOOD TUSKEGEE S
Lemke AA, 2010, PUBLIC HEALTH GENOM, V13, P368, DOI 10.1159/000276767
McGuire AL, 2011, GENET MED, V13, P948, DOI 10.1097/GIM.0b013e3182227589
Meyer M. N, 2018, ADV METHODS PRACTICE, V1, P131, DOI 10.1177/2515245917747656
National Institutes of Health, 2018, NIH DAT SHAR POL
Oliver JM, 2012, PUBLIC HEALTH GENOM, V15, P106, DOI 10.1159/000334718
Rhodes SD, 2016, AIDS EDUC PREV, V28, P191, DOI 10.1521/aeap.2016.28.3.191
Shavers VL, 2002, ANN EPIDEMIOL, V12, P248, DOI 10.1016/S1047-2797(01)00265-4

NR 40
TC 0
Z9 0
U1 3
U2 3
PU SPRINGER
PI NEW YORK
Data Lakes, Clouds, and Commons: A Review of Platforms for Analyzing and Sharing Genomic Data

AB Data commons collate data with cloud computing infrastructure and commonly used software services, tools, and applications to create biomedical resources for the large-scale management, analysis, harmonization, and sharing of biomedical data. Over the past few years, data commons have been used to analyze, harmonize, and share large-scale genomics datasets. Data ecosystems can be built by interoperating multiple data commons. It can be quite labor intensive to curate, import, and analyze the data in a data commons. Data lakes provide an alternative to data commons and simply provide access to data, with the data curation and analysis deferred until later and delegated to those that access the data. We review software platforms for managing, analyzing, and sharing genomic data, with an emphasis on data commons, but also cover data ecosystems and data lakes.

C1 [Grossman, Robert L.] Univ Chicago, Ctr Translat Data Sci, 900 East 57th St,KCBD 10142, Chicago, IL 60637 USA.
RP Grossman, RL (reprint author), Univ Chicago, Ctr Translat Data Sci, 900 East 57th St,KCBD 10142, Chicago, IL 60637 USA.
EM robert.grossman@uchicago.edu
FU NCI, NIH [17X053, 14X050, HHSN261200800001E]
FX This project has been funded in part with federal funds from the NCI, NIH, task order 17X053 and task order 14X050 under contract 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.
CR Afgan E, 2011, NAT BIOTECHNOL, V29, P972, DOI 10.1038/nbt.2028
Alterovitz G., 2018, 191783 BIORXIV
Amstutz P., 2016, COMMON WORKFLOW LANG
Armbrust Michael, 2009, UCBEECS200928
Wilbanks J, 2016, NAT BIOTECHNOL, V34, P377, DOI 10.1038/nbt.3516
Wilkinson M. D., 2017, 225490 BIORXIV
Wilkinson MD, 2016, SCI DATA, V3, DOI 10.1038/sdata.2016.18
Yung C. K., 2017, CANC GENOME COLLABOR

NR 62
TC 0
Z9 0
U1 3
U2 3
PU ELSEVIER SCIENCE LONDON
PI LONDON
PA 84 THEOBALDS RD, LONDON WC1X 8RR, ENGLAND
SN 0168-9525
EI 1362-4555
J9 TRENDS GENET
JI Trends Genet.
PD MAR
PY 2019
VL 35
IS 3
BP 223
EP 234
PG 12
WC Genetics & Heredity
SC Genetics & Heredity
GA HL1CE
UT WOS:000458430700006
PM 30691868
OA Other Gold
DA 2019-08-06
ER

PT J
AU Minicuci, N
Naidoo, N
Corso, B
Rocco, I
Chatterji, S
Kowal, P
AF Minicuci, Nadia
Naidoo, Nirmala
Corso, Barbara
Rocco, Ilaria
Chatterji, Somnath
Kowal, Paul
TI Data Resource Profile: Cross-national and cross-study sociodemographic and health-related harmonized domains from SAGE plus CHARLS, ELSA, HRS, LASI and SHARE (SAGE+ Wave 2)
SO INTERNATIONAL JOURNAL OF EPIDEMIOLOGY
LA English
DT Article
ID COHORT PROFILE; RETIREMENT

C1 [Minicuci, Nadia; Corso, Barbara; Rocco, Ilaria] CNR, Neurosci Inst, Padua, Italy.


[Kowal, Paul] Univ Newcastle, Res Ctr Generat Hlth & Ageing, Callaghan, NSW, Australia.


EM paul.r.kowal@rihes.org

FU US National Institute on Aging [R21AG034263]; WHO; Division of Behavioral and Social Research (BSR) at the National Institute on Aging (NIA) [OGHA 04034785, YA1323-08-CN-0020, Y1-AG-1005-01]; government of China; government of Ghana; government of South Africa; [R01AG034479]

FX SAGE+ Wave 2 was supported by the US National Institute on Aging through grant R21AG034263, 'Harmonizing health outcomes and determinants across longitudinal studies on aging'. SAGE is supported by WHO and the Division of Behavioral and Social Research (BSR) at the National Institute on Aging (NIA) through Interagency Agreements (OGHA 04034785; YA1323-08-CN-0020; Y1-AG-1005-01) with WHO, and Research Project Grant R01AG034479. In addition, the governments of China, Ghana and South Africa have provided financial or other support for their national studies.

CR Ahmad OB, 2001, NEW WHO STANDARD GPE, V31
Arokiasamy P, 2012, AGING ASIA FINDINGS
International Household Survey Network, 2012, MET STAND IHSN TECHN
Background: Comparing gene expression profiles using gene expression datasets of different types of tumors is frequently used to identify molecular mechanisms of cancer. This study aimed to find shared and type specific gene expression profiles of hepatocellular carcinoma (HCC) and B-cell chronic lymphocytic leukemia (B-CLL).

Material and methods: Gene expression microarrays for HCC and B-CLL and RNA-sequencing expression data for liver HCC and lymphoid neoplasm diffuse large B-cell lymphoma (DLBCL) were analyzed and differentially expressed probe sets or genes for each cancer type were detected. Probe sets and genes that were shared or specifically expressed in both cancer types were identified. Kyoto Encyclopedia of Genes and Genomes (KEGG) pathway and Gene Ontology (GO) terms for Biological Process (BP) annotations were performed.

Results: According to our analysis shared upregulated genes were mainly annotated in cell cycle processes. Some of the genes that changed only in HCC were annotated in cell cycle and metabolic processes, and some of the genes, altered only in B-CLL, were annotated in immune response and hemopoiesis.

Conclusion: These results contribute to cancer research that aim to find the conserved gene expression profiles in different cancer types and widen the knowledge of HCC and B-CLL specific mechanisms.
We previously demonstrated how sharing of rare variants (RVs) in distant affected relatives can be used to identify variants causing a complex and heterogeneous disease. This approach tested whether single RVs were shared by all sequenced affected family members. However, as with other study designs, joint analysis of several RVs (e.g., within genes) is sometimes required to obtain sufficient statistical power. Further, phenocopies can lead to false negatives for some causal RVs if complete sharing among affected is required.

Here, we extend our methodology (Rare Variant Sharing, RVS) to address these issues. Specifically, we introduce gene-based analyses, a partial sharing test based on RV sharing probabilities for subsets of affected relatives and a haplotype-based RV definition. RVS also has the desirable feature of not requiring external estimates of variant frequency or control samples, provides functionality to assess and address violations of key assumptions, and is available as open source software for genome-wide analysis. Simulations including phenocopies, based on the families of an oral cleft study, revealed the partial and complete sharing versions of RVS achieved similar statistical power compared with alternative methods (RareIBD and the Gene-Based Segregation Test), and had superior power compared with the pedigree Variant Annotation, Analysis, and Search Tool (pVAAST) linkage statistic. In studies of multiplex cleft families, analysis of rare single nucleotide variants in the exome of 151
affected relatives from 54 families revealed no significant excess sharing in any one gene, but highlighted different patterns of sharing revealed by the complete and partial sharing tests.

C1 [Bureau, Alexandre] Univ Laval, Dept Med Sociale & Prevent, Quebec City, PQ G1V 0A6, Canada.

[Bureau, Alexandre] Ctr Rech CERVO, Quebec City, PQ, Canada.

[Begum, Perdouse; Hetmanski, Jacqueline B.; Beatty, Terri H.] Johns Hopkins Bloomberg Sch Publ Hlth, Dept Epidemiol, Baltimore, MD USA.

[Taub, Margaret A.; Ruczinski, Ingo] Johns Hopkins Bloomberg Sch Publ Hlth, Dept Biostat, Baltimore, MD USA.

[Parker, Margaret M.] Harvard Med Sch, Channing Div Network Med, Boston, MA USA.


[Scott, Alan F.] Johns Hopkins Bloomberg Sch Publ Hlth, Dept Biostat, Baltimore, MD USA.


[Bailey-Wilson, Joan E.] NHGRI, Inherited Dis Res Branch, Baltimore, MD USA.

RP Bureau, A (reprint author), Univ Laval, Dept Med Sociale & Prevent, Quebec City, PQ G1V 0A6, Canada.

EM alexandre.bureau@fmed.ulaval.ca

OI Bureau, Alexandre/0000-0001-9220-9999; Bailey-Wilson, Joan/0000-0002-9153-2920

FU Canadian Statistical Sciences Institute; National Institutes of Health [U01-DE-018993, P50-DE-016215, R01-DE-009886, R01-DE-016148, R03-DE-02579, R37-DE-08559, U01 DE020073, R01-DE-014581, U01-DE024425]; Center for Inherited Disease Research [X01HG006177]; NIH [HHSN268200782096C]

FX Canadian Statistical Sciences Institute, Grant/Award Number: Collaborative Research Team 8; National Institutes of Health, Grant/Award Numbers: U01-DE-018993, P50-DE-016215, R01-DE-009886, R01-DE-016148, R03-DE-02579, R37-DE-08559, U01 DE020073, R01-DE-014581, U01-DE024425; Center for Inherited Disease Research, Grant/Award Number: X01HG006177; NIH to Johns Hopkins University, Grant/Award Number: HHSN268200782096C


Altschuler DM, 2015, NATURE, V526, P68, DOI 10.1038/nature15393

Bamshad MJ, 2011, NAT REV GENET, V12, P745, DOI 10.1038/nrg3031


Dahl M, 2001, CLIN CHEM, V47, P56


Fu WQ, 2013, NATURE, V493, P216, DOI 10.1038/nature11690

Holzinger ER, 2017, MOL GENET GENOM MED, V5, P570, DOI 10.1002/mg3.320

Hu H, 2014, NAT BIOTECHNOL, V32, P663, DOI 10.1038/nbt.2895


Isobe N, 2013, GENES IMMUN, V14, P434, DOI 10.1038/gene.2013.37

Johnston JJ, 2012, AM J HUM GENET, V91, P97, DOI 10.1016/j.ajhg.2012.05.021

Lee S, 2014, AM J HUM GENET, V95, P5, DOI 10.1016/j.ajhg.2014.06.009


Li BS, 2008, AM J HUM GENET, V83, P311, DOI 10.1016/j.ajhg.2008.06.024

Mescheriakova J. Y., 2016, MULT SCLER J, V2

MIKI Y, 1994, SCIENCE, V266, P66, DOI 10.1126/science.7545954

Ng SB, 2010, NAT GENET, V42, P30, DOI 10.1038/ng.499

O'Connell J, 2014, PLOS GENET, V10, DOI 10.1371/journal.pgen.1004234
Risch N, 1990, AM J HUM GENET, V46, P222
Sherman T., 2018, DETECTION RARE DIS V

JG Genetics & Heredity; Mathematical & Computational Biology
SC Genetics & Heredity; Mathematical & Computational Biology

PT J
AU Pisani, AR
Kanuri, N
Filbin, B
Gallo, C
Gould, M
Lehmann, LS
Levine, R
Marcotte, JE
Pascal, B
Rousseau, D
Turner, S
Yen, S
Ranney, ML

AF Pisani, Anthony R.
Kanuri, Nitya
Filbin, Bob
Gallo, Carlos
Gould, Madelyn
Lehmann, Lisa Soleymani
Data sharing between technology companies and academic health researchers has multiple health care, scientific, social, and business benefits. Many companies remain wary about such sharing because of unaddressed concerns about ethics, data security, logistics, and public relations. Without guidance on these issues, few companies are willing to take on the potential work and risks involved in noncommercial data sharing, and the scientific and societal potential of their data goes unrealized. In this paper, we describe the 18-month long pilot of a data-sharing program led by Crisis Text Line (CTL), a not-for-profit technology company that provides a free 24/7 text line for people in crisis. The primary goal of the data-sharing pilot was to design, develop, and implement a rigorous framework of principles and protocols for the safe and ethical sharing of user data. CTL used a stakeholder-based policy process to develop a feasible and ethical data-sharing program. The process comprised forming a data ethics committee; identifying policy challenges and solutions; announcing the program and generating interest; and revising the policy and launching the program. Once the pilot was complete, CTL examined how well the program ran and compared it with other potential program models before putting in place the program that was most suitable for its organizational needs. By drawing on CTL's experiences, we have created a 3-step set of guidelines for other organizations that wish to develop their own data-sharing program with academic researchers. The guidelines explain how to (1) determine the value and suitability of the data and organization for creating a data-sharing program; (2) decide on an appropriate data sharing and collaboration model; and (3) develop protocols and technical solutions for safe and ethical data sharing and the best organizational structure for implementing the program. An internal evaluation determined that the pilot satisfied CTL's goals of sharing scientific data and protecting client confidentiality. The policy development process also yielded key principles and protocols regarding the ethical challenges involved in data sharing that can be applied by other organizations. Finally, CTL's internal review of the pilot program developed a number of alternative models for sharing data that will suit a range of organizations with different priorities and capabilities. In implementing and studying this pilot program, CTL aimed both to optimize its own future data-sharing programs and to inform similar decisions made by others. Open data programs are both important and feasible to establish. With careful planning and appropriate resources, data sharing between big data companies and academic researchers can advance their shared mission to benefit society and improve lives.

C1 [Pisani, Anthony R.] Univ Rochester, Med Ctr, Dept Psychiat, 300 Crittenden Blvd, Box PSYCH, Rochester, NY 14642 USA.

[Pisani, Anthony R.] Univ Rochester, Med Ctr, Dept Pediat, Rochester, NY 14642 USA.

[Kanuri, Nitya] Yale Univ, Yale Sch Management, New Haven, CT USA.
The authors would like to dedicate this paper to the memory of Dr Shalon M Irving. The authors gratefully acknowledge support from the Robert Wood Johnson Foundation. The views expressed do not necessarily reflect the views of the Foundation. The authors would also like to acknowledge the support of the American Foundation for Suicide Prevention grant Youth Who Text a Crisis Line: Understanding Needs and Help-seeking [SRG-0-110-15]; National Institute of Mental Health [K23MH101449, K23MH098566]; National Institute on Drug Abuse [DA027828].

The authors thank Paul Scade for assistance with manuscript preparation.
Public participation, trust and data sharing: gardens as hubs for citizen science and environmental health literacy efforts

Gardenroots: A Citizen Science Project (2015) is the product of a needs assessment, revealing environmental quality concerns of gardeners living near hazardous waste or resource extraction activities. Participants were trained, collected garden samples for analysis, and later received their data visualized (individual and aggregated) via community events or mail. This article describes participant motivations, changes in knowledge and efficacy, and whether these depend on the mode of data sharing and visualization. Motivations were internal, and self-efficacy increased, while knowledge and satisfaction were higher in event attendees due to increased researcher contact. This reveals importance of data-sharing events, data visualizations, and participatory research processes.

C1 [Sandhaus, Shana; Ramirez-Andreetta, Monica] Univ Arizona, Dept Soil Water & Environm Sci, Tucson, AZ 85721 USA.

[Kaufmann, Dorsey] Univ Arizona, Sch Art, Tucson, AZ 85721 USA.

[Ramirez-Andreetta, Monica] Univ Arizona, Coll Publ Hlth, Div Community Environm & Policy, Tucson, AZ 85721 USA.
RP Ramirez-Andreotta, M (reprint author), Univ Arizona, 1177 E Fourth St, Rm 429, Tucson, AZ 85721 USA.
EM mdramire@email.arizona.edu
OI Ramirez-Andreotta, Monica/0000-0001-6220-5763
FU National Institute of Environmental Health Sciences Superfund Research Program [P42ES04940]; French National Center for Scientific Research's Device for Interdisciplinary Research on Human-Environment Interaction Laboratories; Center for Environmentally Sustainable Mining - TRIF; National Science Foundation Division of Research on Learning [DRL-1612554]
FX This work was supported by National Institute of Environmental Health Sciences Superfund Research Program: [grant number P42ES04940]; French National Center for Scientific Research's Device for Interdisciplinary Research on Human-Environment Interaction Laboratories; Center for Environmentally Sustainable Mining - TRIF; National Science Foundation Division of Research on Learning [grant number DRL-1612554].
CR ARTIOLA J.F., 2004, ENV MONITORING CHARA
Bandura A., 1997, SELF EFFICACY EXERCI
Boronow KE, 2017, ENVIRON HEALTH PERSP, V125, pA27, DOI 10.1289/EHP702
Brand E., 2007, CSOIL 2000 EXPOSURE
Cairo A, 2013, FUNCTIONAL ART INTRO
Chess C, 1999, ENVIRON SCI TECHNOL, V33, P2685, DOI 10.1021/es980500g
Cornell Lab of Ornithology, 2015, DEV VAL IMPL SIT EV
Cox R., 2016, ENV COMMUNICATION PU
Gomez J. A., 2015, GAO15812
Hoover E., 2016, JCOM J SCI COMMUNICA, V14, P1
Minkler M, 2010, COMMUNITY BASED PART
National Gardening Association, 2014, GARD TABL 5 YEAR LOO
Overdevest C., 2004, HUMAN ECOLOGY REV, V11, P177
Ramirez-Andreeotta M.D, 2015, INT PUBLIC HLTH, V7, P1
Ramirez-Andreotta MD, 2016, INT J ENV RES PUB HE, V13, DOI
10.3390/ijerph13070690
Ramirez-Andreotta Monica D, 2016, J Environ Stud Sci, V6, P543
Seneca S. L., 2004, COMMUNICATION PUBLIC
Stajkovic A. D., 1979, MOTIVATION WORK BEHA, V126, P140
Stepemick KF, 2015, ECOL SOC, V20, DOI 10.5751/ES-07329-200319
Telg E, 2009, HEALTH PLACE, V15, P1115, DOI 10.1016/j.healthplace.2009.06.003
United States Environmental Protection Agency, 2015, EJSCREEN
United States Environmental Protection Agency, 2017, CLEAN SIT AR
US Census Bureau, 2015, QUICK FACTS GREENL C
US Government Accountability Office, 2013, KEY ISS HAZ WAST
Vallerand R. J., 2001, ADV MOTIVATION SPORT, P263
Wright DR, 2015, SOC NATUR RESOUR, V28, P1013, DOI 10.1080/08941920.2015.1054976

Luo, Y
Jin, H
Li, PL
AF
Luo, Yan
Jin, Hao
Li, Peilong
GP
ACM
TI A Blockchain Future for Secure Clinical Data Sharing
SO PROCEEDINGS OF THE ACM INTERNATIONAL WORKSHOP ON SECURITY IN SOFTWARE DEFINED NETWORKS & NETWORK FUNCTION VIRTUALIZATION (SDN-NFV '19)
LA English
DT Proceedings Paper
CT ACM International Workshop on Security in Software Defined Networks and Network Function Virtualization (SDN-NFV)
AB In the digital healthcare era, it is utmost important to harness medical information scattered across healthcare institutions to support in-depth data analysis. However, the boundaries of cyberinfrastructure of healthcare providers place obstacles on data sharing. In this position paper, we firstly identify the challenges of medical data sharing and management. Then we introduce the background and give a brief survey on the state-of-the-art. Finally, we conclude the paper by discussing a few possible research directions to cope with the challenges in current medical information sharing.

C1 [Luo, Yan; Jin, Hao] UMASS Lowell, Lowell, MA USA.

[Li, Peilong] Elizabethtown Coll, Elizabethtown, PA 17022 USA.

RP Li, PL (reprint author), Elizabethtown Coll, Elizabethtown, PA 17022 USA.

EM Yan Luo@uml.edu; Hao Jin@uml.edu; lip@etown.edu

FU National Science Foundation of USA [1547428, 1738965, 1450996]

FX The authors would like to thank the anonymous referees for their reviews and insightful suggestions to improve this paper. This work is partially supported by the National Science Foundation of USA (Award No. 1547428, No. 1738965 and No. 1450996).

CR [Anonymous], 2017, SUMMARY HIPAA SECURI

Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11

Cachin C., 2016, WORKSH DISTR CRYPT C, V310

Dong YY, 2017, 4TH INTERNATIONAL CONFERENCE ON SMART AND SUSTAINABLE CITY (ICSSC 2017), P69

Ethereum, 2014, PROOF STAK FAQ


Hu L, 2015, IEEE WIREL COMMUN, V22, P67, DOI 10.1109/MWC.2015.7368826

Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97

Li PL, 2017, 2017 IEEE/ACM SECOND INTERNATIONAL CONFERENCE ON CONNECTED HEALTH - APPLICATIONS, SYSTEMS AND ENGINEERING TECHNOLOGIES (CHASE), P373, DOI 10.1109/CHASE.2017.121

Nakamoto Satoshi, 2009, BITCOIN PEER TO PEER

Rui Guo, 2018, IEEE ACCESS, V776, P1


Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843

Xia Q, 2017, INFORMATION, V8, DOI 10.3390/info8020044


Zyskind G, 2015, 2015 IEEE SECURITY AND PRIVACY WORKSHOPS (SPW), P180, DOI 10.1109/SPW.2015.27
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 starts by examining the practices of a Danish laboratory highly experienced in collaborating cross-nationally on genetic research. We focus on a simple query, what makes genetic material and health data flow and which hopes and concerns sit alongside them? We explore what we call the flows, the non-flows, and the overflows of material and information, and we document the work that produces the flows of health data and biomaterial. We call this work "ethics work" and argue that it is crucial for data sharing, despite rarely being included in ethics policies, remaining inadequately funded, and lacking acknowledgment in policies promoting international data sharing.

C1 [Hoeyer, Klaus; Tupasela, Aaro; Bogehus Rasmussen, Malene] Univ Copenhagen, Oster Farimagsgade 5, Room 10-0-09, DK-1014 Copenhagen K, Denmark.
RP Hoeyer, K (reprint author), Univ Copenhagen, Oster Farimagsgade 5, Room 10-0-09, DK-1014 Copenhagen K, Denmark.
EM klho@sund.ku.dk; aaro.tupasela@helsinki.fi; mbr@sund.ku.dk
O1 Tupasela, Aaro/0000-0003-1512-7533
CR Albert M, 2015, Collaboration across Health Research and Medical Care: Healthy Collaboration, P59

Anderson W., 2008, COLLECTORS LOST SOUL
Bjugn R, 2015, BIOPRESERV BIOBANK, V13, P70, DOI 10.1089/bio.2015.1323
Bosk C., 1979, FORGIVE REMEMBER MAN
Cadigan R Jean, 2013, Life Sci Soc Policy, V9, P1
Cambliss D. F., 1996, CARING HOSP NURSES S
Cooper M., 2014, CLIN LABOR TISSUE DO
Security and Privacy of Electronic Health Records: Decentralized and Hierarchical Data Sharing using Smart Contracts

AB Over the last fifty years, medical treatment has seen remarkable advancement, however, the data management and storage systems of medical records has lagged in comparison. In addition, these systems are often inharmonious across platforms and do not put the privacy desires of patients first. While HIPAA and other laws are put in place to protect patient medical record security and privacy, these antiquated systems inherently hinder patient security and privacy. In this paper, we propose a novel data sharing and management scheme that empowers patients over their records by leveraging the security and privacy benefits of blockchain and smart contracts. In comparison to current methods for healthcare records management, our proposed scheme empowers patients over their records and minimizes the dependencies on recordgenerating institutions. It also allows the patients to selectively share their records and disclose certain parts with specific data users based on the privacy preferences desired. In our security and privacy analysis, we show that patients can protect against potential threats to securely and privately share their records. Moreover, in our performance discussions, we show that smart contract design and development is key.

CR Anderson R.J., 2008, SECURITY ENG
Daemen J, 2013, DESIGN RIJNDAEL AES
IBM and Ponemon, 2018, 2018 COST DAT BREACH
Lau F, 2000, IEEE SYS MAN CYBERN, P2275, DOI 10.1109/ICSMC.2000.886455
Nakamoto S., 2008, BITCOIN PEER TO PEER
Szabo N, 1994, SMART CONTRACTS
A Review of Secure and Privacy-Preserving Medical Data Sharing

In the digital healthcare era, it is of the utmost importance to harness medical information scattered across healthcare institutions to support in-depth data analysis and achieve personalized healthcare. However, the cyberinfrastructure boundaries of healthcare organizations and privacy leakage threats place obstacles on the sharing of medical records. Blockchain, as a public ledger characterized by its transparency, tamper-evidence, trustlessness, and decentralization, can help build a secure medical data exchange network.

This paper surveys the state-of-the-art schemes on secure and privacy-preserving medical data sharing of the past decade with a focus on blockchain-based approaches. We classify them into permissionless blockchain-based approaches and permissioned blockchain-based approaches and analyze their advantages and disadvantages. We also discuss potential research topics on blockchain-based medical data sharing.

Jin, H, Luo, Y, Li, PL, Mathew, J

A Review of Secure and Privacy-Preserving Medical Data Sharing

In the digital healthcare era, it is of the utmost importance to harness medical information scattered across healthcare institutions to support in-depth data analysis and achieve personalized healthcare. However, the cyberinfrastructure boundaries of healthcare organizations and privacy leakage threats place obstacles on the sharing of medical records. Blockchain, as a public ledger characterized by its transparency, tamper-evidence, trustlessness, and decentralization, can help build a secure medical data exchange network.

This paper surveys the state-of-the-art schemes on secure and privacy-preserving medical data sharing of the past decade with a focus on blockchain-based approaches. We classify them into permissionless blockchain-based approaches and permissioned blockchain-based approaches and analyze their advantages and disadvantages. We also discuss potential research topics on blockchain-based medical data sharing.

Jin, H, Luo, Y, Li, PL, Mathew, J

A Review of Secure and Privacy-Preserving Medical Data Sharing

In the digital healthcare era, it is of the utmost importance to harness medical information scattered across healthcare institutions to support in-depth data analysis and achieve personalized healthcare. However, the cyberinfrastructure boundaries of healthcare organizations and privacy leakage threats place obstacles on the sharing of medical records. Blockchain, as a public ledger characterized by its transparency, tamper-evidence, trustlessness, and decentralization, can help build a secure medical data exchange network.

This paper surveys the state-of-the-art schemes on secure and privacy-preserving medical data sharing of the past decade with a focus on blockchain-based approaches. We classify them into permissionless blockchain-based approaches and permissioned blockchain-based approaches and analyze their advantages and disadvantages. We also discuss potential research topics on blockchain-based medical data sharing.

Jin, H, Luo, Y, Li, PL, Mathew, J
RP Luo, Y (reprint author), Univ Massachusetts, Dept Elect & Comp Engn, Lowell, MA 01854 USA.

EM yan_luo@uml.edu

FU National Science Foundation of USA [1547428, 1738965, 1450996, 1541434]

FX This work was supported in part by the National Science Foundation of USA under Grant 1547428, Grant 1738965, Grant 1450996, and Grant 1541434.

CR [Anonymous], 2018, HEALTHCARE IND RANKS
[Anonymous], 2018, ARCHITECTING HIPAA S
[Anonymous], 2017, SUMMARY HIPAA SECURI
[Anonymous], 2016, GEN DATA PROTECTION
[Anonymous], 2018, SURVEY 90 PERCENT HE


Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11


Bessani A, 2014, I C DEPEND SYS NETWO, P355, DOI 10.1109/DSN.2014.43

Blaze M, 1998, LECT NOTES COMPUT SC, V1403, P127

Boneh D, 2005, LECT NOTES COMPUT SC, V3621, P258

Boneh D, 2004, LECT NOTES COMPUT SC, V3027, P506


Cachin C., 2016, P WORKSH DISTR CRYPT, P1

Castro M, 1999, USENIX ASSOCIATION PROCEEDINGS OF THE THIRD SYMPOSIUM ON OPERATING SYSTEMS DESIGN AND IMPLEMENTATION (OSDI '99), P173


Chase M, 2007, LECT NOTES COMPUT SC, V4392, P515

Chase M, 2009, CCS'09: PROCEEDINGS OF THE 16TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P121

Dillon T, 2010, INT CON ADV INFO NET, P27, DOI 10.1109/AINA.2010.187

Dwork C., 2006, LECT NOTES COMPUTER, V4052


Esposito C, 2018, IEEE CLOUD COMPUT, V5, P31

Ethereum, 2016, SOL PROGR DOC

Ethereum, 2014, PROOF STAK FAQ

Fabian B, 2015, INFORM SYST, V48, P132, DOI 10.1016/j.is.2014.05.004


Garay JA, 2000, LECT NOTES COMPUT SC, V1880, P333

Gardner J, 2008, COMP MED SY, P254, DOI 10.1109/CBMS.2008.129


Goh E. J., 2003, P NETW DISTR SYST SE, P131

Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418

Green M., 2007, P INT C APPL CRYPT N

Guo R, 2018, IEEE ACCESS, V6, P1167, DOI 10.1109/ACCESS.2018.2801266

Hardjono T., 2019, VERIFIABLE ANONYMOUS

Hu L, 2015, IEEE WIREL COMMUN, V22, P67, DOI 10.1109/MWC.2015.7368826

Jin H, 2018, FUTURE GENER COMP SY, V80, P640, DOI 10.1016/j.future.2016.06.013

Khan KM, 2010, IT PROF, V12, P20, DOI 10.1109/MITP.2010.128


Kuo TT, 2018, MODELCHAIN DECENTRAL
Lewko A, 2011, LECT NOTES COMPUT SC, V6632, P568, DOI 10.1007/978-3-642-20465-4_31
Li J, 2010, INFOCOM 2010 P IEEE, P1, DOI DOI 10.1109/INFOCOM.2010.5462196
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Li P., 2017, ACM INT WORKSH SEC, P69
Li PL, 2017, 2017 IEEE/ACM SECOND INTERNATIONAL CONFERENCE ON CONNECTED HEALTH – APPLICATIONS, SYSTEMS AND ENGINEERING TECHNOLOGIES (CHASE), P373, DOI 10.1109/CHASE.2017.121
Li Tiancheng, 2012, IEEE T KNOWL DATA EN, V24, P3
Liang X., 2017, PERS IND MOB RAD COM, P1, DOI DOI 10.1109/PIMRC.2017.8292361, DOI 10.1109/PIMRC.2017.8292361
Nakamoto Satoshi, 2009, BITCOIN PEER TO PEER
Sousa J., 2018, P 48 ANN IEEE IFIP I, P51, DOI DOI 10.1109/DSN.2018.2594205
Wood G., 2014, 151 ETH, V151
Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843
Xia Q, 2017, INFORMATION, V8, DOI 10.3390/info8020044
Yang H., 2017, P 10 EL EN STOR APPL, P1, DOI DOI 10.1109/PESGM.2017
Zhang AQ, 2018, J MED SYST, V42, DOI 10.1109/s10916-018-0995-5
Zhao HW, 2017, 2017 IEEE 13TH INTERNATIONAL SYMPOSIUM ON AUTONOMOUS DECENTRALIZED SYSTEMS (ISADS 2017), P229, DOI 10.1109/ISADS.2017.22
Zyskind G, 2015, 2015 IEEE SECURITY AND PRIVACY WORKSHOPS (SPW), P180, DOI 10.1109/SPW.2015.27
A Secure Incentive Mechanism for Competitive Organization Data Sharing: A Contract Theoretic Approach

AB With the development of information technology, various data-driven intelligent services have changed our daily life greatly. As the data fuels the development of these services, data sharing is desirable for data availability issues. Many mechanisms and technologies have been proposed to support data sharing. However, some organizations, especially with potential competitive relationships are still reluctant to share their data. On one hand, no data holder wish to see the competitiveness improvement of competitors by data sharing. On the other hand, data sharing suffers from huge privacy security risks. To encourage data sharing, in this paper, a competitiveness-driven and secure incentive mechanism is proposed. By introducing the concept of data competitiveness as incentive motivation, competitiveness worry of data holders is eliminated. Privacy is protected by adopting differential privacy. As the privacy protection levels of data holders are unknown to the data demander, a
contract theoretic approach is proposed to formulate the incentive mechanism. With the design of optimal contracts, the data demander can make the best decisions to pay data holders and data holders can optimize their utilities by choosing proper contracts. The numerical results demonstrate the effectiveness of the proposed incentive scheme.


[Guan, Quansheng] South China Univ Technol, Sch Informat & Elect Engn, Guangzhou 510640, Guangdong, Peoples R China.

RP Tian, J (reprint author), Shandong Normal Univ, Sch Informat Sci & Engn, Jinan 250358, Shandong, Peoples R China.

EM tianjie@sdnu.edu.cn

OI Guan, Quansheng/0000-0001-6159-3194

FU National Science Natural Fund of China [61801278, 61373149]; Guangxi Provincial Education Department Foundation [2017KY0202]; Guangxi Cognitive Radio and Information Processing Key Laboratory by China's Ministry of Education Foundation [CRKL150110]; 2017 Open Foundation [CRKL170203]; Guangxi Broadband Wireless Communication and Signal Processing Key Laboratory Foundation [GXXL06160114]; National Infrastructure Project [NSFC61571143]; Shandong Provincial Natural Science Foundation for Young Scholars of China [ZR2017QP008]; 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 GXXL06160114, 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 ZR2017QP008, 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.


Dhanalakshmi M., 2014, INT J COMPUTER APPL, V96, P7


Dwork C, 2006, LECT NOTES COMPUT SC, V4052, P1

Dwork C, 2006, LECT NOTES COMPUT SC, V3876, P265


Fabian B, 2015, INFORM SYST, V48, P132, DOI 10.1016/j.is.2014.05.004

Feng KY, 2017, 2017 2ND IEEE INTERNATIONAL CONFERENCE ON CLOUD COMPUTING AND BIG DATA ANALYSIS (ICCCBDA 2017), P6, DOI 10.1109/ICCCBDA.2017.7951875


Gao H, 2015, IEEE COMMUN SURV TUT, V17, P918, DOI 10.1109/COMST.2014.2387836

Groves P., 2016, MCKINSEY CO, V2, P13
Think Ahead: Enabling Continuous Sharing of Location Data in Real-Time with Privacy Guarantee

AB A user's location is a sensitive data and can reveal private information about the user's health, habit and preferences. Due to privacy concerns, people may hesitate to share their locations and prohibit the growth of location-based services and analysis. The problem of protecting location privacy has been extensively studied in the literature. Sharing location data in sequence enable adversaries to apply privacy attacks by exploiting spatio-temporal constraints in road networks. In this paper, we identify a novel privacy attack that existing solutions cannot overcome for not considering upcoming sensitive locations in advance. We develop a technique to precompute the warning zone, i.e. the refined area where the disclosure of a user's actual location may enable adversaries to identify the user's sensitive locations in the future. Warning zones also enable users to reduce the frequency of not sharing locations for privacy reasons, and thereby improve the accuracy and utility of shared locations while guaranteeing the required level of location privacy of a user. Experiments using real datasets show that our approach significantly outperforms the state-of-the-art technique in terms of privacy, data utility and computational overhead.

[Anonymous], 2002, USATODAY
[Anonymous], 2004, FOXNEWS
Arain QA, 2017, WIRELESS PERS COMMUN, V97, P2617, DOI 10.1007/s11277-017-4626-0
Ardagna CA, 2012, IEEE INT C COMPUT, P162, DOI 10.1109/ICCSE.2012.31
Bamba B., 2008, WWW, P237
Chakraborty S, 2016, NDSS
Damiani ML, 2010, TRANS DATA PRIV, V3, P123
Damiani ML, 2011, IEEE PERVAS COMPUT, V10, P64, DOI 10.1109/MPRV.2011.18
Fung E, 2015, LECT NOTES COMPUT SC, V9239, P295, DOI 10.1007/978-3-319-22363-16
Ghinita G., 2009, P 17 ACM SIGSPATIAL, P246, DOI DOI 10.1145/1653771.1653807
Hashem T, 2007, LECT NOTES COMPUT SC, V4717, P372
Lim J, 2017, IEEE COMMUN LETT, V21, P540, DOI 10.1109/LCOMM.2016.2637902
LIN D, 2010, DATABASE SYSTEMADV, V5982, P17
This manuscript describes the experiences of three state departments of health (SDoH) that successfully launched data sharing interventions involving surveillance and/or patient data collected in clinics to improve care outcomes among people living with HIV. We examined 58 key informant interviews, gathered at two time points, to describe the development and implementation of data sharing interventions. We identified three common themes across states' experiences: creating standard practices, fostering interoperability, and negotiating the policy environment. Projects were successful when state teams adapted to changing circumstances and were committed to a consistent communication process. Once implemented, the interventions streamlined processes to promote linkage and retention in care among low-income populations living with HIV. Despite using routinely collected data, key informants emphasized the labor-intensive process to develop and sustain the interventions. Lessons learned from these three state experiences can help inform best practices for other SDoH that are considering launching similar interventions.
cambiantes y se comprometieron en un proceso de comunicación constante. Una vez implementadas, las intervenciones racionalizaron los procesos para promover el vínculo y la retención en la atención médica en poblaciones de bajos ingresos que viven con el VIH. A pesar de utilizar datos recopilados rutinariamente, los informantes clave enfatizaron el proceso de trabajo intenso para desarrollar y sostener las intervenciones. Las lecciones aprendidas de estas tres experiencias estatales pueden ayudar a informar mejores prácticas para otros SDoH que estén considerando iniciar intervenciones similares.

[Gruber, DeAnn] Dept Publ Hlth, New Orleans, LA USA.
[Hauge, J. Christian] Dept Publ Hlth, Boston, MA USA.
[Parnell, Heather E.] Duke Univ, Ctr Hlth Policy & Inequal Res, Durham, NC USA.
[Quinlivan, Evelyn Byrd] Univ N Carolina, Inst Global Hlth & Infect Dis, Chapel Hill, NC 27599 USA.

EM Sophia.Zamudio-Haas@ucsf.edu
OI Fuller, Shannon/0000-0001-6070-8172

FU Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) [U90HA22702]

FX This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant Number U90HA22702 for the Systems Linkages and Access to Care for Populations at High Risk for HIV Infection Initiative Evaluation and Technical Assistance Center. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Bove JM, 2015, JAIDS-J ACQ IMM DEF, V70, P262, DOI 10.1097/QAI.0000000000000707
Buchacz K, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0118923
Christopoulos KA, 2015, JAIDS-J ACQ IMM DEF, V69, pS56, DOI 10.1097/QAI.0000000000000571
Cohen MS, 2016, NEW ENGL J MED, V375, P830, DOI 10.1056/NEJMoal600693
Dombrowski JC, 2017, JAIDS-J ACQ IMM DEF, V74, pS81, DOI 10.1097/QAI.0000000000001237
Evans D, 2015, JAIDS-J ACQ IMM DEF, V69, pS31, DOI 10.1097/QAI.0000000000000573
Gardner Ll, 2005, AIDS, V19, P423, DOI 10.1097/01.aids.0000161772.51900.eb
Hague JC, 2017, AIDS BEHAV
Health Resources and Services Administration, 2011, SPNS IN SYST LINK AC
Herwehe J, 2012, J AM MED INFORM ASSN, V19, P448, DOI 10.1136/amiajnl-2011-000412
Lubelchek RJ, 2015, JAIDS-J ACQ IMM DEF, V69, pS25, DOI 10.1097/QAI.0000000000000574
Association score testing for rare variants and binary traits in family data with shared controls

Saad, M Wijsman, EM
Saad, Mohamad Wijsman, Ellen M.

Genome-wide association studies have been an important approach used to localize trait loci, with primary focus on common variants. The multiple rare variant-common disease hypothesis may explain the missing heritability remaining after accounting for identified common variants. Advances of sequencing technologies with their decreasing costs, coupled with methodological advances in the context of association studies in large samples, now make the study of rare variants at a genome-wide scale feasible. The resurgence of family-based association designs because of their advantage in studying rare variants has also stimulated more methods development, mainly based on linear mixed models (LMMs). Other tests such as score tests can have advantages over the LMMs, but
to date have mainly been proposed for single-marker association tests. In this article, we extend several score tests (chi(2)(corrected); W-QLS; and SKAT) to the multiple variant association framework. We evaluate and compare their statistical performances relative with the LMM. Moreover, we show that three tests can be cast as the difference between marker allele frequencies (AFs) estimated in each of the group of affected and unaffected subjects. We show that these tests are flexible, as they can be based on related, unrelated or both related and unrelated subjects. They also make feasible an increasingly common design that only sequences a subset of affected subjects (related or unrelated) and uses for comparison publicly available AFs estimated in a group of healthy subjects. Finally, we show the great impact of linkage disequilibrium on the performance of all these tests.


FU US National Institutes of Health [P50 AG005136, U01 AG049507, R01 MH094293]

FX Funded in part by US National Institutes of Health grants P50 AG005136, U01 AG049507 and R01 MH094293.

CR Abney M, 2002, AM J HUM GENET, V70, P920, DOI 10.1086/339705
Agresti A, 2002, CATEGORICAL DATA ANALY.
Altschuler D, 2010, NATURE, V467, P1061, DOI 10.1038/nature09534
Amin N, 2007, PLOS ONE, V2, DOI 10.1371/journal.pone.0001274
Bansal V, 2010, NAT REV GENET, V11, P773, DOI 10.1038/nrg2867
Botstein D, 2003, NAT GENET, V33, P228, DOI 10.1038/ng1090
Bourgain C, 2003, AM J HUM GENET, V73, P612, DOI 10.1086/378208
Chen GB, 2017, PLOS ONE, V2, DOI 10.1002/gepi.20418
Chen H, 2016, AM J HUM GENET, V98, P653, DOI 10.1016/j.ajhg.2016.02.012
Chen WM, 2007, AM J HUM GENET, V81, P913, DOI 10.1086/521580
Choi Y, 2009, GENET EPIDEMIOLOG, V33, P668, DOI 10.1002/gepi.20418

Evangelou E, 2013, NAT REV GENET, V14, P379, DOI 10.1038/nrg3472
Jakobsdottir J, 2013, AM J HUM GENET, V92, P652, DOI 10.1016/j.ajhg.2013.03.014

Jorde LB, 2000, GENOME RES, V10, P1435, DOI 10.1101/gr.144500
Kang HM, 2010, NAT GENET, V42, P348, DOI 10.1038/ng.548
Kwee LC, 2008, AM J HUM GENET, V82, P386, DOI 10.1016/j.ajhg.2007.10.010
Lee S, 2014, AM J HUM GENET, V95, P5, DOI 10.1016/j.ajhg.2014.06.009
Li BS, 2008, AM J HUM GENET, V83, P311, DOI 10.1016/j.ajhg.2008.06.024
Lippert C, 2011, NAT METHODS, V8, P833, DOI [10.1038/NEUTHE.1681, 10.1038/nmeth.1681]
Madsen BE, 2009, PLOS GENET, V5, DOI 10.1371/journal.pgen.1000384
Manolio TA, 2009, NATURE, V461, P747, DOI 10.1038/nature08494
McCarthy MI, 2008, NAT REV GENET, V9, P356, DOI 10.1038/nrg2344
Ott J, 2011, NAT REV GENET, V12, P465, DOI 10.1038/nrg2989
Mortality, Resource Utilization, and Inpatient Costs Vary Among Pediatric Heart Transplant Indications: A Merged Data Set Analysis From the United Network for Organ Sharing and Pediatric Health Information
Background: Merging United Network for Organ Sharing (UNOS) and Pediatric Health Information Systems databases has enabled a more granular analysis of pediatric heart transplant outcomes and resource utilization. We evaluated whether transplant indication at time of transplantation was associated with mortality, resource utilization, and inpatient costs during the first year after transplantation.

Methods and Results: We analyzed transplant outcomes and resource utilization from 2004 to 2015. Patients were categorized as congenital (CHD), myocarditis, or cardiomyopathy based on UNOS-defined primary indication. CHD complexity subgroup analyses (single-ventricle, complex, and simple biventricular CHD) were also performed. Of 2251 transplants (49% CHD, 5% myocarditis, 46% cardiomyopathy), CHD recipients were younger (2 [IQR 0-10], 6 [IQR 0-12], and 7 [IQR 1-14] years, respectively; P <.001) and less likely to have a ventricular assist device (VAD) at transplantation (3%, 27%, and 13%, respectively; P <.001). Patients with single-ventricle CHD had the longest time on the waitlist and were least likely to receive a VAD before transplantation. After adjusting for patient-level factors, transplant recipients with single-ventricle CHD had the greatest mortality during transplantation admission and within 1 year (odds ratio [OR] 11.8 [95% confidence interval (CI) 5.9-23.6] and OR 6.0 [95% CI 3.6-10.2], respectively, vs cardiomyopathy). Mortality was similar between patients with myocarditis and cardiomyopathy. Post-transplantation length of stay (LOS) was longer in transplant recipients with CHD than myocarditis or cardiomyopathy (25 [interquartile range [IQR] 15-45] vs 21 [IQR 12-35] vs 16 [IQR 12-25] days; P <.001), related in part to longer duration of intensive care unit-level care (ICU LOS 8 [IQR 4-20] vs 6 [IQR 4-13] vs 5 [IQR 3-8] days; P <.001). Similarly, patients with CHD had higher median post-transplantation costs than myocarditis or cardiomyopathy ($415K [IQR $201K-$503K] vs $354K [IQR $179K-$390K] vs $284K [IQR $145K-$319K]; P <.001) that persisted after adjusting for patient level factors (adjusted cost ratio 1.4 [95% CI 1.4-1.5], CHD vs cardiomyopathy) and was primarily driven by longer LOS. More than 50% were readmitted during the first year after transplantation, although readmission rates were similar across transplant indications (P =.42).

Conclusions: Children with CHD, particularly single-ventricle patients, require substantially greater hospital resource utilization and have significantly worse outcomes during the first year after heart transplantation compared with other indications. Further work is aimed at identifying modifiable pre-transplantation risk factors, such as pre-transplantation conditioning with VAD support and cardiac rehabilitation, to improve post-transplantation outcomes and reduce resource utilization in this complex population.


[Huang, Yuan-Shung, V] Childrens Hosp Philadelphia, Healthcare Analyt Unit, Philadelphia, PA 19104 USA.

RP Burstein, DS (reprint author), Childrens Hosp Philadelphia, 34th St & Civ Ctr Blvd, Philadelphia, PA 19104 USA.

EM bursteind@email.chop.edu

CR [Anonymous], 2016, GROWTH CHART TRAIN

PT J
AU Fukushima, M
    Austin, C
    Sato, N
    Maruyama, T
    Navarro, E
    Rocca, M
    Demotes, J
    Haendel, M
    Volchenboum, SL
    Cowperthwaite, M
    Silyerstein, JC
    Webb, C
    Sim, I
    Chase, M
    Speakman, J
    Augustine, E
    Ford, DE
    Kush, R
AF Fukushima, Masanori
    Austin, Christopher
    Sato, Norihiro
    Maruyama, Tatsuya
    Navarro, Eileen
    Rocca, Mitra
    Demotes, Jacques
    Haendel, Melissa
    Volchenboum, Samuel L.
    Cowperthwaite, Matthew
    Silyerstein, Jonathan C.
    Webb, Chris
    Sim, Ida
    Chase, Marianne
    Speakman, John
    Augustine, Erika
    Ford, Daniel E.
    Kush, Rebecca
TI The Global academic research organization network: Data sharing to cure
diseases and enable learning health systems
SO LEARNING HEALTH SYSTEMS
LA English
DT Article
DE data sharing; global; harmonization; registry; standards
AB Introduction Global data sharing is essential. This is the premise of the
Academic Research Organization (ARO) Council, which was initiated in Japan in
2013 and has since been expanding throughout Asia and into Europe and the United
States. The volume of data is growing exponentially, providing not only
challenges but also the clear opportunity to understand and treat diseases in
ways not previously considered. Harnessing the knowledge within the data in a
successful way can provide researchers and clinicians with new ideas for
therapies while avoiding repeats of failed experiments. This knowledge transfer
from research into clinical care is at the heart of a learning health system.
Methods The ARO Council wishes to form a worldwide complementary system for the
benefit of all patients and investigators, catalyzing more efficient and
innovative medical research processes. Thus, they have organized Global ARO
Network Workshops to bring interested parties together, focusing on the aspects
necessary to make such a global effort successful. One such workshop was held in
Austin, Texas, in November 2017. Representatives from Japan, Taiwan, Singapore, Europe, and the United States reported on their efforts to encourage data sharing and to use research to inform care through learning health systems.

Results This experience report summarizes presentations and discussions at the Global ARO Network Workshop held in November 2017 in Austin, TX, with representatives from Japan, Korea, Singapore, Taiwan, Europe, and the United States. Themes and recommendations to progress their efforts are explored. Standardization and harmonization are at the heart of these discussions to enable data sharing. In addition, the transformation of clinical research processes through disruptive innovation, while ensuring integrity and ethics, will be key to achieving the ARO Council goal to overcome diseases such that people not only live longer but also are healthier and happier as they age. Conclusions The achievement of global learning health systems will require further exploration, consensus-building, funding aligned with incentives for data sharing, standardization, harmonization, and actions that support global interests for the benefit of patients.

[Austin, Christopher] NIH, Natl Ctr Advancing Translat Sci, Bldg 10, Bethesda, MD 20892 USA.
[Navarro, Eileen; Rocca, Mirta] US FDA, Silver Spring, MD USA.
[Haendel, Melissa] Oregon Hlth & Sci Univ, Ctr Data Hlth, Portland, OR 97201 USA.
[Volchenboum, Samuel L.] Univ Chicago, Ctr Res Informat, Chicago, IL 60637 USA.
[Cowperthwaite, Matthew] St Davids HealthCare Off Res, Austin, TX USA.
[Silverstein, Jonathan C.] Univ Pittsburgh, Sch Med, Pittsburgh, PA USA.
[Webb, Chris] Univ Texas Austin, Dell Med Sch, Austin, TX 78712 USA.
[Sim, Ida] Univ Calif San Francisco, San Francisco, CA 94143 USA.
[Chase, Marianne] Massachusetts Gen Hosp, Neurol Clin Res Inst, Boston, MA 02114 USA.
[Speakman, John] NYU Langone Hlth, New York, NY USA.
[Augustine, Erika] Univ Rochester, Med Ctr, Rochester, NY 14642 USA.
[Kush, Rebecca] Catalysis, Austin, TX USA.
[Kush, Rebecca] Elligo Hlth Res, Austin, TX USA.

RP Kush, R (reprint author), Catalysis Res Hlth, Austin, TX 78746 USA.; Kush, R (reprint author), Clin Data Interchange Stand Consortium, San Diego, CA 92075 USA.

EM rkush@catalysisresearch.com
Embi Peter J, 2013, AMIA Jt Summits Transl Sci Proc, V2013, P60
Foster I, 2005, SCIENCE, V308, P814, DOI 10.1126/science.1110411
Grossman KL, 2016, COMPUT SCI ENG, V18, P10, DOI 10.1109/MCSE.2016.92
McGinnis JM, 2012, FDN CONTINUOUS IMPRO
Molzon JA, 2011, CLIN PHARMACOL THER, V89, P503, DOI 10.1038/clpt.2011.10
Rachel E, NEJM

NR 9
TC 0
Z9 0
U1 1
 Interstate data sharing of prescription drug monitoring programs and associated opioid prescriptions among patients with non-cancer chronic pain

SO PREVENTIVE MEDICINE
LA English
DT Article
DE Chronic pain; Prescription drug; Interstate data sharing; Drug policy; Ambulatory care
ID UNITED-STATES; THERAPY; ANALGESICS; PHYSICIAN; EPIDEMIC; TRENDS; RISKS; ABUSE

AB All fifty states have implemented prescription drug monitoring programs (PDMPs) to reduce misuse and diversion of controlled drugs. Interstate PDMP data sharing has been called for by clinical practitioners, but evidence to support the effectiveness of PDMP data sharing is lacking. This study examined whether PDMP interstate data sharing with bordering states was associated with prescriptions of opioids. This was a cross-sectional study that included patients with non-cancer chronic pain from the 2014 National Ambulatory Medical Care Survey (weighted N = 66,198,751; unweighted N = 2846). Multinomial logistic regression was performed to examine the association between PDMP interstate data sharing status and patients' being prescribed opioids for pain treatment, controlling for covariates guided by the Eisenberg's model of physician decision-making. Findings indicated that patients residing in states with interstate PDMP data sharing with all or partial bordering states were not less...
likely to be prescribed opioids compared to those living in states without interstate data sharing. Other factors such as patient age, health insurance type, new patient status, and physician adoption of electronic medical records were associated with the likelihood of patients' being prescribed opioids. This study concluded that current practice of interstate PDMP data sharing with bordering states was not associated with patients' being prescribed opioids for non-cancer chronic pain treatment. Future studies and policy efforts that unravel technological, legal, and political barriers to reciprocal and equal interstate data sharing with bordering states should be warranted to inform PDMP redesign and in turn, augment overall PDMP effectiveness in reducing misuse of prescription opioids.

CR American Pharmacists Association, 2015, PATH NAT PRESCR DURG
Ashburn MA, 2012, ANESTHESIOLOGY, V116, P248, DOI
10.1097/ALN.Ob013e31823c1030
AB: Analyzing longitudinal dyadic data is a challenging task due to the complicated correlations from repeated measurements and within-dyad interdependence, as well as potentially informative (or non-ignorable) missing data. We propose a dyadic shared-parameter model to analyze longitudinal dyadic data with ordinal outcomes and informative intermittent missing data and dropouts. We model the longitudinal measurement process using a proportional odds model, which accommodates the within-dyad interdependence using the concept of the actor-partner interdependence effects, as well as dyad-specific random effects. We model informative dropouts and intermittent missing data using a transition model, which shares the same set of random effects as the longitudinal measurement model. We evaluate the performance of the proposed method through extensive simulation studies. As our approach relies on some untestable assumptions on the missing data mechanism, we perform sensitivity analyses to evaluate how the analysis results change when the missing data mechanism is misspecified. We demonstrate our method using a longitudinal dyadic study of metastatic breast cancer.

C1 [Ahn, Jaeil] Georgetown Univ, Dept Biostat, Washington, DC USA.
   [Wang, Wenyi] Univ Texas MD Anderson Canc Ctr, Dept Bioinformat & Computat Biol, Houston, TX 77030 USA.
   [Yuan, Ying] Univ Texas MD Anderson Canc Ctr, Dept Biostat, Houston, TX 77030 USA.
RP Ahn, J (reprint author), Georgetown Univ, 3900 Reservoir Rd NW, Washington, DC 20057 USA.
EM ja1030@georgetown.edu
FU NCI NIH HHS [P30 CA016672, R01 CA183793]
CR Agresti A., 2012, CATEGORICAL DATA ANAL
Carrell SE, 2009, J LABOR ECON, V27, P439, DOI 10.1086/600143
Daniels MJ, 2008, MONOGR STAT APPL PRO, V109, P1
DIGGLE P, 1994, J R STAT SOC C-APPL, V43, P49
Gelman A., 2013, BAYESIAN DATA ANAL
Gottman J, 2002, PERS SOC PSYCHOL REV, V6, P326, DOI
10.1207/S15327957PSPR0604_07
Hjort NL, 2010, BAYESIAN NONPARAMET
Hogan JW, 1997, STAT MED, V16, P259
Ibrahim JG, 2009, TEST-SPAIN, V18, P1, DOI 10.1007/s11749-009-0138-x
LITTLE RJA, 1994, BIOMETRIKA, V81, P471
Little RJA, 2008, ADV LONGITUDINAL DAT
Spiegelhalter DJ, 2002, J ROY STAT SOC B, V64, P583, DOI 10.1111/1467-9868.00353
Verbeke G, 2000, LINEAR MIXED MODELS
Zhang GY, 2012, ANN APPL STAT, V6, P753, DOI 10.1214/11-AOAS515

PI LONDON
SN 0962-2802
EI 1477-0334
J9 STAT METHODS MED RES
PD JAN
PY 2019
VL 28
IS 1
BP 70
EP 83
DI 10.1177/0962280217715051
PG 14

WC Health Care Sciences & Services; Mathematical & Computational Biology; Medical Informatics; Statistics & Probability
SC Health Care Sciences & Services; Mathematical & Computational Biology; Medical Informatics; Mathematics

PT J
AU Lorenzo, AJ
Rickard, M
Braga, LH
Guo, YB
Oliveria, JP
AF Lorenzo, Armando J.
Rickard, Mandy
Braga, Luis H.
Guo, Yanbo
Oliveria, John-Paul
TI Predictive Analytics and Modeling Employing Machine Learning Technology: The Next Step in Data Sharing, Analysis, and Individualized Counseling Explored With a Large, Prospective Prenatal Hydronephrosis Database

ER
PT J
AU Lorenzo, AJ
Rickard, M
Braga, LH
Guo, YB
Oliveria, JP
AF Lorenzo, Armando J.
Rickard, Mandy
Braga, Luis H.
Guo, Yanbo
Oliveria, John-Paul
TI Predictive Analytics and Modeling Employing Machine Learning Technology: The Next Step in Data Sharing, Analysis, and Individualized Counseling Explored With a Large, Prospective Prenatal Hydronephrosis Database

SO UROLOGY
LA English
DT Article
ID PARENCHYMAL AREA; BIG DATA; CHILDREN; ULTRASOUND; INFANTS; FUTURE;
AB OBJECTIVE To explore the potential value of utilizing a commercially available cloud-based machine learning platform to predict surgical intervention in infants with prenatal hydronephrosis (HN).

MATERIALS AND METHODS A prospective prenatal HN database was uploaded into Microsoft Azure Machine Learning Studio. Probabilistic principal component analysis was employed for data imputation. Multiple clinical variables were included in two-class decision jungle and neural network for model training, using surgical intervention as the primary outcome. Models were scored and evaluated after a 70/30 split of the data.

RESULTS A total of 557 entries were included. The optimized model (decision jungle) achieved an area under the curve of 0.9, accuracy of 0.87, and precision of 0.80, employing a threshold of 0.5 to predict surgery. Average time to train, score and evaluate the model was 5 seconds. The predictive model was deployed as a web service in 35 seconds, generating a unique API key for app and webpage development. Individualized prediction based on the included variables was deployed as a web-based and batch execution Excel file in less than one minute.

CONCLUSION This cloud-based ML technology allows easy building, deployment, and sharing of predictive analytics solutions. Using prenatal HN as an example, we propose an opportunity to address contemporary challenges with data analysis, reporting a creative solution that moves beyond the current standard. (C) 2018 Elsevier Inc.
"You cannot collect data using your own resources and put it on open access": Perspectives from Africa about public health data-sharing

Data-sharing is a desired default in the field of public health and a source of much ethical deliberation. Sharing data potentially contributes the largest, most efficient source of scientific data, but is fraught with contextual challenges which make stakeholders, particularly those in under-resourced contexts hesitant or slow to share. Relatively little empirical research has engaged stakeholders in discussing the issue. This study sought to explore relevant experiences, contextual, and subjective explanations around the topic to provide a rich and detailed presentation of what it means to different stakeholders and contexts to share data and how that can guide practice and ethical guidance. A qualitative design involving interviews was undertaken with professionals working in public health institutions endowed with data (HDSS),
ethics committees, and advisory agencies which help shape health research in Africa. A descriptive form of thematic analysis was used to summarize results into six key themes: (1) The role of HDSSs in research using public health data and data-sharing; (2) Ownership and funding are critical factors influencing data-sharing; (3) Other factors discourage data-sharing; (4) Promoting and sustaining data-sharing; (5) Ethical guidance structures; and (6) Establishing effective guidance. The themes reveal factors regarding the willingness or not to share and an intricate ethical system that current discourse could reflect. Many of the concerns resonate with the literature, but a whole other gamut of people and process issues; commitments, investments, careers, and the right ethical guidance are needed to realize a sustainable goal of reaching 'share' as a default.

[Wangmo, Tenzin; Elger, Bernice Simone] IBMB, Basel, Switzerland.
[Ward, Claire Leonie] IBMB, Hlth Eth, Basel, Switzerland.
[Tanner, Marcel] Univ Basel, Epidemiol & Med Parasitol, Basel, Switzerland.
[Tanner, Marcel] Univ Basel, Swiss Trop & Publ Hlth Inst, Basel, Switzerland.

RP Anane-Sarpong, E (reprint author), Univ Basel, Inst Biomed Eth, CH-4056 Basel, Switzerland.
EM evelyn.anane-sarpong@unibas.ch
RI Elger, Bernice Simone/V-7265-2017
OI Elger, Bernice Simone/0000-0002-4249-7399; Wangmo, Tenzin/0000-0003-0857-0510

FU Institute for Biomedical Ethics (IBMB) of the University of Basel; Swiss Tropical and Public Health Institute of the University of Basel; Basel-Stadt Commission for Scholarships for Young Professionals from Developing Countries; INDEPTH Network

FX This paper is written as part of an academic project on 'New models of public health research: Developing an ethical framework for research using public health data in resource-limited countries'. The project is undertaken under the kind auspices of the Institute for Biomedical Ethics (IBMB) and the Swiss Tropical and Public Health Institute of the University of Basel. Partial funding for the project also came from the Basel-Stadt Commission for Scholarships for Young Professionals from Developing Countries. We are grateful to the INDEPTH Network for its support throughout the project. We also benefitted a great deal from assistance to the overall project by Dr. Charles Mayombana of the Ifakara Health Institute. We are indebted to all participants for taking time from their busy schedules to grant us interviews.

CR Aellah G., 2016, GLOBAL HLTH RES UNEQ
Anane-Sarpong E, 2016, APPL ETHICAL PRINCIP
[Anonymous], 2016, ISSHARE2
[Anonymous], 2015, INDEPTH SCI C
[Anonymous], 2016, US
Asia Pacific Association of Medical Journal Editors, 2015, MAN DECL AV US HLTH
Ault A, 2013, EXPERTS CALL BROAD S
Bayer R., 2017, ETHICAL ISSUES BE CO
Brack M., 2015, DATA SHARING PUBLIC
Braun V., 2006, QUALITATIVE ISSUES PSYC, V3, P77, DOI DOI 10.1191/1478088706QP0630A
Use of an electronic health record data sharing system for identifying current contraceptive use within the WWAMI region Practice and Research Network

Objective: To evaluate the ability of electronic health record (EHR) data extracted into a data-sharing system to accurately identify contraceptive use.

Study design: We compared rates of contraceptive use from electronic extraction of EHR data via a data-sharing system and manual abstraction of the EHR among 142 female patients ages 15-49 years from a family medicine clinic within a primary care practice-based research network (PBRN). Cohen's kappa coefficient measured agreement between electronic extraction and manual abstraction.

Results: Manual abstraction identified 62% of women as contraceptive users, whereas electronic extraction identified only 27%. Long acting reversible (LARC) methods had 96% agreement (Cohen's kappa 0.78; confidence interval, 0.57-0.99) between electronic extraction and manual abstraction. EHR data extracted via a data-sharing system was unable to identify barrier or over-the-counter contraceptives.

Conclusions: Electronic extraction found substantively lower overall rates of contraceptive method use, but produced more comparable LARC method use rates when compared to manual abstraction among women in this study's primary care clinic. Implications: Quality metrics related to contraceptive use that rely on EHR data in this study's data-sharing system likely under-estimated true contraceptive use. (C) 2018 Elsevier Inc. All rights reserved.

The authors thank Rex Force, PharmD, and Loni Chacon, of the Idaho State University Department of Pharmacy Practice and Family Medicine and Alyce Sutko, MD, of the University of Washington Department of Family Medicine for their assistance with this study. The data extraction was supported...
Imaging biomarkers refer to radiological measurements that characterize biological processes of imaged subjects and help clinicians particularly in the assessment of therapeutic responses and the early prediction of pathologies. Several imaging features (size of a lesion, volume of a tumor, blood perfusion in a specific anatomical region, anisotropic water diffusion in a particular tissue region, etc.) are quantified and reported in the clinical practice. The growth of the number of research studies addressing imaging biomarkers and the increasing use of these measurements in the radiological routine necessitates the use of semantic research tools. The use of semantic technologies will enable to efficiently retrieve imaging-related data and to enhance the interoperability in the biomedical field. While many efforts have been conducted regarding the definition of a standardized vocabulary to support the sharing of the imaging biomarker knowledge, the definition of the term imaging biomarker stills inconsistent. In this paper, we introduce our motivation for semantically describing this concept and we outline shortcomings of the state-of-the-art methods. Here, we propose a semantic representation of the imaging biomarker concept that is based on the articulation of its three main semantic axes, namely the measured quality, the measurement tool and the decision tool. The developed ontology is called the Imaging Biomarker Ontology (IBO) and uses existing biomedical ontologies. A preliminary use case is studied to illustrate the utility of IBO in annotating quantitative and qualitative imaging data from the TCGA (The Cancer Genome Atlas) collection.
What is Happening with Quality of Life Among the Oldest People in Southern European Countries? An Empirical Approach Based on the SHARE Data

Population aging in developed countries has created new challenges to improve the well-being of individuals at different age cohorts. This issue is especially significant for Southern European countries, where aging societies have worse health and less socio-economic resources. The aim of this study is to contribute to this body of literature and to estimate the effect of aging on quality of life of oldest people. This paper uses the latest available data (6th wave) from the Survey on Health, Ageing and Retirement in Europe (SHARE). Specifically, robust ordinary least squares and multilevel regressions are employed to analyse the effects of socioeconomic, health, and community factors on quality of life among the oldest population for Southern European countries. Our findings confirm the significance of several factors on life satisfaction among the oldest population in this group of countries. Moreover, we show that the determinants which are correlated with quality of life include predisposing, health, geographic area and social isolation factors.

C1 [Cantarero-Prieto, David; Pascual-Saez, Marta; Blazquez-Fernandez, Carla] Univ Cantabria, Dept Econ, Avda Los Castros S-N, E-39005 Santander, Spain.
RP Cantarero-Prieto, D (reprint author), Univ Cantabria, Dept Econ, Avda Los Castros S-N, E-39005 Santander, Spain.
EM david.cantarero@unican.es; marta.pascual@unican.es; carla.blazquez@unican.es

FX This paper uses data from SHARE Wave 6 (http
see Borsch-Supan et al. (2017) 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, SHARE-LIFE: CIT4-CT-2006028812) 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 U.S. National Institute on Aging (U01_AG09740-13S2, P01_AG005842, P01_AG08291, P30_AG12815, R21_AG025169, Y1-AG-4553-01, TAG_BSR06-11, OGHA_04-064, HHSN271201300071C) and from various national funding sources is gratefully acknowledged (see www.share-project.org).
Big Data Sharing: A Crucial Democratic Issue for Genomic Medicine

This opinion paper is based on a research funded by the Fonds Avenir/Masfip pour la Recherche, 2016.
Mayer-Schonberger Viktor, 2013, BIG DATA REVOLUTION
Murray F, 2010, AM J SOC IOSL, V116, P341, DOI 10.1086/653599

Parthasarathy S, 2005, COMMUNITY GENET, V8, P235, DOI 10.1159/000087961
Parthasarathy S, 2017, BUILDING GENETIC MED
Parthasarathy S, 2006, SHAPING SCI TECHNOLO
Pollack Andrew, 2015, NY TIMES
Reuter, 2017, NEW ILL TECH COULD U

Star SL, 1996, INFORM SYST RES, V7, P111, DOI 10.1287/isre.7.1.111
Stoppa-Lyonnet D., 2014, SCIENCE, V439, P12
Strasser BJ, 2011, ISIS, V102, P60, DOI 10.1086/658657

NR 41
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 2296-2565
J9 FRONT PUBLIC HEALTH
JI Front. Public Health
PD NOV 28
PY 2018
VL 6
AR 334
DI 10.3389/fpubh.2018.00334
PG 4
WC Public, Environmental & Occupational Health
SC Public, Environmental & Occupational Health
GA HC3HW
UT WOS:000451694000001
PM 30547022
OA DOAJ Gold, Green Published
DA 2019-08-06
ER

PT J
AU Yeo, J
  Miller, DP
AF Yeo, Jungwon
  Miller, Daniel P.
TI Estimating switching costs with market share data: an application to
  Medicare Part D
SO INTERNATIONAL JOURNAL OF INDUSTRIAL ORGANIZATION
LA English
DT Article
Choice inertia and switching frictions are well-documented features of the demand for health insurance. In this paper, we estimate switching costs in the Medicare Part D market with aggregate market share data using standard discrete choice models for differentiated products. We consider various modelling assumptions: myopic and forward-looking consumers, and with and without random coefficients. Both myopic and forward-looking consumer models with no random coefficients yield switching cost estimates that closely match the actual average switching frequency, with implied dollar-valued switching costs of $1600 to $2000. We find the inclusion of random coefficients to the myopic consumer model results in smaller estimates of switching costs, but only at the expense of the model's fit to the switching frequency. The estimated welfare losses from switching frictions are large, but they are smaller under the forward-looking consumer model, amounting to around $500 per enrollee annually, compared to over $1000 under the myopic model. (c) 2018 Elsevier B.V. All rights reserved.

C1 [Yeo, Jungwon] Singapore Management Univ, Sch Econ, Singapore, Singapore.
Miller, Daniel P.] Clemson Univ, Dept Econ, Clemson, SC 29631 USA.
RP Yeo, J (reprint author), Singapore Management Univ, Sch Econ, Singapore, Singapore.
EM jungwonyeo.econ@gmail.com; dmille7@g.clemson.edu

Carlin C., 2009, ADVERSE SELECTION WE
Decarolis F., 2012, 12026 PENN I EC RES
Dube JP, 2009, J MARKETING RES, V46, P435, DOI 10.1109/jmkr.46.4.435
Ericson KMM, 2014, AM ECON J-ECON POLIC, V6, P38, DOI 10.1257/pol.6.1.38
Goldenberg-Hart Diane, 2008, EC VOICE, P1
Gowrisankaran G, 2012, J POLIT ECON, V51, P433
Handel BR, 2013, AM ECON REV, V103, P2643, DOI 10.1257/aer.103.7.2643
Heckman JJ, 1981, STUDIES LABOR MARKET, P91
Heiss F, 2006, HEALTH AFFAIR, V25, pW344, DOI 10.1377/hlthaff.25.w344
Heiss Florian, 2010, RES FINDINGS EC AGIN, P413, DOI DOI 10.7208/CHICAGO/9780226903088.003.0015
Ho CY, 2015, INT ECON REV, V56, P723, DOI 10.1111/iere.12120
Ketcham JD, 2012, AM ECON REV, V102, P2639, DOI 10.1257/aer.102.6.2639
Melnikov O., 2012, ECON INQ, V51, P1277
Miller DP, 2019, AM J HEALTH ECON, V5, P191, DOI 10.1112/ajhe_a_00119
Miravete EJ, 2014, REV ECON STAT, V96, P524, DOI 10.1112/REST_a_00386
Nosal K, 2012, WORKING PAPER
Polyakova M, 2016, AM ECON J-APPL ECON, V8, P165, DOI 10.1257/app.20150004
Samuelson W., 1988, J RISK UNCERTAINTY, V1, P7, DOI DOI 10.1007/BF00055564
Strombom BA, 2002, J HEALTH ECON, V21, P89, DOI 10.1016/S0167-6296(01)00124-2

PT J
AU Fadda, M
  Jobin, A
  Blasimme, A
  Tzovaras, BG
  Ball, MP
  Vayena, E
AF Fadda, Marta
  Jobin, Anna
  Blasimme, Alessandro
  Tzovaras, Bastian Greshake
  Ball, Mad Price
  Vayena, Effy
TI User Perspectives of a Web-Based Data-Sharing Platform (Open Humans) on Ethical Oversight in Participant-Led Research: Protocol for a Quantitative Study
SO JMIR RESEARCH PROTOCOLS
LA English
DE ethics; data sharing; patient participation; patient-generated health data; survey; questionnaire; mobile phone
ID PERSONALIZED MEDICINE; SELF-EXPERIMENTATION; CENTRIC INITIATIVES; SYSTEMS BIOLOGY; CITIZEN SCIENCE; HEALTH-CARE; ENGAGEMENT; ONLINE; PARTNERS; VIEWS
AB Background: Advances in medicine rely to a great extent on people's willingness to share their data with researchers. With increasingly widespread
use of digital technologies, several Web-based communities have emerged aiming to enable their users to share large amounts of data, some of which can possibly be employed for research purposes by scientists, or to conduct participant-led research (PLR). Scholarship has recently addressed the necessity of interrogating how existing ethical standards can and should be applied and adapted in view of the specificities of such Web-based activities. So far, no study has explored participants' beliefs about and attitudes toward ethical oversight when it comes to platforms that involve medical data sharing.

Objective: This paper presents the protocol for a survey study aimed at understanding users' beliefs about Web-based data-sharing platforms regarding how research ethics principles should be applied in such a setting. Furthermore, the study aims at quantitatively assessing the relationship between participants' perspectives on ethical oversight and other variables such as previous participation in research, beliefs about data sharing, and attitudes toward self-experimentation.

Methods: We are conducting a Web-based survey with users of a popular Web-based data-sharing platform, Open Humans. The survey has been sent to approximately 4640 users registered for the Open Humans newsletter. To fill out the survey, participants need to have an account on Open Humans. We expect a 5%-10% response rate (between 200 and 400 completed surveys out of approximately 4000 survey invitations sent). Independent variables include past data-sharing behavior and intention, beliefs about data sharing, past participation in research, attitudes toward self-experimentation, perceived knowledge of the platform's guidelines and terms, perceived importance of having transparent guidelines, and governance-related beliefs. The main dependent variable is participants' expectations regarding who should ensure that ethical requirements are met within research projects conducted on open data-sharing platforms, based on Emanuel et al's ethical framework. We will use chi-square tests to assess the relationship between participants' expectations regarding ethical oversight and their past behavior, future intentions, beliefs, attitudes, and knowledge.

Results: Data collection started on June 13, 2018. A reminder to fill out the survey was sent to participants in mid-July. We expect to gain insights on users' perspectives on the ethical oversight of Web-based data-sharing platforms and on the associated experiences, beliefs, and sociodemographic characteristics.

Conclusions: When digital tools allow people to engage in PLR including medical data, understanding how people interpret and envision the ethical oversight of their data-sharing practices is crucial. This will be the first study to explore users' perspectives on ethical oversight of Web-based data-sharing platforms. The results will help inform the development of a framework that can be employed for platforms hosting various kinds of research projects to accommodate participants' ethical oversight needs.

C1 [Fadda, Marta; Jobin, Anna; Blasimme, Alessandro; Vayena, Effy] Swiss Fed Inst Technol, Dept Hlth Sci & Technol, Hlth Eth & Policy Lab, Mauer 17, CH-8092 Zurich, Switzerland.
[Tzovaras, Bastian Greshake; Ball, Mad Price] Open Humans Fdn, Boston, MA USA.
[Tzovaras, Bastian Greshake] Lawrence Berkeley Natl Lab, Div Environm Genom & Syst Biol, Berkeley, CA USA.
RP Vayena, E (reprint author), Swiss Fed Inst Technol, Dept Hlth Sci & Technol, Hlth Eth & Policy Lab, Mauer 17, CH-8092 Zurich, Switzerland.
EM effy.vayena@hest.ethz.ch
RI Jobin, Anna/I-2280-2017
OI Jobin, Anna/0000-0002-4649-7812; Greshake Tzovaras, Bastian/0000-0002-9925-9623; Fadda, Marta/0000-0003-3537-0346
FU Swiss National Science Foundation
FX The authors would like to thank the Swiss National Science Foundation for funding this study.
CR Altman LK, 1987, WHO GOES 1 STORY SEL
Masciocchi, C.
van Soest, J.
Dinapoli, N.
Lenkowicz, J.
Chiloiro, G.
Gambacorta, M. A.
Corvari, B.
Meldolesi, E.
Alitto, A. R.
Boldrini, L.
Dekker, A.
Valentini, V.

TI Learning a Cox Model Predicting Survival Based on 3413 Routine Clinical Rectal Cancer Patients Without Sharing Patient Data

SO INTERNATIONAL JOURNAL OF RADIATION ONCOLOGY BIOLOGY PHYSICS

LA English

DT Meeting Abstract

CT 60th Annual Meeting of the American-Society-for-Radiation-Oncology (ASTRO)

CY OCT 21-24, 2018
CL San Antonio, TX

SP Amer Soc Radiat Oncol


RI Alitto, Anna Rita/K-7233-2018
OI Alitto, Anna Rita/0000-0001-6718-4404
FU Varian Medical Systems


NR 0
TC 0
29 0
U1 0
U2 0

FU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 0360-3016
EI 1879-355X
J9 INT J RADIAT ONCOL
PD NOV 1
PY 2018
VL 102
IS 3
SU S
MA 1121
Background and objective: Clinical prognosis prediction plays an important role in clinical research and practice. The construction of prediction models based on electronic health record data has recently become a research focus. Due to the lack of external validation, prediction models based on single-center, hospital-specific datasets may not perform well with datasets from other medical institutions. Therefore, research investigating prognosis prediction model construction based on a collaborative analysis of multi-center electronic health record data could increase the number and coverage of patients used for model training, enrich patient prognostic features and ultimately improve the accuracy and generalization of prognosis prediction.

Materials and methods: A web service for individual prognosis prediction based on multi-center clinical data collaboration without patient-level data sharing (POPCORN) was proposed. POPCORN focuses on solving key issues in multi-center collaborative research based on electronic health record systems; these issues include the standardization of clinical data expression, the preservation of patient privacy during model training and the effect of case mix variance on the prediction model construction and application. POPCORN is based on a multivariable meta-analysis and a Bayesian framework and can construct suitable
prediction models for multiple clinical scenarios that can effectively adapt to complex clinical application environments.

Results: POPCORN was validated using a joint, multi-center collaborative research network between China and the United States with patients diagnosed with colorectal cancer. The performance of the models based on POPCORN was comparable to that of the standard prognosis prediction model; however, POPCORN did not expose raw patient data. The prediction models had similar AUC, but the BMA model had the lowest ECI across all prediction models, indicating that this model had better calibration performance than the other models, especially for patients in Chinese hospitals.

Conclusions: The POPCORN system can build prediction models that perform well in complex clinical application scenarios and can provide effective decision support for individual patient prognostic predictions.

C1 [Tian, Yu; Shang, Yong; Tong, Dan-Yang; Chi, Sheng-Qiang; Li, Jing-Song] Zhejiang Univ, Engn Res Ctr EMR & Intelligent Expert Syst, Minist Educ, Key Lab Biomed Engn, Coll Biomed Engn, Collaborat Innovat Ctr Diag & Treatment Infect Di, 38 Zheda Rd, Hangzhou 310027, Zhejiang, Peoples R China.


EM ljs@zju.edu.cn

FU National Key Research and Development Program of China [2016YFF0103200, 2017YFC0908200]; National Natural Science Foundation of China [81771936, 81672916]; Key Technology Research and Development Program of Zhejiang Province [2017C03017]

FX This work was supported by the National Key Research and Development Program of China (Grant Nos. 2016YFF0103200 and 2017YFC0908200), the National Natural Science Foundation of China (Grant Nos. 81771936 and 81672916) and the Key Technology Research and Development Program of Zhejiang Province (Grant No. 2017C03017).

Collins FS, 2014, J AM MED INFORM ASSN, V21, P576, DOI 10.1136/amiajnl-2014-002864
Debray TPA, 2015, J CLIN EPIDEMIOL, V68, P280, DOI 10.1016/j.jclinepi.2014.06.018
Fong Y, 1999, ANN SURG, V230, P309, DOI 10.1097/00000658-199909000-00004
Holmes JH, 2014, J AM MED INFORM ASSN, V21, P730, DOI 10.1136/amiajnl-2013-002370
Hong SN, 2017, PLOS ONE, V12, DOI 10.1371/journal.pone.0181040
Hripcsak G, 2015, STUD HEALTH TECHNOL, V216, P574, DOI 10.3233/978-1-61499-564-7-574
Li Y, 2016, J AM MED INFORM ASSN, V23, P570, DOI 10.1093/jamia/ovc146
Martin AD, 2011, J STAT SOFTW, V42, P1
Meeker D, 2015, J AM MED INFORM ASSN, V22, P1187, DOI 10.1093/jamia/ovc017
Growing demand for e-healthcare across the globe has raised concerns towards the secure and authentication enhanced medical image sharing. One of the services offered by health informatics in hospitals include an user interface through the Local Area Network (LAN) for enabling storage and access of medical records. In this paper, a security enhanced DICOM image sharing over a LAN addressing confidentiality, integrity and authentication has been proposed. Initially, the AES encrypted patient history was combined along with the thumb impression and Quick Response (QR) code of patient ID as watermark. This watermark was encrypted employing Integer Wavelet Transform (IWT), chaotic map and attractors with confusion-diffusion operations. Further, the encrypted watermark was embedded in the selected Region Of Non-Interest (RONI) pixels of DICOM image. Username & unique password credentials, Face identification and FPGA generated One Time Password (OTP) form the three layer authentication scheme for secure DICOM image access through the LAN. Web publishing medium of storing secured DICOM images in cloud has also been addressed in this work. To validate the proposed hybrid crypto-watermarking system, parameters such as key sensitivity, key space, correlation, entropy, histogram, cropping attack, Mean Square Error (MSE), Peak Signal to Noise Ratio (PSNR) and Structural Similarity Index Metric (SSIM) were performed and the results obtained have proved the strength of the proposed algorithm against brute force, statistical and cropping attacks.

C1 [Arumugham, Sridevi; Rajagopalan, Sundararaman; Rayappan, John Bosco Balaguru; Amirtharajan, Rengarajan] SASTRA Deemed Univ, Sch Elect & Elect Engn, Thanjavur 613401, India.
RP Amirtharajan, R (reprint author), SASTRA Deemed Univ, Sch Elect & Elect Engn, Thanjavur 613401, India.
EM amir@ece.sastra.edu
RI ; Amirtharajan, Rengarajan/C-6471-2011
OI Sundararaman, Rajagopalan/0000-0003-3505-3260; Amirtharajan, Rengarajan/0000-0003-1574-3045
FU SASTRA Deemed University, Thanjavur [R&M/0026/SEE 010/2012 - 13]
FX The authors express their sincere thanks to SASTRA Deemed University, Thanjavur for providing infrastructure through the Research & Modernization Fund (Ref. No: R&M/0026/SEE 010/2012 - 13) to carry out the research work.

CR Ajili S, 2015, I C SCI TECH AUTO CO, P69, DOI 10.1109/STA.2015.7505164
Fu C, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0115773
Fu ZJ, 2017, IEEE T INF FOREN SEC, V12, P1874, DOI 10.1109/TIFS.2017.2692728
Objective: We executed the Social Media Mining for Health (SMM4H) 2017 shared tasks to enable the community-driven development and large-scale evaluation of automatic text processing methods for the classification and normalization of health-related text from social media. An additional objective was to publicly release manually annotated data.

Materials and Methods: We organized 3 independent subtasks: automatic classification of self-reports of 1) adverse drug reactions (ADRs) and 2) medication consumption, from medication-mentioning tweets, and 3) normalization of ADR expressions. Training data consisted of 15 717 annotated tweets for (1), 10 260 for (2), and 6650 ADR phrases and identifiers for (3); and exhibited typical properties of social-media-based health-related texts. Systems were evaluated using 9961, 7513, and 2500 instances for the 3 subtasks, respectively.
We evaluated performances of classes of methods and ensembles of system combinations following the shared tasks.

Results: Among 55 system runs, the best system scores for the 3 subtasks were 0.435 (ADR class F1-score) for subtask-1, 0.693 (micro-averaged F1-score over two classes) for subtask-2, and 88.5% (accuracy) for subtask-3. Ensembles of system combinations obtained best scores of 0.476, 0.702, and 88.7%, outperforming individual systems.

Discussion: Among individual systems, support vector machines and convolutional neural networks showed high performance. Performance gains achieved by ensembles of system combinations suggest that such strategies may be suitable for operational systems relying on difficult text classification tasks (eg, subtask-1).

Conclusions: Data imbalance and lack of context remain challenges for natural language processing of social media text. Annotated data from the shared task have been made available as reference standards for future studies (http://dx.doi.org/10.17632/rxwfb3tysd.1).

C1 [Sarker, Abeed; Gonzalez-Hernandez, Graciela] Univ Penn, Perelman Sch Med, Dept Biostatist Epidemiol & Informat, 423 Guardian Dr 421A, Philadelphia, PA 19104 USA.


[Friedrichs, Jasper] Infosys Ltd, Palo Alto, CA USA.

[Hakala, Kai; Mehrarchy, Farrokh; Ginter, Filip] Univ Turku, Dept Future Technol, Turku NLP Grp, Turku, Finland.

[Kiritchenko, Svetlana; de Bruijn, Berry; Mohammad, Saif M.] Natl Res Council Canada, Digital Technol Res Ctr, Ottawa, ON, Canada.

[Han, Sifei; Tung Tran; Rios, Anthony; Kavuluru, Ramakanth] Univ Kentucky, Dept Comp Sci, Lexington, KY 40506 USA.

[Kavuluru, Ramakanth] Univ Kentucky, Dept Internal Med, Div Biomed Informat, Lexington, KY USA.

[Mahata, Debanjan] Bloomberg, New York, NY USA.

RP Sarker, A (reprint author), Univ Penn, Perelman Sch Med, Dept Biostatist Epidemiol & Informat, 423 Guardian Dr 421A, Philadelphia, PA 19104 USA.

EM abeed@pennmedicine.upenn.edu

OI Sarker, Abeed/0000-0001-7358-544X; Mehrarchy, Farrokh/0000-0002-5555-2828; Mohammad, Saif/0000-0003-2716-7516

FU National Institutes of Health (NIH) National Library of Medicine (NLM) [NIH NLM R01LM011176]; ATT Tieto kayttoon grant; NIH National Cancer Institute [R21CA218231]; NVIDIA Corporation; UK EPSRC [EP/I028099/1, EP/N027280/1]

FX AS and GG were partially supported by the National Institutes of Health (NIH) National Library of Medicine (NLM) grant number NIH NLM R01LM011176. KH, FM, and FG (TurkuNLP) are supported by ATT Tieto kayttoon grant. SH, TT, AR, and RK (UKNLP) are supported by the NIH National Cancer Institute through grant R21CA218231 and NVIDIA Corporation through the Titan X Pascal GPU donation. MB and GN are supported by the UK EPSRC (grants EP/I028099/1 and EP/N027280/1). The content is solely the responsibility of the authors and does not necessarily represent the official views of the funding agencies.

CR [Anonymous], 2017, SIGNLL C COMP NAT LA

Aphinyanaphongs Y, 2016, BIOCOMPUT-PAC SYM, P480


Belousov M, 2017, P 2 WORKSH SOC MED M, P54

Bouma G., 2009, P GSCL, P31
Brennan PF, 2018, J AM MED INFORM ASSN, V25, P2, DOI 10.1093/jamia/ocx146
Charles-Smith LE, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0139701
CLEF eHealth, 2018, LAB OV CLEF EHEALTH
Coppersmith G, 2015, P 2 WORKSH COMP LING, P31
Demmer-Fushman D, 2016, Yearb Med Inform, P224
Dodds PS, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0026752
Friedrichs J, 2017, P 2 WORKSH SOC MED M, P68
Godin F, 2015, ACL IJCNLP, V2015, P146, DOI 10.1126/SCIENCE.1247727
Hakala K, 2017, P 2 WORKSH SOC MED M, P59
Han B, 2013, ACM T INTEL SYST TEC, V4, DOI 10.1145/2414425.2414430
Han S, 2017, P 2 WORKSH SOC MED M, P49
Jain S, 2017, P 2 WORKSH SOC MED M, P72
Jozefowicz R, EMPIRICAL EXPLORATION
Kennedy B., 2015, PUBLIC INTEREST SCI
Kiritchenko S, 2017, P 2 WORKSH SOC MED M, P1
Klein A, P BIONLP 2017 WORKSH, P136
Magge A, 2017, P 2 WORKSH SOC MED M, P76
Mollemia L, 2015, J MED INTERNET RES, V17, DOI 10.2196/jmir.3863
National Institute of Standards and Technology, 2017, TEXT AN C
Paul Michael J, 2011, ICWSM, P265
PEW Research Center, 2017, DEM SOC MED US AD US
Sarker A, 2017, CEUR WORKSHOP P, P43
Sarker A, 2016, BIOCOMPUT-PAC SYM, P581
Sarker A, 2015, J BIOMED INFORM, V54, P202, DOI 10.1016/j.jbi.2015.02.004
Savova GK, 2010, J AM MED INFORM ASSN, V17, P507, DOI 10.1136/jamia.2009.001560
Shin B., 2017, P 8 WORKSH COMP APPR, P149
Souverign J, 2016, J BIOMED INFORM, V63, P100, DOI 10.1016/j.jbi.2016.06.010
Struik Laura Louise, 2014, J Med Internet Res, V16, pe170, DOI 10.2196/jmir.3189
Tsui F, 2017, P 2 WORKSH SOC MED M, P64
Wang C-K, 2017, P 2 WORKSH SOC MED M, P83
Warriner AB, 2013, BEHAV RES METHODS, V45, P1191, DOI 10.3758/s13428-012-0314-x
Z9 0
TC 0
Z9 0
Improved Functional Proxy Re-encryption Schemes for Secure Cloud Data Sharing

AB Recently Liang et al. propose an interesting privacy-preserving ciphertext multi-sharing control for big data storage mechanism, which is based on the cryptographic primitive of anonymous multi-hop identity based conditional proxy re-encryption scheme AMH-IBCPRE. They propose a concrete AMH-IBCPRE scheme and conclude their scheme can achieve IND-sCon-sID-CCA secure (indistinguishable secure under selectively conditional selectively identity chosen ciphertext attack). However, our research show their scheme can not be IND-sCon-sID-CCA secure for single-hop and multi-hop data sharing. Also in 2014, Liang et al. propose an interesting deterministic finite automata-based functional proxy reencryption scheme DFA-based FPRE for secure public cloud data sharing, they
also conclude their scheme can achieve IND-CCA secure (indistinguishable secure under chosen ciphertext attack), we also show their scheme can not be IND-CCA secure either. For these two proposals, the main reason of insecurity is that part of the re-encryption key has the same structure as the valid ciphertext, thus the adversary can query on the decryption oracle with this part of the re-encryption key to get secret keys, which will break the CCA-security of their scheme. We give an improved AMH-IBC-PRE scheme and an improved DFA-based FPRE scheme for cloud data sharing and show the new schemes can resist our attack and be CCA-secure. We also demonstrate our improved AMH-IBC-PRE scheme’s efficiency compared with other related identity based proxy re-encryption schemes, the results show our scheme is almost the most efficient one.

Cl [Wang, Xu An; Yang, Xiaoyuan; Li, Cong; Liu, Yudong] Engn Univ Chinese Armed Police Force, Key Lab Informat & Network Secur, Xian, Shaanxi, Peoples R China.

[Wang, Xu An; Ding, Yong] Guilin Univ Elect Technol, Guangxi Key Lab Cryptog & Informat Secur, Guilin, Peoples R China.

RP Wang, XA (reprint author), Engn Univ Chinese Armed Police Force, Key Lab Informat & Network Secur, Xian, Shaanxi, Peoples R China.; Wang, XA (reprint author), Guilin Univ Elect Technol, Guangxi Key Lab Cryptog & Informat Secur, Guilin, Peoples R China.

EM wangxazjd@163.com; xyyangwj@126.com; wugongcong@163.com; 1269124170@qq.com; 284722748@qq.com

FU National Natural Science Foundation of China [61772550, 61572521, U1636114, 61402531]; National Cryptography Development Fund of China [MMJJ20170112]; National Key Research and Development Program of China [2017YFB0802000]; Natural Science Basic Research Plan in Shaanxi Province of china [2018JM6028]; Guangxi Key Laboratory of Cryptography and Information Security [GCIS201610]

FX This work is supported by National Natural Science Foundation of China (Grant Nos. 61772550, 61572521, U1636114, 61402531), National Cryptography Development Fund of China Under Grants No. MMJJ20170112, National Key Research and Development Program of China Under Grants No. 2017YFB0802000, Natural Science Basic Research Plan in Shaanxi Province of china (Grant Nos. 2018JM6028) and Guangxi Key Laboratory of Cryptography and Information Security (No. GCIS201610).

CR Akinyele A., 2015, ACM CCS 20015, P1370
Aranha D., RELCC IS EFFICIENT L
Ateniese G., 2005, NDSS, P29
Ateniese G., 2016, ACM TRANSACTION INFORM, V9, P1
Blaze M, 1998, LECT NOTES COMPUT SC, V1403, P127
Canetti R, 2007, CCS'07: PROCEEDINGS OF THE 14TH ACM CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P185
Chow SSM, 2010, LECT NOTES COMPUT SC, V6055, P316
Deng RH, 2008, LECT NOTES COMPUT SC, V5339, P1, DOI 10.1007/978-3-540-89641-8_1
Green M, 2007, LECT NOTES COMPUT SC, V4521, P288
Li FG, 2017, COMPUTING, V99, P465, DOI 10.1007/s00607-017-0548-7
Libert B, 2008, LECT NOTES COMPUT SC, V4939, P360, DOI 10.1109/TIFS.2014.2346023
Miao YB, 2018, IEEE INTERNET THINGS, V5, P3008, DOI 10.1109/JIOT.2017.2779124
Shao J., 2009, SECURITY COMMUNICATI, V2, P1
Shao J, 2009, LECT NOTES COMPUT SC, V5443, P357
Torbjorn G., 2012, GNU MP GNU MULTIPLE
Weng J, 2009, LECT NOTES COMPUT SC, V5735, P151, DOI 10.1007/978-3-642-04474-8_13
Zhu SS, 2015, INT J GRID UTIL COMP, V6, P91
Cancer survivor viewpoints on sharing patient generated health data with central cancer registries

TI Cancer survivor viewpoints on sharing patient generated health data with central cancer registries
SO QUALITY OF LIFE RESEARCH
LA English
DT Meeting Abstract
C1 [Smith, Tenbroeck] Amer Canc Soc, Atlanta, GA 30329 USA.
[Aaronson, Neil; van de Poll-Franse, Lonneke] Netherlands Canc Inst, Amsterdam, Netherlands.
[Levin, Kerry; Tsakraklides, Sophia; Dunn, Marsha] Westat Corp, Rockville, MD USA.
[Wu, Xiao-Cheng] Louisiana Tumor Registry, New Orleans, LA USA.
[Wiggins, Charles] New Mexico Tumor Registry, Albuquerque, NM USA.
[Ward, Kevin] Emory Univ, Atlanta, GA 30322 USA.
[Mitchell, Sandra; Penberthy, Lynne] NCI, Bethesda, MD 20892 USA.
[Hurlbert, Marc] Metastat Breast Canc Alliance, New York, NY USA.
FU Metastatic Breast Cancer Alliance; American Cancer Society;
Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute
FX Intramural funding was provided by the Metastatic Breast Cancer Alliance and the American Cancer Society. Support was also provided by the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute.

NR 0
TC 0
Z9 0
U1 0
U2 0
FU SPRINGER
PI DORDRECHT
PA VAN GODEWIJCKSTRAAT 30, 3311 GZ DORDRECHT, NETHERLANDS
SN 0962-9343
Background: The importance of data and information sharing for the prevention and control of infectious diseases has long been recognised. In recent years, public health emergencies such as avian influenza, drug-resistant malaria, and Ebola have brought renewed attention to the need for effective communication channels between health authorities, particularly in regional contexts where neighbouring countries share common health threats. However, little empirical research has been conducted to date to explore the range of factors that may affect the transfer, exchange, and use of public health data and expertise across borders, especially in developing contexts.

Methods: To explore these issues, 60 interviews were conducted with domestic and international stakeholders in Cambodia and Vietnam, selected amongst those who were involved in regional public health programmes and networks. Data analysis was structured around three categories mapped across the dataset: (1) the nature of shared data and information; (2) the nature of communication channels; and (3) how information flow may be affected by the local, regional, and global system of rules and arrangements.

Results: There has been a great intensification in the circulation of data, information, and expertise across borders in Southeast Asia. However, findings from this study document ways in which the movement of data and information from
production sites to other places can be challenging due to different standards and practices, language barriers, different national structures and rules that govern the circulation of health information inside and outside countries, imbalances in capacities and power, and sustainability of financing arrangements.

Conclusions: Our study highlights the complex socio-technical nature of data and information sharing, suggesting that best practices require significant involvement of an independent third-party brokering organisation or office, which can redress imbalances between country partners at different levels in the data sharing process, create meaningful communication channels and make the most of shared information and data sets.


[Liverani, Marco; Coker, Richard] Mahidol Univ, Fac Publ Hlth, Bangkok, Thailand.


EM marco.liverani@lshtm.ac.uk

FU UK Economic and Social Research Council (ESRC) [ES/K009990/1]

FX This study was supported by the UK Economic and Social Research Council (ESRC) (grant no ES/K009990/1). The funding body had no role in the design or execution of the present study or the writing of this paper.

CR Acharya Amitav, 2014, CONSTRUCTING SECURIT

ADB, 2014, PREV CONTR AC INFL A

Annear PL, 2015, KINGDOM CAMBODIA HLT

[Anonymous], 2013, EM RESP ART RES GRE A

ASEAN, 2016, WORK TOG ADDR COMPL


Bwire G, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0156674


Chatham House, 2017, GUID SHAR DAT BEN PU


Collins-Dogrul J, 2006, SOC SCI MED, V63, P3199, DOI

10.1016/j.socscimed.2006.07.031


Goffman E., 1967, INTERACTION RITUAL E


Gulrajani N., 2016, BILATERAL VERSUS MUL


Hate K, 2015, J EMPIR RES HUM RES, V10, P239, DOI 10.1177/1556264615592383


Jao I, 2015, PLOS ONE, V10, DOI 10.1371/journal.pone.0135545


Lazarou E., 2017, FUTURE MULTILATERALI
Leonelli S., 2016, DATA CENTRIC BIOL PH
Leventhal A, 2013, EMERG HLTH THREATS J, V6, P1
Leventhal A, 2006, BRIT MED J, V333, P856, DOI 10.1136/bmj.38994.420926.80
Liverani M, 2013, REGIONAL MECH COMMUN
Moore M, 2012, GLOBAL HLTH GOVERNAN, V5, P1
Obstfeld D, 2005, ADMIN SCI QUART, V50, P100, DOI 10.1215/03616878-1813772
OECD, 2011, UNL POT S S COOP
Ope Maurice, 2013, EMERGING HLTH THREAT, V6, P1
Phommasack Bounlay, 2013, EMERGING HLTH THREAT, V6, P1
Raymond CW, 2014, PATIENT EDUC COUNS, V97, P38, DOI 10.1016/j.pec.2014.05.020
Rhee H, 2011, CATALYZING DEVELOPMENT: A NEW VISION FOR AID, P260
Ross E., 2014, PERSPECTIVES DATA SH
Socheat Doung, 2003, Southeast Asian Journal of Tropical Medicine and Public Health, V34, P1
Strauss A, 1998, BASICS QUALITATIVE R
Tarantola A, 2014, PLOS NEGL TROP DIS, V8, DOI 10.1371/journal.pntd.0002533
Thomas N, 2006, ASIAN SURV, V46, P917, DOI 10.1525/as.2006.46.6.917
UN, 2012, HIG LEV COMM S S CO
UNDP, 2007, EV UNDP CONTR S S CO
UNOCHA, 2015, EB B
WHO, 2017, WHO M ETH DAT SOUR GL
WHO, 2007, BI REG M BANGK 26 28
Yin R. K., 2014, CASE STUDY RES DESIG
Yu-Hung Lai A, 2013, E S E ASIA INT RELAT

ER 65
TC 0
29 0
U1 3
U2 8
PU BMC
PI LONDON
PA CAMPUS, 4 CRINAN ST, LONDON N1 9XW, ENGLAND
SN 1744-8603
J9 GLOBALIZATION HEALTH
JI Global. Health
PD SEP 29
PY 2018
VL 14
AR 94
DI 10.1186/s12992-018-0415-0
PG 12
WC Public, Environmental & Occupational Health
The Importance of Relevance: Willingness to Share eHealth Data for Family Medicine Research

Objective: To determine the proportion of family medicine patients unwilling to allow their eHealth data to be used for research purposes, and evaluate how patient characteristics and the relevance of research impact that decision.

Design: Cross-sectional questionnaire.

Setting: Acute care respiratory clinic or an outpatient family medicine clinic in Montreal, Quebec.

Participants: Four hundred seventy-four waiting room patients recruited via convenience sampling.

Main Outcome Measures: A self-administered questionnaire collected data on age, gender, employment status, education, mother tongue and perceived health status. The main outcome of was self-reported relevance of three research scenarios and willingness or refusal to share their anonymized data. Responses were compared for family practice vs. specialty care patients.

Results: The questionnaire was completed by 229 family medicine respondents and 245 outpatient respondents. Almost a quarter of all respondents felt the research was not relevant. Family medicine patients (15.7%) were unwilling to allow their data to be used for at least one scenario vs. 9.4% in the outpatient clinic. Lack of relevance (OR 11.55; 95% CI 5.12-26.09) and being in family practice (OR 2.13; 95% CI 1.06-4.27) increased the likelihood of refusal to share data for research.

Conclusion: Family medicine patients were somewhat less willing to share eHealth data, but the overall refusal rate indicates a need to better engage patients in understanding the significance of full access to eHealth data for the purposes of research. Personal relevance of the research had a strong impact on the responses arguing for better efforts to make research more pertinent to patients.

Data was provided from funds awarded to GB through the McGill University Health Centre Research Institute for the Clinical, Evaluative and Public Health Research Pilot Project Competition entitled, Informing patients: A pilot project to develop different methods of gaining consent for the use of data from electronic health records in healthcare research.


Gunter TD, 2005, J MED INTERNET RES, V7, DOI 10.2196/jmir.7.1.e3


Jensen PB, 2012, NAT REV GENET, V13, P395, DOI 10.1038/nrg3208


McCarthy DB, 1999, HEALTH SERV RES, V34, P417

Parker Michael, 2005, J Health Serv Res Policy, V10, P183, DOI 10.1258/1355819054338960

Phillips RL, 2014, ANN FAM MED, V12, pS1, DOI 10.1370/afm.1699


Wager K A, 2000, J Am Board Fam Pract, V13, P338


Willison DJ, 2008, J MED ETHICS, V34, P308, DOI 10.1136/jme.2006.020032


Woolf SH, 2000, ARCH FAM MED, V9, P1111, DOI 10.1001/archfami.9.10.1111

Yawn BP, 1998, J FAM PRACTICE, V47, P361

NR 24

TC 0

Z9 0

U1 0

U2 5

FU FRONTIERS MEDIA SA

PI LAUSANNE

PA AVENUE DU TRIBUNAL FEDERAL 34, LAUSANNE, CH-1015, SWITZERLAND

SN 2296-2565

J9 FRONT PUBLIC HEALTH

JI Front. Public Health

PD SEP 4

FY 2018

VL 6

AR 255
Sharing data from electronic health records within, across, and beyond healthcare institutions: Current trends and perspectives

JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION

McCormick, Barry Hill, Peter-Sam Redding, Stuart
Objective Various studies find that the share of emergencies in hospital admissions is higher in deprived areas, but both the explanation and policy implications are unclear. We estimate the extent to which this finding is due to a different disease mix in deprived areas, rather than other explanations such as patient behaviour and general practitioner effectiveness.

Design Secondary analysis using English Hospital Episode Statistics data, with disease for elective and emergency admissions in 2008/2009 coded at 186 blocks or 1230 categories and aggregated to lower layer super output area of residence. It is then linked to an appropriate measure of deprivation.

Outcome measures The difference in the share of emergencies in hospital admissions between communities in the highest and lowest deciles of deprivation; and the percentage of this difference that is explained if areas in the least deprived decile have the same disease mix as those in the most deprived decile.

Results Using the finest disease classification scheme (1230 categories), 71% of the higher share of admissions that were emergencies in decile 1 areas relative to decile 10, is explained by the adverse case mix (CM) in deprived areas. The remainder reflects the higher relative use of emergency care in deprived areas for the same conditions. Higher incidence of respiratory and circulatory diseases in deprived areas explains about 30% of the CM contribution. Diseases of the digestive system and abdomen have a high relative use of emergency care in deprived areas.

Conclusions The higher use of emergency care in deprived areas is primarily a symptom of the higher prevalence of diseases which have high national rates of emergency to elective care especially respiratory diseases rather than an indication of less effective primary care. Nevertheless, there is a higher share of emergency care in admissions in deprived areas for several diseases, most notably of the digestive system.


EM stuart.redding@phc.ox.ac.uk


Allin S, 2011, APPL ECON, V43, P2229, DOI 10.1080/00036840903196621

Ashworth M, 2007, BRIT J GEN PRACT, V57, P441


Blatchford O, 1999, BRIT J GEN PRACT, V49, P551

Cabinet Office and Department of Health, 2010, INCL HLTH IMPR WAY W

CHATURVEDI N, 1995, BRIT J GEN PRACT, V45, P127

Cookson R, 2012, SOC SCI MED, V75, P1514, DOI 10.1016/j.socscimed.2012.05.033


Dixon Anna, 2007, J Health Serv Res Policy, V12, P104, DOI 10.1258/135581907780279549
Duffy R, 2002, BRIT J GEN PRACT, V52, P14
Marmot M., 2010, MARMOT REV FAIR SOC
Noble M, 2008, ENGLISH INDICES DEPR
Purdy S., 2010, AVOIDING HOSP ADMISS
Reid FDA, 1999, BRIT MED J, V319, P98, DOI 10.1136/bmj.319.7202.98
Stirling AM, 2001, BRIT J GEN PRACT, V51, P456
Van der Heyden JHA, 2003, HEALTH POLICY, V65, P153, DOI 10.1016/S0168-8510(02)00213-0
Wang Y, 2009, SINGLE HANDED GEN PR
Wright J, 2006, BRIT J GEN PRACT, V56, P277
Sharing massive amounts of medical data is critical to precision medicine. The California Department of Public Health recently started to partner with certain hospitals in the state to better understand cancer trends by collecting and securely sending standardized cancer data directly to the California Cancer Registry. This initiative is the first of its kind in the United States. This has afforded the cancer registry the opportunity to perform real-time surveillance on data reported via participating hospitals, and researchers can use advanced methods to analyze these data. Other states are likely to follow California's lead. However, there are barriers to increased data-sharing efforts. How these barriers can be addressed to facilitate data sharing while protecting individual privacy, reducing the risk of data misuse, and enhancing public trust becomes critical as precision medicine moves forward.

NDEx, the Network Data Exchange: Collaboration, publication and data sharing for cancer pathways

CANCER RESEARCH

ENGLISH

Meeting Abstract

Annual Meeting of the American-Association-for-Cancer-Research (AACR)

APR 14-18, 2018

Chicago, IL

Amer Assoc Canc Res
A Cloud Based Solution for Collaborative and Secure Sharing of Medical Data

Healthcare sector is under pressure to reduce costs while delivering high quality of care services. This situation requires that clinical staff, equipment and IT tools to be used more equitably, judiciously and efficiently. In this sense, collaborative systems have the ability to provide opportunities for healthcare organizations to share resources and create a collaborative working environment. The lack of interoperability between dissimilar systems and operating costs are the major obstacle to the implementation of this concept. Fortunately, cloud computing has great potential for addressing interoperability issues and significantly reducing operating costs. Since the laws and regulations prohibit the disclosure of health information, it is necessary to carry out a comprehensive study on security and privacy issues in cloud computing. Based on their analysis of these constraints, the authors propose a simple and efficient method that enables secure collaboration between healthcare institutions. For this reason, they propose Secure Multi-party Computation (SMC) protocols to ensure compliance with data protection legislation. Specifically, the authors use Paillier scheme to protect medical data against unauthorized usage when outsourcing computations to a public cloud. Another useful feature of
this algorithm is the possibility to perform arithmetic operations over encrypted data without access to the original data. In fact, the Paillier algorithm is an efficient homomorphic encryption that supports addition operations on ciphertexts. Based on the simulation results, the proposed framework helps healthcare organizations to successfully evaluate a public function directly on encrypted data without revealing their private inputs. Consequently, the proposed collaborative application ensures privacy of medical data while completing a task.

C1 [Marwan, Mbarek; Kartit, Ali; Ouahmane, Hassan] Chouaib Doukkali Univ, LTI Lab, ENSA, El Jadida, Morocco.
RP Marwan, M (reprint author), Chouaib Doukkali Univ, LTI Lab, ENSA, El Jadida, Morocco.
Abouelmehdi K., 2018, J BIG DATA, V5
Anjum A, 2018, COMPUT SECUR, V72, P196, DOI 10.1016/j.cose.2017.09.014
Bajwa NK, 2017, INT J HEALTHC INF SY, V12, P1, DOI 10.4018/IJHISI.2017040101
Canetti R, 2000, J CRYPTOLOG, V13, P143, DOI 10.1007/s001459910006
Deepthi S, 2017, 2017 2ND IEEE INTERNATIONAL CONFERENCE ON WIRELESS COMMUNICATIONS, SIGNAL PROCESSING AND NETWORKING (WISPNET), P147, DOI 10.1109/WISPNET.2017.8300008
Feng YS, 2015, INTELL AUTOM SOFT CO, V21, P51, DOI 10.1080/10798587.2014.915109
Goldreich O, 2009, FDN CRYPTOGRAPHY, V2
Harsha Sandaruwan G. P, 2013, THESIS
Hu N, 2006, IEEE IMAGE PROC, P1553, DOI 10.1109/ICIP.2006.312603
Iqbal S, 2016, SECUR COMMUN NETW, V9, P4726, DOI 10.1002/sec.1585
Jarecki J, 2007, LECT NOTES COMPUT SC, V4515, P97
Jouini M, 2016, INT J ENTERP INF TECHNOL WE, V11, P50, DOI 10.4018/IJITWE.2016070104
Krishna BH, 2016, PROCEDIA COMPUT SCI, V87, P246, DOI 10.1016/j.procs.2016.05.156
Lee LJH, 2016, INT J ENTERP INF SYS, V12, P47, DOI 10.4018/IJEIS.2016040104
Li SD, 2014, INFORM SCIENCES, V282, P401, DOI 10.1016/j.ins.2014.04.004
Mell P., 2009, NIST DEFINITION CLOU, V53, P1
Paillier P, 1999, LECT NOTES COMPUT SC, V1592, P223
Sifou F., 2018, LECT NOTES NETWORKS, V37, P255, DOI [10.1007/978-3-319-74500-8_23, DOI 10.1007/978-3-319-74500-8_23]
Tawfik A. M., 2018, ARAB J SCI ENG, P1
Yao A. C., 1986, 27th Annual Symposium on Foundations of Computer Science (Cat. No.86CH2354-9), P162, DOI 10.1109/SFCS.1986.25
Yi X, 2015, P 10 ACM S INF COMP, P439, DOI DOI 10.1145/2714576.2714603
PB 1
PF 1
PG 18
PJ INT J ENTERP INF SY
PJ Int. J. Enterp. Inf. Syst.
PL JUL-SEP
PL 2018
PM JUL
PL 14
JR 1
JA 1
J9 INT J ENTERP INF SY
J9 Int. J. Enterp. Inf. Syst.
J8 Computer Science, Information Systems
J8 Computer Science
J7 HI0IE
J6 WOS:000456124500007
J5 2019-08-06
J4 2019-07-21
J3 2019-07-19
J1 2019-07-18
J0 2019-07-17
ER 1
EU 5
EV 5
EA 7
EI 145
E9 0
E8 0
E7 0
E6 0
E5 0
E4 0
E3 0
E2 0
E1 0
DC 0
CT 0
CA 79
BP 145
AE 4
AI 4
AU Rendina, HJ
AU Mustanski, B
AT Mustanski, Brian
AF Rendina, H. Jonathon
AF Mustanski, Brian
AT Privacy, Trust, and Data Sharing in Web-Based and Mobile Research: Participant Perspectives in a Large Nationwide Sample of Men Who Have Sex With Men in the United States
SO JOURNAL OF MEDICAL INTERNET RESEARCH
Background: Modern research is heavily reliant on online and mobile technologies, which is particularly true among historically hard-to-reach populations such as gay, bisexual, and other men who have sex with men (GBMSM). Despite this, very little empirical research has been published on participant perspectives about issues such as privacy, trust, and data sharing.

Objective: The objective of our study was to analyze data from an online sample of 11,032 GBMSM in the United States to examine their trust in and perspectives on privacy and data sharing within online and mobile research.

Methods: Participants were recruited via a social networking site or sexual networking app to complete an anonymous online survey. We conducted a series of repeated measures analyses adjusted for between-person factors to examine within-person differences in the following: (1) trust for guarding personal information across different venues (eg, online research conducted by a university vs. an online search engine); (2) privacy concerns about 12 different types of data for three distinct data activities (ie, collection by app owners, anonymous selling to third parties, and anonymous sharing with researchers); and (3) willingness to share those 12 different types of data with researchers. Due to the large sample size, we primarily reported measures of effect size as evidence of clinical significance.

Results: Online research was rated as most trusted and was more trusted than online and mobile technology companies, such as app owners and search engines, by magnitudes of effect that were moderate-to-large ($\eta^2_{(partial)}=0.06-0.11$). Responding about 12 different types of data, participants expressed more concerns about data being anonymously sold to third-party partners (mean 7.6, median 10.0) and fewer concerns about data being collected by the app owners (mean 5.8, median 5.0) or shared anonymously with researchers (mean 4.6, median 3.0); differences were small-to-moderate in size ($\eta^2_{(partial)}=0.01-0.03$). Furthermore, participants were most willing to share their public profile information (eg, age) with researchers but least willing to share device usage information (eg, other apps installed); the comparisons were small-to-moderate in size ($\eta^2_{(partial)}=0.03$).

Conclusions: Participants reported high levels of trust in online and mobile research, which is noteworthy given recent high-profile cases of corporate and government data security breaches and privacy violations. Researchers and ethical boards should keep up with technological shifts to maintain the ability to guard privacy and confidentiality and maintain trust. There was substantial variability in privacy concerns about and willingness to share different types of data, suggesting the need to gain consent for data sharing on a specific rather than broad basis. Finally, we saw evidence of a privacy paradox, whereby participants expressed privacy concerns about the very types of data-related activities they have likely already permitted through the terms of the apps and sites they use regularly.

C1 [Rendina, H. Jonathon] CUNY Hunter Coll, Dept Psychol, 695 Pk Ave, New York, NY 10065 USA.


RP Rendina, HJ (reprint author), CUNY Hunter Coll, Dept Psychol, 695 Pk Ave, New York, NY 10065 USA.

EM hrendina@hunter.cuny.edu

RI Rendina, H. Jonathon/M-9286-2016
FX HJR was supported in part by a career development award from the National Institute on Drug Abuse (K01-DA039060; PI: HJR). Data collection for this paper was supported in part by the Fordham HIV Prevention Ethics Training Institute (RETI) via a training grant sponsored by the National Institute on Drug Abuse (R25-DA031608, PI: Celia B Fisher). The authors also acknowledge the generous funding provided by the offices of the President, Provost, and the Dean of Arts & Sciences of Hunter College, CUNY; additional support was also provided by Hunter College's Center for HIV Educational Studies & Training (CHEST). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health, the Fordham HIV Prevention Research Ethics Training Institute, or Hunter College, CUNY.
It is increasingly recognised that effective and appropriate data sharing in biobanking research requires the development of models of good data-sharing policy capable of ensuring that the rights and privacy interests of participants are protected. However, the effectiveness and efficacy of biobank research depend on data and samples. In the same vein, making such data available to the...
research community generates tension between two important goals: advancing scientific goals, and protecting the individual privacy interests of the tissue source. More critically, data sharing requires the development of models that promote an environment in which privacy rights and interests of the tissue source. These issues are further exacerbated in Nigeria by cultural and religious inflections. In this paper, to analyse the implications of data sharing within the legal framework of an LMIC, an analysis of existing laws in Nigeria was conducted. It was discovered that there were no provisions relating directly to data sharing, and its governance framework could only be gleaned from the patchwork of laws on privacy and confidentiality in Nigeria. There is a need for ethical guidelines in Nigeria to be adapted to the changing landscape of science, which increasingly involves storage and secondary use of samples and data. Current laws are inadequate for the challenges presented by biobanking.

RP Akintola, S O (reprint author), Univ Ibadan, Fac Law, Dept Private & Property Law, Ibadan, Nigeria.
EM simiakintola@yahoo.com
RI Akintola, Simisola o/H 9242-2017
CR Akintola Simisola O., 2013, Current Pharmacogenomics & Personalized Medicine, V11, P267

Belo-Osagie Udoma U, 2015, DATA PRIVACY PROTECT
Chalmers D, 2011, METHODS MOL BIOL, V675, P1, DOI 10.1007/978-1-59745-423-0_1
Chokshi DA, 2006, B WORLD HEALTH ORGAN, V84, P382, DOI 10.2471/BLT.06.029843
Diallo DA, 2005, CLIN INFECT DIS, V41, P255, DOI 10.1086/430707
Egea Marina, 2015, Accountability and Security in the Cloud. First Summer School: Cloud Accountability Project, A4Cloud. Revised Selected Papers and Lectures: LNCS 8937, P248, DOI 10.1007/978-3-319-17199-9_11
Ekpe CP, 1983, SOCIOLOGY SOCIAL WEL, V10, P484, DOI 10.1097/YCO.0B013E3282F3AD89, DOI 10.1097/YCO.0B013E3282F3AD89
Federal Republic of Nigeria, 2005, COMP SEC CRIT INF IN
German National Ethics Council, 2004, BIOB RES OP
House of Representatives Federal Republic of Nigeria, 2008, ORD PAP
Jemilohun B. O., 2015, GLOB J POL LAW RES, V3, P1
Lunshof JE, 2008, NAT REV GENET, V9, P406, DOI 10.1038/nrg2360
McGuire AL, 2008, NAT REV GENET, V9, P152, DOI 10.1038/nrg2302
Menkti I., 1984, AFRICAN PHILOS INTRO, P171
Molyneux CS, 2004, SOC SCI MED, V59, P2547, DOI 10.1016/j.socscimed.2004.03.037
Resnick, Adam
Nazarian, Javad

TI BLACKFYNN: A SECURE, CLOUD-BASED PLATFORM FOR SHARING AND ANALYZING RESEARCH READY DATA FOR PEDIATRIC CNS CANCERS

SO NEURO-ONCOLOGY
LA English
DT Meeting Abstract
CT 18th International Symposium on Pediatric Neuro-Oncology (ISPNO)
CY JUN 30-JUL 03, 2018
CL Denver, CO
CI [Johnson, Courtney; Kambhampati, Madhuri; Packer, Roger; Nazarian, Javad]
Childrens Natl Hlth Syst, Med Genet Res Ctr, Washington, DC USA.
[Felmeister, Alex; Waanders, Angela; Mason, Jennifer; Resnick, Adam]
Childrens Hosp Philadelphia, Philadelphia, PA 19104 USA.
[Christini, Amanda; Baglieri, Chris] Blackfynn Inc, Philadelphia, PA USA.
[Waanders, Angela; Mason, Jennifer; Resnick, Adam; Nazarian, Javad] Childrens Brain Tumor Tissue Consortium, Philadelphia, PA USA.

NR 0
TC 0
Z9 0
U1 1
U2 1
PU OXFORD UNIV PRESS INC
PI CARY
PA JOURNALS DEPT, 2001 EVANS RD, CARY, NC 27513 USA
SN 1522-8517
EI 1523-5866
J9 NEURO-ONCOLOGY
JI Neuro-Oncology
PD JUN
PY 2018
VL 20
SU 2
MA DIPG-51
BP 59
EP 59
PG 1
WC Oncology; Clinical Neurology
SC Oncology; Neurosciences & Neurology
GA GM7DM
UT WOS:000438339000146
DA 2019-08-06
ER

PT J
AU Handelsman, D
Murphy, MJ
AF Handelsman, Dave
Murphy, Martin J.
TI A legal methodology to enable broad-access sharing and investigation of clinical trial cancer data.
SO JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Meeting Abstract
NR 0
TC 0
Z9 0
U1 0
In this era of high health care cost and limited research resources, open access to de-identified clinical research study data may promote increased scientific transparency and rigor, allow for the combination and re-analysis of similar data sets, and decrease un-necessary replication of unpublished negative studies. Driven by expanded computing capabilities, advocacy for data sharing to maximize research value is growing in both translational and clinical research communities. The focus of this study is to report on the current status of publicly available research data from studies published in the top 40 neurology and neurosurgery clinical research journals by impact factor. The top journals were carefully reviewed for data sharing policies. Of the journals with data sharing policies, the 10 most current original research papers from December 2015 - February 2016 were reviewed for data sharing statements and data availability. A data sharing policy existed for 48% (19/40) of the 40 journals investigated. Of the 19 journals with an existing data sharing policy, 58% (11/19) of the policies stated that data should be made available to interested
parties upon request and 21% (4/19) of these journals encouraged authors to provide a data sharing statement in the article of what data would be available upon request. Of the 190 articles reviewed for data availability, 21% (40/190) of these articles included some source data in the results, figures, or supplementary sections. This evaluation highlights opportunities for neurology and neurosurgery investigators and journals to improve access to study data and even publish the data prospectively for the betterment of clinical outcome analysis and patient care.

C1 [Johnson, Jeremiah N.] Baylor Coll Med, Dept Neurosurg, Houston, TX 77030 USA.
[Johnson, Jeremiah N.] Baylor Coll Med, Dept Neurosurg, Houston, TX 77030 USA.

[Jones, Caleb A.; Guerrero, Jaime] Univ Texas Hlth Sci Ctr San Antonio, Sch Med, San Antonio, TX 78229 USA.


[Rodriguez, Jesse S.] Univ Texas Hlth Sci Ctr San Antonio, Dept Neurosurg, San Antonio, TX 78229 USA.

RP Johnson, JN (reprint author), Baylor Coll Med, Dept Neurosurg, Houston, TX 77030 USA.

EM jjohnson.neuro@gmail.com

CR Aarts AA, 2015, SCIENCE, V349, DOI 10.1126/science.aac4716

Adamson T, 2016, J NEUROSURG-SPINE, V24, P878, DOI 10.3171/2015.8.SPINE14284


[Anonymous], 2017, DATA IN BRIEF

[Anonymous], 2017, NATURE SCI DATA

Baker M, 2016, NATURE, V533, P452, DOI 10.1038/533452a

Begley CG, 2012, NATURE, V483, P531, DOI 10.1038/483531a

Biering-Sorensen F, 2015, SPINAL CORD, V53, P265, DOI 10.1038/sc.2014.246


Button KS, 2013, NAT REV NEUROSCI, V14, P365, DOI 10.1038/nrn3475

Carreon LY, 2016, J NEUROSURG-SPINE, V24, P916, DOI 10.3171/2015.10.SPINE15917


Ferguson AR, 2014, NAT NEUROSCI, V17, P1442, DOI 10.1038/nn.3838

Hirsch JE, 2005, P NATL ACAD SCI USA, V102, P16569, DOI 10.1073/pnas.0507655102


Roche DG, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001779

Savage CJ, 2009, PLOS ONE, V4, DOI 10.1371/journal.pone.0007078

Song F, 2010, HEALTH TECHNOL ASSES, V14, P1, DOI 10.3310/hta14080


van Assen MALM, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0084896


Wallis JC, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0067332

PU CUREUS INC

PI PALO ALTO
Public attitudes in England towards the sharing of personal data following a mass casualty incident: a cross-sectional study

Objectives To assess public attitudes towards data sharing to facilitate a mental health screening programme for people caught up in a mass casualty incident.

Design Two, identical, cross-sectional, online surveys, using quotas to ensure demographic representativeness of people aged 18-65 years in England. Participants were randomly allocated to consider a scenario in which they witness a terrorism-related radiation incident or mass shooting, after which a police officer records their contact details.

Setting Participants were drawn from an online panel maintained by a market research company. Surveys were conducted before and immediately after a series of terrorist attacks and a large tower block fire occurred in England.

Participants One thousand people aged 18-65 years participated in each survey.

Main outcome measures Three questions asking participants if it would be acceptable for police to share their contact details, without asking first, with 'a health-related government organisation, so they can send you a questionnaire to find out if you might benefit from extra care or support', 'a specialist NHS team, to provide you with information about ways to get support for any physical or mental health issues' and 'your GP, so they can check how you are doing'.
Results A minority of participants reported that it would be definitely not acceptable for their details to be shared with the government organisation (n=259, 13.0%), the National Health Service (NHS) (n=141, 7.1%) and their general practitioner (GP) (n=166, 8.3%). There was a small, but significant increase in acceptability for the radiation incident compared with the mass shooting. No major differences were observed between the preincident and postincident surveys.

Conclusions Although most people believe it is acceptable for their details to be shared in order to facilitate a mental health response to a major incident, care must be taken to communicate with those affected about how their information will be used.


EM Gideon.rubin@kcl.ac.uk
RI Webster, Rebecca/J-7145-2019
OI Webster, Rebecca/0000-0002-5136-1098

FU National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Emergency Preparedness and Response at King's College London; Public Health England (PHE); NIHR HPRU in Evaluation of Interventions at the University of Bristol; PHE [HPRU-2012-10414]

FX The research was funded by the National Institute for Health Research Health Protection Research Unit (NIHR HPRU) in Emergency Preparedness and Response at King's College London in partnership with Public Health England (PHE), and by the NIHR HPRU in Evaluation of Interventions at the University of Bristol in partnership with PHE. HPRU-2012-10414.

CR Barrett G, 2006, BRIT MED J, V332, P1068, DOI 10.1136/bmj.38805.473738.7C

Borschmann R, 2014, DIE PSYCHIAT, V11, P43


Close RM, 2014, ENVIRON INT, V72, P75, DOI 10.1016/j.envint.2014.05.003

Excellence NIfHaC, 2005, POSTSTR STRES DIS MAN

HMGovernment, 2007, DAT PROT SHAR GUID E

Ipsos M., 2014, PUBLIC ATTITUDES USE


National Readership Survey, 2015, NAT READ SURV 2015

Office for National Statistics, 2015, INT US


Whalley MG, 2007, BRIT J PSYCHIAT, V190, P94, DOI 10.1192/bjp.bp.106.026427
Data quality and timeliness of outbreak reporting system among countries in Greater Mekong subregion: Challenges for international data sharing

Cross-border disease transmission is a key challenge for prevention and control of outbreaks. Variation in surveillance structure and national guidelines used in different countries can affect their data quality and the timeliness of outbreak reports. This study aimed to evaluate timeliness and data quality of national outbreak reporting for four countries in the Mekong Basin Disease Surveillance network (MBDS). Data on disease outbreaks occurring from 2010 to 2015 were obtained from the national disease surveillance reports of Cambodia, Lao PDR, Myanmar, and Vietnam. Data included total cases, geographical information, and dates at different timeline milestones in the outbreak detection process. Nine diseases or syndromes with public health importance were selected for the analysis including: dengue, food poisoning & diarrhea, severe
diarrhea, diphtheria, measles, H5N1 influenza, H1N1 influenza, rabies, and pertussis. Overall, 2,087 outbreaks were reported from the four countries. The number of outbreaks and number of cases per outbreak varied across countries and diseases, depending in part on the outbreak definition used in each country. Dates on index onset, report, and response were >95% complete in all countries, while laboratory confirmation dates were 10%-100% incomplete in most countries. Inconsistent and out of range date data were observed in 1%-5% of records. The overall timeliness of outbreak report, response, and public communication was within 1-15 days, depending on countries and diseases. Diarrhea and severe diarrhea outbreaks showed the most rapid time to report and response, whereas diseases such as rabies, pertussis and diphtheria required a longer time to report and respond. The hierarchical structure of the reporting system, data collection method, and country's resources could affect the data quality and timeliness of the national outbreak reporting system. Differences in data quality and timeliness of outbreak reporting system among member countries should be considered when planning data sharing strategies within a regional network.


[Sovann, Ly; Sreng, Bun] Minist Hlth, Dept Communicable Dis Control, Phnom Penh, Cambodia.


[Smolinski, Mark S.; Crawley, Adam W.] Ending Pandem, San Francisco, CA USA.


EM saranath.law@mahidol.ac.th; moe@mbdsnet.org

FU Skoll Global Threats Fund [15-02979]

FX This study was supported by the Skoll Global Threats Fund, award number 15-02979 to the Mekong Basin Disease Surveillance Foundation. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

CR Bond K. C., 2013, Emerging Health Threats Journal, V6, P19913

Bond KC, 2013, EMERG HLTH THREATS J, V6

Buehler James W, 2004, MMWR Recomm Rep, V53, P1

Bwire G, 2016, PLOS ONE, V11, DOI 10.1371/journal.pone.0156674


Chan EH, 2010, P NATL ACAD SCI USA, V107, P21701, DOI 10.1073/pnas.1006219107

Coulombier D, 2013, EUROSURVEILLANCE, V18, P2

Gresham Louise, 2011, J COMMERCIAL BIOTECH, V17, P241


Knoblauch AM, 2015, SWISS MED WKLY, V145, DOI 10.4414/swr.2015.14182

Comparing Outcomes and Resource Utilization Among Pediatric Heart
Transplant Indications Using a Novel, Merged Data Set from the United Network for Organ Sharing and the Pediatric Health Information System (UNOS-PHIS) Databases

SO JOURNAL OF HEART AND LUNG TRANSPLANTATION
LA English
DT Meeting Abstract
CT 38th Annual Meeting and Scientific Sessions of the International-Society-for-Heart-and-Lung-Transplantation (ISHLT)
CY APR 11-14, 2018
CL Nice, FRANCE
SP Int Soc Heart & Lung Transplantat
Childrens Hosp Philadelphia, Cardiol, Philadelphia, PA 19104 USA.
[Huang, Y.] Childrens Hosp Philadelphia, Healthcare Analyt Unit, Philadelphia, PA 19104 USA.
NR 0
TC 0
Z9 0
U1 0
U2 2
PU ELSEVIER SCIENCE INC
PI NEW YORK
PA 360 PARK AVE SOUTH, NEW YORK, NY 10010-1710 USA
SN 1053-2498
EI 1557-3117
J9 J HEART LUNG TRANSPL
JI J. Heart Lung Transplant.
PD APR
PY 2018
VL 37
IS 4
SU S
MA 1033
BP S401
EP S402
PG 2
WC Cardiac & Cardiovascular Systems; Respiratory System; Surgery; Transplantation
SC Cardiovascular System & Cardiology; Respiratory System; Surgery; Transplantation
GA GD7XS
UT WOS:000430727300426
DA 2019-08-06
ER

PT J
AU Burstein, D
   Li, YM
   Getz, KD
   Huang, YS
   Rossano, JW
   O'Connor, M
   Lin, K
   Aplenc, R
AF Burstein, Danielle
Comparing Resource Utilization Among Pediatric Heart Transplant Indications Using a Novel, Merged Data Set from the United Network for Organ Sharing and the Pediatric Health Information Systems (UNOS-PHIS) Databases

Journal of the American College of Cardiology

67th Annual Scientific Session and Expo of the American College of Cardiology (ACC)

Orlando, FL

[Burstein, Danielle; Li, Yimei; Getz, Kelly D.; Huang, Yuan-Shung; Rossano, Joseph William; O'Connor, Matthew; Lin, Kimberly; Aplenc, Richard] Children's Hospital Philadelphia, Philadelphia, PA 19104 USA.
Purpose To develop a public-private partnership to study the feasibility of a new approach in collecting and analyzing clinically annotated imaging data from landmark phase III trials in advanced solid tumors.

Patients and Methods The collection of clinical trials fulfilled the following inclusion criteria: completed randomized trials of > 300 patients, highly measurable solid tumors (non-small-cell lung cancer, colorectal cancer, renal cell cancer, and melanoma), and required sponsor and institutional review board sign-offs. The new approach in analyzing computed tomography scans was to transfer to an academic image analysis laboratory, draw contours semi-automatically by using in-house-developed algorithms integrated into the open source imaging platform Weasis, and perform serial volumetric measurement.

Results The median duration of contracting with five sponsors was 12 months. Ten trials in 7,085 patients that covered 12 treatment regimens across 20 trial arms were collected. To date, four trials in 3,954 patients were analyzed. Source imaging data were transferred to the academic core from 97% of trial patients (n = 3,837). Tumor imaging measurements were extracted from 82% of transferred computed tomography scans (n = 3,162). Causes of extraction failure were nonmeasurable disease (n = 392), single imaging time point (n = 224), and secondary captured images (n = 59). Overall, clinically annotated imaging data were extracted in 79% of patients (n = 3,055), and the primary trial end point analysis in each trial remained representative of each original trial end point.

Conclusion The sharing and analysis of source imaging data from large randomized trials is feasible and offer a rich and reusable, but largely untapped, resource for future research on novel trial-level response and progression imaging metrics. (C) 2018 by American Society of Clinical Oncology.
[Derck, Laurent; Zhao, Binsheng; Schwartz, Lawrence H.] New York Presbyterian Hosp, New York, NY USA.

[Gonen, Mithat; Hilden, Patrick; Moskowitz, Chaya S.] Mem Sloan Kettering Canc Ctr, 1275 York Ave, New York, NY 10021 USA.

[Connors, Dana E.; Adam, Stacey J.] Fdn Natl Inst Hlth, North Bethesda, MD USA.

[Tang, Ying] CCS Associates, San Jose, CA USA.

[Karlovic, Sanja; Maitland, Michael] Inova Schar Canc Inst, Fairfax, VA USA.

[Kelloff, Gary] NCI, Rockville, MD USA.

[Oxnard, Geoffrey R.] Dana Farber Canc Inst, Boston, MA 02115 USA.


RP Schwartz, LH (reprint author), Columbia Univ, Dept Radiol, New York Presbyterian Hosp, Med Ctr, 168th St, New York, NY 10032 USA.

EM lhs2120@cumc.columbia.edu

RI Dercle, Laurent/C-9740-2018

FU Amgen; Boehringer Ingelheim; Merck; Genentech; Merck Sharp & Dohme; Regeneron Pharmaceuticals; Takeda Pharmaceuticals; National Institutes of Health [U01 CA140207]; Cancer Clinical Investigator Team Leadership - National Cancer Institute [P30 CA006516]; [P30 CA008748]

FX Scientific and financial support for the Foundation for the National Institutes of Health Biomarkers Consortium project Vol-PACT (Advanced Metrics and Modeling With Volumetric Computed Tomography for Precision Analysis of Clinical Trial Results) by Amgen, Boehringer Ingelheim, Merck, Genentech, Merck Sharp & Dohme, Regeneron Pharmaceuticals, and Takeda Pharmaceuticals. In-kind donations of phase II and III trial data to support the project are being provided to Foundation for the National Institutes of Health by Amgen, Boehringer Ingelheim, Novartis, Merck Sharp & Dohme, and Sanofi. Also supported by the National Institutes of Health (U01 CA140207) and a Cancer Clinical Investigator Team Leadership Award by the National Cancer Institute through a supplement to P30 CA006516. Support provided to Memorial Sloan Kettering by the core grant P30 CA008748.


Bosworth A, 2013, J CLIN ONCOL, V31

Choi VL, 2015, J CLIN ONCOL, V33, P3541, DOI 10.1200/JCO.2015.61.6870


Li CH, 2016, CTS-CLIN TRANS SCI, V9, P43, DOI 10.1111/cts.12384


Miller VA, 2012, LANCET ONCOL, V13, P528, DOI 10.1016/S1470-2245(12)70087-6


Oxnard GR, 2016, JAMA ONCOL, V2, P772, DOI 10.1001/jamaoncol.2015.6315


Schwartz LH, 2003, CLIN CANCER RES, V9, P4318

Seymour L, 2017, LANCET ONCOL, V18, P143, DOI 10.1016/S1470-2245(17)30074-8
Patients find it easy to select data they don't want to share.
A clear and comprehensive policy framework is needed to make data sharing more useful, robust, and efficient. Based on decades of experience as a CIO in
the healthcare sector, the author recommends ways to address various existing privacy, reliability, interoperability, security, and trust challenges.

C1 [Handler, Ivan] Insightamation, Chicago, IL 60613 USA.
RP Handler, I (reprint author), Insightamation, Chicago, IL 60613 USA.
EM ivan.handler@gmail.com
CR [Anonymous], 2013, FRAM HLTH INF EXCH
Global Alliance Genomics Hlth, 2016, SCIENCE, V352, P1278, DOI 10.1126/science.aaf6162
Grassi P. A., 2017, SPECIAL PUBLICATION
this paper has designed a Data Resource Sharing and Exchange Platform (DRSEP) to solve the demand for comprehensive data of City Public Management (CPM). Firstly, we analyze the basic functional requirements of the platform. Secondly, we study the characteristics of the DRSEP from three aspects: data type, data volume and data transmission/application methods. Thirdly, we provide the overall technical architecture of the DRSEP, which includes: the data resource layer, the resource site layer, the resource integration layer, the resource service layer and the resource application layer. In particular, we devise a Data Organization System (DOS) based on a Data Resource Directory (DRD), a Public Basic Database (PBcDB) and a Public Business Database (PBuDB). The DRD is the metadata standard and resource directory of the platform. Through this directory, the authority, accuracy and unity of the data resources can be ensured. The PBcDB consists of four types of databases: a population database, a corporation database, a macroeconomic database and a geospatial database. The PBuDB includes a video database, an environmental safety supervision database, a building database, a government affairs and emergency database, a credit database and a comprehensive human resources database. Finally, the DRSEP is deployed, tested, applied and evaluated in a city with a population of 2.19 million in western China. Moreover, the test evaluation results show that the platform exhibits an outstanding performance in the integration technology of multi-source heterogeneous data and the reliable transmission technology of massive data.

C1 [Hui, Huaihai] Chinese Acad Sci, Sch Econ & Management, Beijing, Peoples R China.


RP Hui, HH (reprint author), Chinese Acad Sci, Sch Econ & Management, Beijing, Peoples R China.

EM huihuaihai@ucas.ac.cn; d.c.mclernon@leeds.ac.ukAli; s.a.zaidi@leeds.ac.uk

FU Chinese Scholarship Council (CSC)

FX Our thanks to Chinese Scholarship Council (CSC).


Foster I.T., 2008, P GRID COMP ENV WORK, P1, DOI DOI 10.1109/GCE.2008.4738445


Suzuki L CSR, 2016, THESIS

Taylor M, 2015, LANDMARK CASE, P175

NR 6

TU 0

Z9 0

U1 0

U2 0

FU ASSOC COMPUTING MACHINERY

PI NEW YORK

PA 1515 BROADWAY, NEW YORK, NY 10036-9998 USA

BN 978-1-4503-6502-4

PY 2018

BP 78

EP 83

DI 10.1145/3268891.3268908

PG 6

WC Computer Science, Theory & Methods; Engineering, Electrical & Electronic

SC Computer Science; Engineering

GA BNORB

UT WOS:000473336900015

OA Green Published

DA 2019-08-06

ER
The huge amounts of self-tracked health data collected by Internet of Things (IoT) fitness devices offer important opportunities to the research community. If properly exploited, IoT health and fitness datasets can help to gain valuable insights into the human health in order to provide better healthcare.

However, IoT health data come from a variety of different heterogeneous sources and in proprietary formats, which means that they require an integration process, normally manually done by domain experts, in order to be analysed. This task is not only significantly time consuming but in many cases, error prone.

In this study, we designed and developed a web platform for collecting and publishing IoT health and fitness datasets according to Linked Data principles. We leveraged the IFO ontology and the Semantic Web technologies to make the IoT health and fitness datasets freely available to the community in a shared, semantically meaningful, easily discoverable, and reusable manner.

The system introduced in this article shows that Semantic Web technologies can be a viable and comprehensive solution for describing, integrating and sharing heterogeneous IoT datasets, thus overcoming the issues of data silos that nowadays dominate the IoT landscape.

CR Abian D, 2017, INT KEYSTONE C SEM K, P142
Brunetti Josep Maria, 2013, P INT C INF INT WEB, DOI 10.1145/2539150.2539162
Carbonaro A, 2010, J E-LEARN KNOWL SOC, V6, P67
Carbonaro A, 2010, COMM COM INF SC, V73, P141
Carbonaro A, 2007, CONSUM COMM NETWORK, P1087, DOI 10.1109/CCNC.2007.219
Carbonaro Antonella, 2010, WORLD SUMMIT KNOWLED, P131
Carbonaro Antonella, 2008, SOCIAL INFORM RETRIE, P270
Carbonaro Antonella, 2009, P 3 INT WORKSH SOC I
Dan Brickley, 2014, RDF SCHEMA W3C RECOM
Dimou A., 2014, LDOW
Dimou A., 2014, IEEE INT C SEMANT CO, P151, DOI 10.1109/ICSC.2014.25
Hardt Dick, 2012, TECHNICAL REPORT
Iguchi, M
Uematsu, T
Fujii, T
AF Iguchi, Makoto
Uematsu, Taro
Fujii, Tatsuro
BE Inomata, A
Yasuda, K
TI The Anatomy of the HIPAA Privacy Rule: A Risk-Based Approach as a Remedy for Privacy-Preserving Data Sharing
SO ADVANCES IN INFORMATION AND COMPUTER SECURITY, IWSEC 2018
SE Lecture Notes in Computer Science
LA English
DT Proceedings Paper
This paper explores the effectiveness of a risk-based approach methodology in constructing systematic standards for privacy-conscious data sharing and disclosure. We consider the HIPAA (Health Insurance Portability and Accountability Act of 1996) Privacy Rule as an example and show that the data disclosure methods defined in the HIPAA Privacy Rule are well-constituted, by assessing the privacy risks of each disclosure method. We further explore factors that contribute to the success of the HIPAA Privacy Rule and discuss how we can leverage these factors as a reference for constructing privacy-conscious and systematic data disclosure rules and regulations in other domains.

C1 [Iguchi, Makoto; Uematsu, Taro; Fujii, Tatsuro] Kii Corp, Tokyo 1070052, Japan.
RP Iguchi, M (reprint author), Kii Corp, Tokyo 1070052, Japan.
EM makoto.iguchi@kii.com; taro.uematsu@kii.com; tatsuro.fujii@kii.com
CR [Anonymous], 2017, 291342017 ISOIEC
[Anonymous], 2011, 270052011 ISOIEC
Arbuckle L, 2013, ANONYMIZING HLTH DAT
Chesanow N, 2013, IS HIPAA CREATING MO
Commission Nationale de l'Informatique et des Libertes (CNIL), 2012, METH PRIV RISK MAN
de Montjoye YA, 2015, SCIENCE, V347, P536, DOI 10.1126/science.1256297
douriez M, 2016, PROCEEDINGS OF 3RD IEEE/ACM INTERNATIONAL CONFERENCE ON DATA SCIENCE AND ADVANCED ANALYTICS, (DSAA 2016), P140, DOI 10.1109/DSAA.2016.21
Elliot M, 2016, ANONYMISATION DECIS
Information and Privacy Commissioner of Ontario, 2016, DEID GUID STRUCT DAT
Information Commissioner's Office (ICO), 2014, COND PRIV IMP ASS CO
Open Web Application Security Project (OWASP), 2016, OW RISK RAT METH
U.S. Department of Health & Human Services Office for Civil Rights, 2015, HLTH INF PRIV
U.S. Department of Health & Human Services Office for Civil Rights, 2017, GUID HIP CLOUD COMP
U.S. Department of Health & Human Services Office for Civil Rights, 2015, GUID REG METH DEID P
NR 20
TC 0
Z9 0
U1 0
U2 0
PU SPRINGER INTERNATIONAL PUBLISHING AG
PI CHAM
PA GEWERBESTASSE 11, CHAM, CH-6330, SWITZERLAND
SN 0302-9743
EI 1611-3349
Electronic medical record (EMR) is a crucial form of healthcare data, currently drawing a lot of attention. Sharing health data is considered to be a critical approach to improve the quality of healthcare service and reduce medical costs. However, EMRs are fragmented across decentralized hospitals, which hinders data sharing and puts patients' privacy at risks. To address these issues, we propose a blockchain based privacy-preserving data sharing for EMRs, called BPDS. In BPDS, the original EMRs are stored securely in the cloud and the indexes are reserved in a tamper-proof consortium blockchain. By this means, the risk of the medical data leakage could be greatly reduced, and at the same time, the indexes in blockchain ensure that the EMRs can not be modified arbitrarily. Secure data sharing can be accomplished automatically according to the predefined access permissions of patients through the smart contracts of blockchain. Besides, the joint-design of the CPABE-based access control mechanism and the content extraction signature scheme provides strong privacy preservation in data sharing. Security analysis shows that BPDS is a secure and effective way to realize data sharing for EMRs.
Cl [Liu, Jingwei; Li, Xiaolu] Xidian Univ, State Key Lab ISN, Xian 710071, Peoples R China.
[Guizani, Mohsen] Univ Idaho, Dept Elect & Comp Engn, Mosocow, ID USA.
RP Liu, JW (reprint author), Xidian Univ, State Key Lab ISN, Xian 710071, Peoples R China.
EM jwliu@mail.xidian.edu.cn; lixiaolu0318@163.com; hityelin@hit.edu.cn; zhanghongli@hit.edu.cn; dxj@ieee.org; mguizani@ieee.org
FU Key Program of NSFC-Tongyong Union Foundation [U1636209]; 111 Project [B08038]; Collaborative Innovation Center of Information Sensing and Understanding at Xidian University
FX This work is supported by the Key Program of NSFC-Tongyong Union Foundation under Grant U1636209, the 111 Project (B08038) and Collaborative Innovation Center of Information Sensing and Understanding at Xidian University.
CR Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11
Biswas S, 2014, 2014 17TH INTERNATIONAL CONFERENCE ON COMPUTER AND INFORMATION TECHNOLOGY (ICCIT), P286, DOI 10.1109/ICCITech.2014.7073139
Du XJ, 2009, IEEE T WIREL COMMUN, V8, P1223, DOI 10.1109/TWC.2009.060598
Guo L, 2018, IEEE ACCESS, V6, P73001, DOI 10.1109/ACCESS.2018.2879832
Hei XL, 2013, IEEE INFOCOM SER, P3030
Nakamoto S., 2008, BITCOIN PEER TO PEER
Rahab K., 2017, MARA RES J MED HLTH, V1, P45
Tama BA, 2017, 2017 INTERNATIONAL CONFERENCE ON ELECTRICAL ENGINEERING AND COMPUTER SCIENCE (ICECOS), P109, DOI 10.1109/ICECOS.2017.8167115
Tawalbeh LA, 2016, IEEE ACCESS, V4, P6171, DOI 10.1109/ACCESS.2016.2613278
Wood G, 2014, ETHEREUM SECURE DECE, V151, P1
Wu LF, 2016, IEEE T VEH TECHNOL, V65, P6678, DOI 10.1109/TVT.2015.2472993
Xia Q, 2017, IEEE ACCESS, V5, P14757, DOI 10.1109/ACCESS.2017.2730843
Zhang HL, 2015, IEEE T VEH TECHNOL, V64, P5610, DOI 10.1109/TVT.2015.2480004
Zhou ZG, 2013, IEEE INFOCOM SER, P2643
2008, IEEE WIRELESS COMMUN, V15, P60

NR 21
TC 0
Z9 0
U1 2
U2 2
FU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2334-0983
BN 978-1-5386-4727-1
J9 IEEE GLOB COMM CONF
PY 2018
PG 6
Patients rely on their public health records shared among medical institutions to receive the appropriate treatment they require. They must completely trust that these institutions will secure their records, protect their privacy, and efficiently share them when requested by other institutions. Unfortunately, medical institutions cannot fully be trusted for several reasons. First, patient records are stored on the servers of the medical institutions which could result in security issues and also a single point of failure. Second, centralized storage may also result in privacy concerns if records are incorrectly shared or leaked. Third, institutions may purposely delay sharing patient records for competitive reasons. To address these issues, we propose an attribute-based distributed data sharing scheme for patients to control how their records are shared. The distributed file sharing can effectively prevent the single point of failure and ensure data availability upon its request. Moreover, patients are also given the capability of selectively sharing their records for privacy protection. Our analysis shows that while ensuring attribute-based sharing of medical records, the proposed scheme can also work with the peer-to-peer distributed network storage such as InterPlanetary File System (IPFS) to improve efficient data retrieval.

CR Baumgart I., 2007, P ICPADS, P1, DOI DOI 10.1109/ICPADS.2007.4447808
Beimel A., 1996, SECURE SCHEMES SECRE
Benet J., IPFS CONTENT ADDRESS
Cipriani T., 2016, VISUALIZING GITS MER
Freedman M J, 2004, NSDI, P18
USA. gov, 2017, HLTH INF EXCH

NR 7
TC 0
Z9 0
UI 0
U2 0
PU IEEE
PI NEW YORK
With the development of information and storage technologies, electronic document recording has become an unalterable trend, which transforms the way that people store, access and operate the data generated in various applications. Healthcare is the leader application domain that pioneers in usage of electronic medical records (EMRs). Cross-organizational EMRs' sharing has many constructive effects in motivating the domain innovation, introducing better domain understanding and overall the domain intelligence. However, the privacy concern, trust issue as well as the sophisticated legal regulation of the sensitive EMRs' use leads to inefficiency in the data sharing process. In this paper, we propose a cross-organizational medical data sharing framework based on permissioned blockchain technology, named "EMRShare", to resolve the trust concern existing in EMRs sharing practice among different participants like patients, clinicians and researchers, and other relevant parties such as the insurance agent and government, to make medical data sharing and access secure, efficient,
transparent, immutable, traceable and auditable. A working prototype system is implemented to demonstrate the key features for the cross-organizational medical data sharing and access management. The objective of this work targets at explaining the essential design considerations along with the working principle and operation logics using the blockchain technology to facilitate the medical data sharing in a highly-cooperative healthcare ecosystem.

C1 [Xiao, Zhe; Li, Zengxiang; Liu, Yong; Feng, Ling; Zhang, Weiwen; Lertwuthikarn, Thanarit; Goh, Rick Slow Mong] ASTAR, Dept Comp Sci, Inst High Performance Comp, Singapore, Singapore.


EM xiaoz@ihpc.a-star.edu.sg; liiz@ihpc.a-star.edu.sg; liuyong@ihpc.a-star.edu.sg; fengl@ihpc.a-star.edu.sg; zhangww@ihpc.a-star.edu.sg; Thanaritlertwuthikarn@gmail.com; gohsm@ihpc.a-star.edu.sg


Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11

Dubovitskaya A., 2017, SECURE TRUSTABLE ELE

Kish Lj, 2015, NAT BIOTECHNOl, V33, P921, DOI 10.1038/nbt.3340

Liang X., 2018, IEEE INT S PERS IND, P1

Sankar LS, 2017, INT CONF ADVAN COMPU

Vian K., 2016, NIST WORK BLOCKCHAIN, P1


Zyskind G, 2015, 2015 IEEE SECURITY AND PRIVACY WORKSHOPS (SPW), P180, DOI 10.1109/SPW.2015.27
Consumer feedback is collected in many industries, including in healthcare where patient feedback contributes to a higher quality of care. Current collection methods include complaints, local surveys, and patient stories, but these methods yield low participation at high costs. Providers need affordable and effective ways to collect feedback, and smartphone applications present as suitable solutions. However, previous research shows that patients are hesitant to provide smartphone-based feedback in a care setting due to perceived risks and apparent futility of expecting change as a result. We will conduct a study to observe consumer behaviour using smartphones to provide service feedback in healthcare spaces versus non-healthcare spaces. We will identify addressable barriers that impact the adoption of smartphone technology to gather patient experience data in healthcare spaces.

Aagaard, Christian, 2013, NEW BUILDING HLTH SE
Giesbrecht M, 2015, PALLIAT SUPPORT CARE, V13, P555, DOI 10.1017/S1478951513001028
Ng Denise, 2017, UWSpace
The Canadian Institute of Health Information, 2014, CAN PAT EXP SURV INP
Tuan Yi-Fu, 2001, SPACE PLACE PERSPECT
The need for data sharing in stem cell research will continue to grow as the field keeps advancing. Yet, without a comprehensive and harmonized governance system to ensure ethical and responsible data and sample sharing, the field is threatened by unethical practices, compromise of participants’ privacy and loss of public trust. In 2014, the Global Alliance for Genomics and Health (GA4GH) developed a common Framework for Responsible Sharing of Genomic and Health-Related Data. At the same year, Jordan passed the first of its kind law in the region for stem cells, Statute number 10 on Stem Cells. Using specific policy principles of the GA4GH Framework and the work of the International Stem Cell Forum (ISCF) Ethics Working Party, we identified several gaps in the Jordanian Statute of Stem Cell including active participation of the public, transparency in the data sharing and access processes, ensuring the quality and safety of the
data, maintaining the privacy, security & confidentiality of individuals, their samples and associated data, preforming in-depth risk-benefit analysis and maintaining sustainability of stem cell banks and registries. We recommend revisiting the current Statue in light of the GA4GH Framework, which can be integrated to foster national and international collaboration and support responsible innovation in the discovery of new therapies for cancer treatment.


RP Al-Tabba, A (reprint author), King Hussein Canc Ctr, Off Human Res Protect Program, Amman, Jordan.

EM AA.11661@KHCC.JO; ASOmari@KHCC.JO;
mhussaini@KHCC.JO


Bredenoord AL, 2015, REGEN MED, V10, P857, DOI 10.2217/rme.15.42


Dajani R, 2014, NATURE, V510, P189, DOI 10.1038/510189a

Global Alliance for Genomics and Health, 2014, FOR TERR FIGHT FTF I, P1

Hashemite Kingdom of Jordan, 2014, JORD STEM CELL LAW A

International Intellectual Property Institute (IIPI), 2004, JORD PHARM IND

Rep R

Isasi R, 2014, CELL STEM CELL, V14, P427, DOI 10.1016/j.stem.2014.03.014


Knoppers BM, 2010, REGEN MED, V5, P5, DOI 10.2217/rme.09.84

Lo B, 2009, ENDOCR REV, V30, P204, DOI 10.1210/er.2008-0031

Mathews DJH, 2011, SCIENCE, V331, P725, DOI 10.1126/science.1201382


Tran C, 2015, ADV DRUG DELIVER REV, V82-83, P1, DOI 10.1016/j.addr.2014.10.007

This paper presents requirements to DeepLinQ and its architecture. DeepLinQ proposes a multi-layer blockchain architecture to improve flexibility, accountability, and scalability through on-demand queries, proxy appointment, subgroup signatures, granular access control, and smart contracts in order to support privacy-preserving distributed data sharing. In this data-driven AI era where big data is the prerequisite for training an effective deep learning model, DeepLinQ provides a trusted infrastructure to enable training data collection in a privacy-preserved way. This paper uses healthcare data sharing as an application example to illustrate the key properties and design of DeepLinQ.

[Chang, Edward Y.; Liu, Chun-Ting; Mei, Chung-Huan; Chang, Emily J.] HTC DeepQ, Res & Healthcare, Taipei, Taiwan.
The more healthcare center linking their information system to the global computer network such as the Internet, then it opens access from all over the world and makes the potential for leakage of information getting bigger. The importance of an eHealth record for the patient's health is to be protected from illegal users that can be misused for other purposes. Identity-based encryption
IBE) is one of the appropriate security solutions to protect eHealth record data. The IBE algorithm addresses the problems inherent in conventional cryptographic techniques by using any string as a public key. The system is capable of enhancing the security of e-health records by adding verification processes to three interconnected servers. In this system communication on three servers using data that has been encrypted using IBE, so that each server is able to perform the process of encryption-decryption during data exchange. Only servers that have IDs are able to receive and extract e-health record data. Meanwhile, the experimental results show the practicality regarding the speed of the algorithm used on the system.

EM dneipa12@gmail.com; amang@pens.ac.id; prima@pens.ac.id
CR Bogdanov D., 2008, LECT NOTES COMPUTER, V5283
Cybernetica, FREQ ASK QUEST
Frontoni E., 2014, P INT CARN C SEC TEC
Jahan S., 2017, 2017 INT C IM VIS CO, P1
Kemenkes RI, 2008, PERATURAN MENTERI KE, P7
Sudarsono A., 2017, 2017 3RD INTERNATIONAL CONFERENCE ON SCIENCE IN
INFORMATION TECHNOLOGY (ICSITECH), P429, DOI 10.1109/ICSITech.2017.8257151
Trappe W., 2005, INTRO CRYPTOGRAPHY C
Data exchange; smart devices; shared object store; security

AB Nowadays, smart devices have become incredibly popular—literally everybody has one. Due to an enormous quantity of versatile apps, these devices positively affect almost every aspect of their users' lives. E.g., there are apps collecting and monitoring health data from a certain domain such as diabetes-related or respiration-related data. However, they cannot display their whole potential since they have only access to their own data and cannot combine it with data from other apps, e.g., in order to create a comprehensive electronic health record. On that account, we introduce a secure shared object store called CURATOR. In CURATOR apps cannot only manage their own data in an easy and performant way, but they can also share it with other apps. Since some of the data is confidential, CURATOR has several security features, including authentication, fine-grained access control, and encryption. In this paper, we discuss CURATOR's design and implementation and evaluate its performance.

ER Stach, Christoph; Mitschang, Bernhard] Univ Stuttgart, IPVS, AS, Stuttgart, Germany.
RP Stach, C (reprint author), Univ Stuttgart, IPVS, AS, Stuttgart, Germany.
EM stachch@ipvs.uni-stuttgart.de; mitsch@ipvs.uni-stuttgart.de
OI Stach, Christoph/0000-0003-3795-7909
FU BW-Stiftung
FX This paper is part of the PATRON research project which is commissioned by the Baden-Württemberg Stiftung gGmbH. The authors would like to thank the BW-Stiftung for the funding of this research.

Ben Scofield, 2010, NOSQL DEATH REL DAT
Chau Melissa, 2017, SMARTPHONE OS MARKET
Chun B.-G., 2012, P 10 INT C MOB SYST, P141
Elenkov Nikolay, 2014, ANDROID SECURITY INT
Enck W, 2009, IEEE SECUR PRIV, V7, P50, DOI 10.1109/MSP.2009.26
Felt Adrienne Porter, 2012, P 8 S US PRIV SEC SO
Google Inc, 2016, CONT PROV
Google Inc, 2017, ANDR THINGS
Google Inc, 2017, INT ANDR DEV
Google Inc, 2016, STOR OPT
Google Inc, 2017, COP PAST
Hassanshahi Behnaz, 2017, P 2017 ACM AS C COMP, P625
Knoll Martin, 2015, P 10 INT SPAC SYNT S
Martinelli P., 2016, P 31 ANN ACM S APPL, P2049
Murphy Mark L., 2017, BUSY CODERS GUIDE AN
Nicole Anne D. C. Lopez, 2017, SECURING HLTH INFORM, P136
Ongtang M, 2010, 26TH ANNUAL COMPUTER SECURITY APPLICATIONS CONFERENCE (ACSAC 2010), P221
Ostrovsky David, 2015, COUCHBASE LITE ANDRO, P307
Perrier Trevor, 2013, TECHNICAL REPORT
rehacktive, 2016, WASPDB GITHUB
Shahriar Hossain, 2014, P 7 INT C SEC INF NE
Shahzad F, 2015, 2015 17TH INTERNATIONAL CONFERENCE ON E-HEALTH NETWORKING, APPLICATION & SERVICES (HEALTHCOM), P120, DOI 10.1109/HealthCom.2015.7454484
SimoneMuti Enrico Bacis, 2015, P 31 ANN COMP SEC AP, P411
Stach Christoph, 2016, 2016 17th IEEE International Conference on Mobile Data Management (MDM), P292, DOI 10.1109/MDM.2016.50
Stach Christoph, 2016, 2016 17th IEEE International Conference on Mobile Data Management (MDM), P361, DOI 10.1109/MDM.2016.64
Stach C., 2012, 2012 IEEE International Conference on Pervasive Computing and Communications Workshops (PerCom Workshops), P501, DOI 10.1109/PerComW.2012.6197547
Stach C, 2015, 2015 16TH IEEE INTERNATIONAL CONFERENCE ON MOBILE DATA MANAGEMENT, VOL 1, P167, DOI 10.1109/MDM.2015.17
Stach C, 2013, 2013 IEEE 14TH INTERNATIONAL CONFERENCE ON MOBILE DATA MANAGEMENT (MDM 2013), VOL 1, P305, DOI 10.1109/MDM.2013.45
Stach Christoph, 2015, DATENBANK SPEKTRUM, V15, P109
Weigel Frank, 2012, BENCHMARKING COUCHBA
Yan TT, 2016, OXID MED CELL LONGEV, DOI 10.1155/2016/4512309
Zhang Xiao, 2014, ATTACKS ANDROID CLIP, P72
Zhou Y., 2013, P 20 NETW DISTR SYST, P1

Exploring the Data Tracking and Sharing Preferences of Wheelchair Athletes
AB Sports are increasingly data-driven. Athletes use a variety of physical activity monitors to capture their movements, improve performance, and achieve excellence. To understand how wheelchair athletes want to use and share their activity data, we conducted a study using a prototype wheelchair fitness tracking device, which served as a probe to facilitate discussions. We interviewed 15 wheelchair basketball players about the use of performance data in the context of wheelchair basketball, and we discuss several implications for using and sharing automatically-tracked data. We find that the wheelchair basketball community is less concerned about the privacy of their data, and, in contrast to health data, athletes are motivated by competition. We conclude with a set of design opportunities that leverage digitized performance metrics within wheelchair basketball, which could apply to the broader wheelchair and adaptive athletics community.

Carrington, Patrick; Laput, Gierad; Bigham, Jeffrey P. Carnegie Mellon Univ, HCI Inst, Pittsburgh, PA 15213 USA.


CR Ahmad F, 2006, J MED INTERNET RES, V8, DOI 10.2196/jmir.8.3.e22
Carrington P., 2017, P 19 INT ACM SIGACCE, P130
The Portuguese Severe Asthma Registry (Registo de Asma Grave Portugal, RAG) was developed by an open collaborative network of asthma specialists. RAG collects data from adults and pediatric severe asthma patients that despite treatment optimization and adequate management of comorbidities require step 4/5 treatment according to GINA recommendations. In this paper, we describe the development and implementation of RAG, its features, and data sharing policies. The contents and structure of RAG were defined in a multistep consensus process. A pilot version was pretested and iteratively improved. The selection of data elements for RAG considered other severe asthma registries, aiming at characterizing the patient's clinical status whilst avoiding overloading the standard workflow of the clinical appointment. Features of RAG include automatic assessment of eligibility, easy data input, and exportable data in natural language that can be pasted directly in patients' electronic health record and security features to enable data sharing (among researchers and with other international databases) without compromising patients' confidentiality. RAG is a national web-based disease registry of severe asthma patients, available at...
asmagrave.pt. It allows prospective clinical data collection, promotes standardized care and collaborative clinical research, and may contribute to inform evidence-based healthcare policies for severe asthma.

C1 [Sa-Sousa, Ana; Fonseca, Joao Almeida; Pereira, Ana Margarida; Ferreira, Ana] Univ Porto, Fac Med, Ctr Hlth Technol & Serv Res CINESSIS, Porto, Portugal.
[Fonseca, Joao Almeida; Pereira, Ana Margarida] Univ Porto, Fac Med, Dept Allergy Unit, Porto, Portugal.
[Arrobas, Ana; Almeida, Teresa] Ctr Hosp & Univ Coimbra, Pulmonol Dept, Coimbra, Portugal.
[Mendes, Ana; Costa, Celia; Carvalho, Francisca] Ctr Hosp Lisboa Norte, EPE, Immunol & Allergy Dept, Lisbon, Portugal.
[Videira, Wanda; Pinto, Paula] Ctr Hosp Lisboa Norte, Pulmonol Dept, Lisbon, Portugal.
[Costa, Tiago; Farinha, Pedro; Soares, Jose; Rocha, Pedro] VirtualCare, Porto, Portugal.
[Sokolova, Anna] Hosp Prof Doutor Fernando Fonseca, EPE, Immunol & Allergy Dept, Amadora, Portugal.
[Loureiro, Carla Chaves] Ctr Hosp & Univ Coimbra, Dept Pediat, Coimbra, Portugal.
[Longo, Cecilia; Pardal, Cecilia] Hosp Prof Doutor Fernando Fonseca, EPE, Pulmonol Dept, Amadora, Portugal.
[Cruz, Cintia] Ctr Hosp Setubal, EPE, Immunol & Allergy Dept, Setubal, Portugal.
[Loureiro, Claudia Chaves] Ctr Hosp & Univ Coimbra, Hosp Univ Coimbra, Pulmonol Unit, Coimbra, Portugal.
[Loureiro, Claudia Chaves] Univ Coimbra, Fac Med, Ctr Pulmonol, Coimbra, Portugal.
[Faria, Emilia; Regateiro, Frederico S.; Viana, Jorge] Ctr Hosp & Univ Coimbra, Immunol & Allergy Dept, Coimbra, Portugal.
[Menezes, Fernando; Castanho, Margarida] Hosp Garcia Orta, EPE, Pulmonol Dept, Almada, Portugal.
[Fernandes, Ivone] Ctr Hosp Setubal, Pulmonol Dept, Setubal, Portugal.

[Silva, Jose Manuel] EPE, Unidade Local Saude Guarda, Pulmonol Dept, Guarda, Portugal.

[Simao, Laura] Ctr Hosp Tamega & Sousa, EPE, Pulmonol Dept, Penafiel, Portugal.


[Quaresma, Marcia] Ctr Hosp Tras Os Montes & Alto Douro, EPE, Dept Pediat, Vila Real, Portugal.

[Andre, Natalia] Ctr Hosp Oeste, Pulmonol Dept, Torres Vedras, Portugal.


[Calvo, Teresa] Ctr Hosp Tras Os Montes Alto Douro, EPE, Pulmonol Dept, Vila Real, Portugal.


EM fonseca.ja@gmail.com

RI Cruz, Carla/I-7806-2013; Fonseca, Joao Almeida/B-7562-2008; Loureiro, Carla/M-8681-2019; Sa-Sousa, Ana/J-1941-2014; Regateiro, Frederico/F-3914-2011

OI Cruz, Carla/0000-0001-6630-1242; Fonseca, Joao Almeida/0000-0002-0887-8796; Loureiro, Carla/0000-0002-6326-8173; Sa-Sousa, Ana/0000-0002-9429-6863; Regateiro, Frederico/0000-0002-6332-3056

FU European Social Fund; ERDF (European Regional Development Fund) - Programa Operacional Competitividade e Internacionalizacao - COMPETE2020 [POCI-01-0145-FEDER-007746]; FCT - Fundacao para a Ciencia e a Tecnologia within CINTESIS, RD Unit [UID/IC/4255/2013]; MCTES (Ministerio da Ciencia, Tecnologia e Ensino Superior) through FCT (Fundacao para a Ciencia e Tecnologia) [PD/0003/2013]; Novartis Farma-Produtos Farmaceuticos, S.A.; [PD/BD/113665/2015]

FX The authors thank all members of the REAG (Rede de Especialistas em Asma Grave), namely, Ana Morete, Ana Sofia Barroso, Antonio Reis, Aurora Carvalho, Carmen Botelho, Catarina Ferreira, Claudia Pinto, Dolores Moniz, Elza Tomas, Emilia Alves, Eugenia Almeida, Filipa Inacio, Isabel Carrapatoso, Isabel Pereira, Jorge Romariz, Jose Pedro Moreira da Silva, Leonor Cunha, Luisa Barata, Luisa Geraldes, Luiza Semedo, Madalena Emillion, Manuel Barbosa, Margarida Raposo, Maria Jose Silvestre, Mariana Mendes, Marta Dias Sousa, Nuno Sousa, Orlando Santos, Paula Duarte, Rosario Ferreira, Sofia Furtado, and Vitor Teixeira. RAG was financed by an unrestricted grant from Novartis Farma-Produtos Farmaceuticos, S.A., which had no participation in any part of the development and implementation of the registry and has no access to the stored data for any purpose. The first author is financed by a PhD Grant (PD/BD/113665/2015) and financed by the European Social Fund and national funds of MCTES (Ministerio da Ciencia, Tecnologia e Ensino Superior) through FCT (Fundacao para a Ciencia e Tecnologia, I.P) PhD
Programme Ref. PD/0003/2013-Doctoral Programme in Clinical and Health Services Research (PDICSS). The publication of this article was supported by ERDF (European Regional Development Fund) through the operation POCI-01-0145-FEDER-007746 funded by the Programa Operacional Competitividade e Internacionalizacao - COMPETE2020 and by National Funds through FCT - Fundacao para a Ciencia e a Tecnologia within CINTESIS, R&D Unit (reference UID/IC/4255/2013).

Belvisi M., 2015, ERS RES AGENCYWHITE
Casella N., SANI PROJECT VERSO G
Dobrer D, 2015, WIEN KLIN WOCHENSCHR, V127, P821
Drazen JM, 2018, NEW ENGL J MED, V378, P2533, DOI 10.1056/NEJMe1806037
GINA, 2018, GLOB STRAT ASTHM MAN
Heaney LG, 2010, THORAX, V65, P787, DOI 10.1136/thx.2010.137414
JONES J, 1995, BRIT MED J, V311, P376, DOI 10.1136/bmj.311.7001.376
Newby C, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0102987
O’Neill S, 2015, THORAX, V70, P376, DOI 10.1136/thoraxjnl-2013-204114
Parliament E. Council, 2016, OFFICIAL J EUROPEA L, VL119, P1
R E Gliklich, 2014, REGISTRIES EVALUATIN
Sousa AS, 2015, REV PORT PNEUMOL, V21, P327, DOI 10.1016/j.rppnen.2015.03.002
Zervas E., 2018, ERS MONOGRAPH, V4

NR 37
TC 0
Z9 0
U1 2
U2 5
PU HINDAWI LTD
PI LONDON
PA ADAM HOUSE, 3RD FLR, 1 FITZROY SQ, LONDON, W1T 5HF, ENGLAND
Mass spectrometry imaging (MSI) is a transformative imaging method that supports the untargeted, quantitative measurement of the chemical composition and spatial heterogeneity of complex samples with broad applications in life sciences, bioenergy, and health. While MSI data can be routinely collected, its broad application is currently limited by the lack of easily accessible analysis methods that can process data of the size, volume, diversity, and complexity generated by MSI experiments. The development and application of cutting-edge analytical methods is a core driver in MSI research for new scientific discoveries, medical diagnostics, and commercial-innovation. However, the lack of means to share, apply, and reproduce analyses hinders the broad application, validation, and use of novel MSI analysis methods. To address this central challenge, we introduce the Berkeley Analysis and Storage Toolkit (BASTet), a novel framework for shareable and reproducible data analysis that supports standardized data and analysis interfaces, integrated data storage, data provenance, workflow management, and a broad set of integrated tools. Based on BASTet, we describe the extension of the OpenMSI mass spectrometry imaging science gateway to enable web-based sharing, reuse, analysis, and visualization of data analyses and derived data products. We demonstrate the application of BASTet and OpenMSI in practice to identify and compare characteristic substructures in the mouse brain based on their chemical composition measured via MSI.

C1 [Rubel, Oliver] Lawrence Berkeley Natl Lab, Computat Res Div, Alameda, CA USA. [Bowen, Benjamin P.] LBNL, Environm Genom & Syst Biol Div, Alameda, CA USA.
RP Rubel, O (reprint author), Lawrence Berkeley Natl Lab, Computat Res Div, 
Alameda, CA USA.
EM oruebel@lbl.gov; bpbowen@lbl.gov
FU Berkeley Lab's Laboratory Directed Research and Development (LDRD); 
National Energy Research Scientific Computing Center (NERSC); Office of 
Science of the U.S. Department of Energy; and the Low-Dose Radiation 
Research of the Office of Science; Office of Biological and 
Environmental Research; U. S. Department of Energy [DE-AC02-05CH11231]
FX This work was supported by and used resources of Berkeley Lab's 
Laboratory Directed Research and Development (LDRD) support; the 
National Energy Research Scientific Computing Center (NERSC) supported 
by the Office of Science of the U.S. Department of Energy; and the 
Low-Dose Radiation Research of the Office of Science, Office of 
Biological and Environmental Research, of the U. S. Department of Energy 
under Contract No. DE-AC02-05CH11231. We thank S. Cholia and the 
Scientific Data Services team at NERSC for their ongoing efforts and 
support to help deliver scientific data and high-performance computing 
to science communities. We thank the Northen Lab (LBNL) and all OpenMSI 
users for their help, support, feedback, and contributions of MSI data.
[Anonymous], 2011, P SCIDAC 2011, P2011
Balderrama JR, 2014, 2014 9th Workshop on Workflows in Support of Large-Scale 
Science (WORKS), P50, DOI 10.1109/WORKS.2014.14
Bokeh Development Team, 2014, BOK PYTH LIB INT VIS
Bostock M, 2011, IEEE T VIS COMPUT GR, V17, P2301, DOI 10.1109/TVCG.2011.185
Brown P. G., 2010, P 2010 ACM SIGMOD IN, P963, DOI DOI
10.1145/1807167.1807271
Callahan SP, 2008, LECT NOTES COMPUT SC, V5272, P120, DOI 10.1007/978-3-540-89665-5_13
Chollà Shreyas, 2010, GAT COMP ENV WORKSH, P1
Chughtai K, 2010, CHEM REV, V110, P3237, DOI 10.1021/cr100012c
Costa MA, 2013, PLOS ONE, V8, DOI 10.1371/journal.pone.0083169
Dalisay DS, 2015, J NAT PROD, V78, P1231, DOI 10.1021/acs.jnatprod.5b00023
Deelman E., 2005, Scientific Programming, V13, P219
Dong B., 2013, CLUST COMP CLUSTER 2, P1
DoYupLee V. P., 2012, INTEGRATIVE BIOL QUA, V4, P693
Fehninger TE, 2011, ANAL CHEM, V83, P8329, DOI 10.1021/ac2014349
Fischer CR, 2016, ARCH BIOCHEM BIOPHYS, V589, P18, DOI
10.1016/j.abb.2015.08.021
Fontaine E., 2016, IMABIO TECH SIGNS LIC
Foster I, 2011, IEEE INTERNET COMPUT, V15, P70, DOI 10.1109/MIC.2011.64
Hock L., 2015, R D MAGAZINE
Jain A., 2015, CONCURRENCY COMPUTAT
Johnson H. J., 2013, ITK SOFTWARE GUIDE B, V1
Lagarrigue M, 2014, ANAL CHEM, V86, P5775, DOI 10.1021/ac500313s
Louie KB, 2013, ANAL CHEM, V85, P10856, DOI 10.1021/ac402240q
Maia FRNC, 2012, NAT METHODS, V9, P854, DOI 10.1038/nmeth.2110
Martens L., 2011, MOL CELLULAR PROTOTI, V10, pR110, DOI DOI
10.1074/MCP.R110.000133
Moreland K, 2016, IEEE COMPUT GRAPH, V36, P48, DOI 10.1109/MCG.2016.48
Parry R. M., OMNISPECT OPEN MATLA
Pedregosa F., MEMORY PROFILER
Raad M., ANAL CHEM UNPUB
Rubel O, 2013, ANAL CHEM, V85, P10354, DOI 10.1021/ac402540a
Satyanarayan A, 2016, IEEE T VIS COMPUT GR, V22, P659, DOI
10.1109/TVCG.2015.2467091
Schindelin J, 2012, NAT METHODS, V9, P676, DOI [10.1038/NMETH.2019,
10.1038/nmeth.2019]
Schneider CA, 2012, NAT METHODS, V9, P671, DOI 10.1038/nmeth.2089
Schroeder W., 2006, VISUALIZATION TOOLKI
Shasharina S., 2009, IADIS INT C COMP GRA, P49
Silva LP, 2015, CURR OPIN BIOTECH, V34, P209, DOI
10.1016/j.copbio.2015.03.015
The HDF Group, 1997, HIER DAT FORM VERS 5
Thomas R., 2017, CRA US GROUP CUG C P
Williams DN, 2013, COMPUTER, V46, P68, DOI 10.1109/MC.2013.119
Yang JY, 2015, ANAL CHEM, V87, P4658, DOI 10.1021/ac5040264
NR 51
TC 0
Z9 0
U1 0
U2 4
PU IEEE COMPUTER SOC
FI LOS ALAMITOS
PA 10662 LOS VAQUEROS CIRCLE, PO BOX 3014, LOS ALAMITOS, CA 90720-1314 USA
SN 1077-2626
EI 1941-0506
J9 IEEE T VIS COMPUT GR
PJ JAN
PY 2018
VL 24
IS 1
BP 1025
EP 1035
DI 10.1109/TVCG.2017.2744479
PG 11
WC Computer Science, Software Engineering
SC Computer Science
GA FQ0IM
UT WOS:000418038400101
PM 28866551
DA 2019-08-06
ER
PT S
AU Duan, TY
Lan, HR
Zhong, HT
Zhou, M
Gao, F
AF Duan, Tingyang
AB As an emerging hybrid imaging modality, photoacoustic imaging has attracted intensive research interest in recent years in various applications, such as breast cancer detection, brain imaging, and intravascular imaging, which provides functional and molecular information. In a typical photoacoustic imaging system, laser intensity fluctuation needs to be monitored by a photodiode (PD) that can provide proper normalization for photoacoustic signals. Conventionally, at least two data acquisition channels are necessary to receive both photoacoustic signal and photodiode signal. In this paper, we propose a simple and efficient method to receive both photoacoustic and photodiode signals using single data acquisition channel, which gives lower system cost and faster system speed. After connecting the photodiode output and ultrasound transducer for hybrid signal acquisition, sharing channel can be achieved in two ways: Use a direct separation algorithm when received a PA signal with desirable signal-to-noise. Filters are exploited to keep low SNR PA signal immune from the photodiode signal and separate them from the receiving hybrid signal. 2D PA images based on the separated PA and PD signals will be illustrated to demonstrate their performance and efficiency. This method will be valuable especially when designing a PAT imaging system with multi-channel ultrasound array and data-acquisition card.

FU Start-up grant of ShanghaiTech University [F-0203-17-004]; Natural Science Foundation of Shanghai [18ZR1425000]; Natural Science Foundation of China [61805139]

FX This research was funded by Start-up grant of ShanghaiTech University (F-0203-17-004), Natural Science Foundation of Shanghai (18ZR1425000), and Natural Science Foundation of China (61805139)
Background: Fascinating developments in big data technologies and unprecedented diffusion of social networking sites (SNSs) generate unseen opportunities for scientific fields, including psychiatry. This study focuses on the use of SNSs by adolescent psychiatric patients and the potential use of SNS-generated data to help medical practitioners diagnose and treat patients' mental health. Our objective is to understand and measure the psychiatric and individual conditions in which symptom-sharing occurs on SNSs and the frequency of these conditions. Based on literature, we hypothesized that the perceived value of social network sites positively affects adolescents' sharing of symptoms on these sites.

Subjects and methods: An empirical test of this hypothesis was conducted with a survey of 224 adolescents admitted to a psychiatry clinic in Turkey. The hypothesis was tested using a hierarchical multiple regression analysis.

Results: The perceived value of SNSs explained an additional 37.8% of variation in symptom sharing on SNSs above and beyond the control variables, which are gender, age, type of disorder, and amount of internet and SNS use. The findings suggested that adolescents share symptoms on SNSs only if they attribute value to the SNSs that they use. We also found that 72% of adolescents in our sample shared their symptoms on SNSs.

Conclusions: There is an attractive opportunity for information technology companies to develop, together with health professionals; data analytics that are able to detect symptoms to support psychiatric diagnoses and pave the way for big-data enabled personalized medicine.
Demir U, 2016, SELCUK U ILETISIM FA, V9, P27
Denti L, 2012, GOTHENBURG RES I, V3, P5
DesChoudhury M., 2013, ICWSM, V13, P1
Durukan I, 2011, DUNSEN ADAM, V24, P113, DOI 10.5350/DAJPN2011240204
Friso n E, 2015, COMPUT HUM BEHAV, V44, P315, DOI 10.1016/j.chb.2014.11.070
Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
Gittelman S, 2015, J MED INTERNET RES, V17, DOI 10.2196/jmir.3970
Hair J. F., 1998, MULTIVARIATE DATA AN
Hazar M, 2011, J COMMUNICATION THEO, V2011, P32
Howes Christine, 2014, P WORKSH COMP LING C, P7
Kayyali B, 2013, BIG DATA REVOLUTION, V2, P1
Kuss DJ, 2011, J ENV RES PUB HE, V8, P3528, DOI 10.3390/ijerph8093528
Liu D, 2014, COMPUT HUM BEHAV, V38, P213, DOI 10.1016/j.chb.2014.06.003
Liu F, 2015, CYBERPSYCH BEH SOC N, V18, P373, DOI 10.1089/cyber.2015.0022
Moreno M. A., 2013, OPEN J DEPRESSION, V2, P35
Nambisan P, 2015, SYST SCI HICSS 2015
Ozteke HI, 2015, ONLINE J COUNSELING, V4, P15
Pallant J., 2001, SPSS SURVIVAL MANUAL
Pantic I, 2012, PSYCHIAT DANUB, V24, P90
Settanni M, 2015, FRONT PSYCHOL, V6, DOI 10.3389/fpsyg.2015.01045
Singleton A, 2016, COMPUT HUM BEHAV, V61, P394, DOI 10.1016/j.chb.2016.03.011
Tabachnick B. G., 2001, USING MULTIVARIATE S
Ucar H, 2014, ULUDAG U TIP FAKULTE, V40, P75
van den Eijnden RJJM, 2016, COMPUT HUM BEHAV, V61, P478, DOI 10.1016/j.chb.2016.03.038
Van Gool E, 2015, COMPUT HUM BEHAV, V44, P230, DOI 10.1016/j.chb.2014.11.036

NR 50
TC 0
Z9 0
U1 1
U2 1
PU MEDICINSKA NAKLADA
PI ZAGREB
A Cheating Detectable Privacy-Preserving Data Sharing Scheme for Cloud Computing

Cloud computing provides a new, attractive paradigm for the effective sharing of storage and computing resources among global consumers. More and more enterprises have begun to enter the field of cloud computing and storing data in the cloud to facilitate the sharing data among users. However, in many cases, users may be concerned about data privacy, trust, and integrity. It is challenging to provide data sharing services without sacrificing these security requirements. In this paper, a data sharing scheme of reliable, secure, and privacy protection based on general access structure is introduced. The proposed scheme is not only effective and flexible, but also is capable of protecting privacy for the cloud owner, supporting data sharing under supervision, enabling accountability of users' decryption keys, and identifying cheaters if some users behave dishonestly. Security analysis and efficiency analysis demonstrate that our proposed scheme has better performance in computational costs compared with most related works. The scheme is versatile to be used in various environments. For example, it is particularly suitable to be employed to protect personal health data and medical diagnostic data in information medical environment.

C1 [Wang, Xin; Yang, Bo; Zhao, Yanqi] Shaanxi Normal Univ, Sch Comp Sci, Xian 710119, Shaanxi, Peoples R China.


[Wang, Xin; Yang, Bo] Chinese Acad Sci, Inst Informat Engn, State Key Lab Informat Secur, Beijing 100093, Peoples R China.


RP Yang, B (reprint author), Shaanxi Normal Univ, Sch Comp Sci, Xian 710119, Shaanxi, Peoples R China.; Yang, B (reprint author), Chinese Acad Sci, Inst Informat Engn, State Key Lab Informat Secur, Beijing 100093, Peoples R China.

EM byang@snnu.edu.cn

OI Yu, huifang/0000-0003-4711-3128

FU National Key R&D Program of China [2017YFB0802000]; National Natural Science Foundation of China [61572303, 61772326, 61802241, 61802242, 61872289]; National Cryptography Development Fund [MMJJ20180217]; Foundation of State Key Laboratory of Information Security [2017-MS-03]; Provincial Natural Science Foundation Research Project of Shaanxi [2017JQ6029]; Shaanxi Provincial Department of Education Special Scientific Research Project [16JK1109]; Shaanxi University of Science and Technology [BJ11-12]

FX This work is supported by National Key R&D Program of China (no. 2017YFB0802000), the National Natural Science Foundation of China (61572303, 61772326, 61802241, 61802242, and 61872289), National Cryptography Development Fund during the 13th Five-year Plan Period (MMJJ20180217), the Foundation of State Key Laboratory of Information Security (2017-MS-03), the Provincial Natural Science Foundation Research Project of Shaanxi (no. 2017JQ6029), the Shaanxi Provincial Department of Education Special Scientific Research Project (no. 16JK1109), and the Doctoral Scientific Fund Project of Shaanxi University of Science and Technology (BJ11-12).

CR Beimel, 1996, THESIS
Boyen X, 2006, LECT NOTES COMPUT SC, V4117, P290
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Hoshino H, 2016, INT SYMPOS COMPUT NE, P623, DOI [10.1109/CANDAR.2016.85, 10.1109/CANDAR.2016.0112]
Jiang SR, 2015, SENSORS-BASEL, V15, P22419, DOI 10.3390/s150922419
Kallahalla M., 2003, FAST, P29
Nishide T, 2008, LECT NOTES COMPUT SC, V5037, P111, DOI 10.1007/978-3-540-68914-0_7
Obana S, 2011, LECT NOTES COMPUT SC, V6632, P284, DOI 10.1007/978-3-642-20465-4_17
Shucheng Y, 2010, P IEEE INFOCOM, P1, DOI DOI 10.1109/INFCOM.2010.5462174

TC 0
Z9 0
U1 2
U2 4
AB Complex patient health needs and care delivery models such as patient participatory medicine require the ability to share data across multiple touch points. Achieving systematic performance management of care processes require an infrastructure that addresses interoperability and data standardization while supporting data governance and privacy compliance. In this paper, we present a framework for operationalizing privacy compliance for correlated cloud-hosted data using Data Sharing Agreements (DSAs) in support of performance management of community healthcare. Our focus is to show how DSAs can be used to operationalize privacy compliance for a cloud-hosted surveillance and performance management infrastructure by leveraging selective anonymization based on both organizational and patient consents. This allows a cloud-computing infrastructure to configure processes and services, including anonymization to ensure privacy compliance and a systematic approach to data governance.

Cl [Eze, Benjamin; Peyton, Liam] Univ Ottawa, Sch Elect Engn & Comp Sci, Ottawa, ON K1N 6N5, Canada.

[Kuziemsky, Craig] Univ Ottawa, Telfer Sch Management, Ottawa, ON K1N 6N5, Canada.
This work was partially supported by funding from the Canadian Natural Sciences and Engineering Research Council (NSERC) and Ontario Graduate Scholarship (OGS).
SHARE: a data set for ageing research
Sharing health data in Belgium: A home care case study using the Vitalink platform

AB In 2013, the Flemish Government launched the Vitalink platform. This initiative focuses on the sharing of health and welfare data to support primary healthcare. In this paper, the objectives and mission of the Vitalink initiative are discussed. Security and privacy measures are reviewed, and the technical implementation of the Vitalink platform is presented. Through a case study, the possibility of interaction with cloud solutions for healthcare is also investigated upon; this was initially not the focus of Vitalink. The Vitalink initiative provides support for secure data sharing in primary healthcare, which in the long term will improve the efficiency of care and will decrease costs. Based on the results of the case study, Vitalink allowed cloud solutions or applications not providing end-to-end security to use their system. The most important lesson learned during this research was the need for firm regulations and stipulations for cloud solutions to interact with the Vitalink platform. However, these are currently still vague.

CR [Anonymous], 2015, HUBS MET EXCH PLATTF
[Anonymous], 2010, STS SEC TOK SERV EHE
[Anonymous], 2013, FLEM GOVT
[Anonymous], 2011, AWS SEC TOK SERV
Background To investigate whether sharing and linking routinely collected violence data across health and criminal justice systems can provide a more comprehensive understanding of violence, establish patterns of under-reporting and better inform the development, implementation and evaluation of violence prevention initiatives.

Methods Police violence with injury (VWI) crimed data and emergency department (ED) assault attendee data for South Wales were collected between 1 April 2014 and 31 March 2016 to examine the rates and patterns of VWI. Person identifiable data (PID) were cross-referenced to establish if certain victims or events were less likely to be reported to criminal justice services.

Results A total of 18 316 police crimed VWI victims and 10 260 individual ED attendances with an assault-related injury were considered. The majority of ED assault attendances (59.0%) were unknown to police. The key demographic identified as under-reporting to police were young males aged 18-34 years, while...
a significant amount of non-reported assaults involved a stranger. The combined monthly age-standardised rates were recalculated and on average were 74.7 (95% CI 72.1 to 77.2) and 66.1 (95% CI 64.0 to 68.2) per 100 000 population for males and females, respectively. Consideration of the additional ED cases resulted in a 35.3% and 18.1% increase on the original police totals for male and female VVI victims.

Conclusions This study identified that violence is currently undermeasured, demonstrated the importance of continued sharing of routinely collected ED data and highlighted the benefits of using PID from a number of services in a linked way to provide a more comprehensive picture of violence.

MULTIPLE CHRONIC CONDITIONS IN OLDER PEOPLE AND THEIR EFFECTS ON HEALTH CARE UTILIZATION: A NETWORK ANALYSIS APPROACH USING SHARE DATA

Skrakar, A.; Rupel, V.; Prevolnik, V.
Inst Econ Res, Ljubljana, Slovenia.
Univ Ljubljana, Fac Econ, Ljubljana, Slovenia.
Sharing human samples and patient data: Opening Pandora's box

Background: Sharing of clinical research data is a much-debated topic. Actions are being taken at various levels ranging from industry cooperative data sharing models to high-level policy interventions. Similar approaches for sharing biological samples are lacking.

Aims and methods: An in-depth understanding of the motives for sharing, and the still too often lack thereof, is acquired through semi-structured interviews with 32 experts.

Results: Moral, societal, scientific, and economic reasons favoring sharing are driving a change in the behavior of both commercial and non-commercial organizations. Whereas concerns of losing control, the impact on incentives to invest, privacy and data protection considerations, pragmatic impediments, and samples' finite nature greatly impede exploiting the scientific potential of these valuable patient resources.

Conclusion: Addressing these concerns by mitigating the risks can provide incentives for sharing, and thereby leverage scientific research. Finally, a collective vision is necessary by all stakeholders that sharing will stimulate science and innovation in the medium and long term, and thereby outweigh potential short term disadvantages.

[Broes, Stefanie; Lacombe, Denis; Verlinden, Michiel] European Org Res Treatment Canc, Brussels, Belgium.


EM stefanie.broes@eortc.be

FU EORTC

FX SB received a PhD scholarship of the EORTC.

Drazen JM, 2016, NEW ENGL J MED, V374, pE24, DOI 10.1056/NEJM1601087
Eicher H., 2014, NEW ENGL J MED, V369, P1577
Esterov A, 2018, NAGOYA MATH J, V231, P1, DOI 10.1017/nmj.2017.8
Green A.K., 2015, ONCOLOGIST, V20
Hunter P, 2015, EMBO REP, V16, P21, DOI 10.15252/embr.201439894
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
Kim D, 2016, FOOD DRUG LAW J, V71, P673
Lacombe D, 2014, NAT REV CLIN ONCOL, V11, P492, DOI 10.1038/nrclinonc.2014.98
Mascalzoni D, 2015, EUR J HUM GENET, V23, P721, DOI 10.1038/ejhg.2014.197
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
Sariyar M, 2015, BIOPRESERV BIOBANK, V13, P263, DOI 10.1089/bio.2015.0014
Taichman DB, 2016, NEW ENGL J MED, V374, P384, DOI 10.1056/NEJMMe1515172
The European Organization for Research and Treatment of Cancer (EORTC), REL
DAT EORTC STUD U
Wright JT, 2015, NEW ENGL J MED, V373, P2103, DOI 10.1056/NEJMoa1511939

NR 27
TC 0
Z9 0
U1 2
U2 7
PU ELSEVIER SCI LTD
PI OXFORD
PF THE BOULEVARD, LANGFORD LANE, KIDLINGTON, OXFORD OX5 1GB, OXON, ENGLAND
SN 2213-5383
J9 J Cancer Policy
JI J. CANCER POLICY
PD SEP
PY 2017
VL 13
BP 65
EP 69
DI 10.1016/j.jcpo.2017.07.006
PG 5
WC Health Policy & Services
SC Health Care Sciences & Services
GA FU6EN
UT WOS:000423944800010
DA 2019-08-06
ER

PT J
AU Beninger, P
Connelly, J
Natarajan, C
AF Beninger, Paul
Connelly, James
Natarajan, Chandrasekhar
TI Data Sharing in the Pharmaceutical Enterprise: The Genie's Out of the Bottle
AB Objective: This Commentary shows that the present emphasis on the sharing of data from clinical trials can be extended to the entire pharmaceutical enterprise.

Methods: The authors constructed a Data Sharing Dashboard that shows the relationship between all of the life-cycle domains of the pharmaceutical enterprise from discovery to obsolescence and the domain bridging disciplines, such as target credentialing, structure-activity relationships, and exposure-effect relationships.

Findings: The published literature encompassing the pharmaceutical enterprise is expansive, covering the major domains of discovery, translation, clinical development, and post-marketing outcomes research, all of which have even larger, though generally inaccessible, troves of legacy data bases. Notable exceptions include the fields of genomics and bioinformatics.

Implications: We have the opportunity to broaden the present momentum of interest in data sharing to the entire pharmaceutical enterprise, beginning with discovery and extending into health technology assessment and post-patent expiry generic use with the plan of integrating new levels and disciplines of knowledge and with the ultimate goal of improving the care of our patients. (C) 2017 Elsevier HS Journals, Inc. All rights reserved.

C1 [Beninger, Paul] Tufts Univ, Sch Med, Publ Hlth & Community Med, 136 Harrison Ave, Boston, MA 02111 USA.
[Connelly, James] ClinDataPro LLC, Waltham, MA USA.
[Natarajan, Chandrasekhar] ViNa Pharma Consultants LLC, Cambridge, MA USA.

CR Berger ML, 2015, VALUE HEALTH, V18, P127, DOI 10.1016/j.jval.2014.10.009
Connelly J, 2015, 13 ANN PHARM IT C
Danhof M, 2015, J PHARMACOKINET PHAR, V42, P447, DOI 10.1007/s10928-015-9437-x

European Medicines Agency, EUR MED AG POL PUBL
European, LINK OP DAT
Guha Rajarshi, 2013, Methods Mol Biol, V993, P81, DOI 10.1007/978-1-62703-342-8 6

Institute of Medicine, 2015, SHAR CLIN TRIAL DAT

Kaye J, 2009, NAT REV GENET, V10, P331, DOI 10.1038/nrg2573
Lhasa Limited, VIT NEX CHEM DAT INF

National Institutes of Health, CLINICALTRIALS GOV S
Roland D., 2017, WALL STREET J, pB1
Springer Nature, TARG ID
The Georgetown Database of Cancer (G-DOC): A web-based data sharing platform for precision medicine
TI MULTIPLE CHRONIC CONDITIONS IN OLDER PEOPLE AND THEIR EFFECTS ON HEALTH CARE UTILIZATION: A NETWORK ANALYSIS APPROACH USING SHARE DATA
SO VALUE IN HEALTH
LA English
DT Meeting Abstract
C1 [Srakar, A.; Rupel, Prevolnik, V] Inst Econ Res, Ljubljana, Slovenia. [Srakar, A.] Univ Ljubljana, Fac Econ, Ljubljana, Slovenia.

PT J
AU Srakar, A
Rupel, VP
AF Srakar, A.
Rupel, Prevolnik, V

TI Data Sharing and Data Registries in Physical Medicine and Rehabilitation
SO PM&R
LA English
DT Article
ID HEALTH-CARE; OUTCOMES PARTNERSHIP; NEUROTROPHIC FACTOR; DATA MODELS;
The field of physical medicine and rehabilitation (PM&R), along with all the disciplines it encompasses, has evolved rapidly in the past 50 years. The number of controlled trials, systematic reviews, and meta-analyses in PM&R increased 5-fold from 1998 to 2013. In recent years, professional, private, and governmental institutions have identified the need to track function and functional status across providers and settings of care and on a larger scale. Because function and functional status are key aspects of PM&R, access to and sharing of reliable data will have an important impact on clinical practice. We reviewed the current landscape of PM&R databases and data repositories, the clinical applicability and practice implications of data sharing, and challenges and future directions. We included articles that (1) addressed any aspect of function, disability, or participation; (2) focused on recovery or maintenance of any function; and (3) used data repositories or research databases. We identified 398 articles that cited 244 data sources. The data sources included 66 data repositories and 179 research databases. We categorized the data sources based on their purposes and uses, geographic distribution, and other characteristics. This study collates the range of databases, data repositories, and data-sharing mechanisms that have been used in PM&R internationally. In recent years, these data sources have provided significant information for the field, especially at the population-health level. Implications and future directions for data sources also are discussed.

Kho, Abet N.; Rosenman, Marc B.] Northwestern Univ, Feinberg Sch Med, Ctr Hlth Informat Partnerships, Inst Publ Hlth & Med, Chicago, IL 60611 USA.
[Capo-Lugo, CE (reprint author), Northwestern Univ, Feinberg Sch Med, Inst Publ Hlth & Med, Ctr Educ Hlth Sci, 633 N St Clair St, 20th Floor, Chicago, IL 60611 USA.
Kho, Abet N.; Rosenman, Marc B.] Northwestern Univ, Dept Med, Feinberg Sch Med, Chicago, IL 60611 USA.
O'Dwyer, Linda C.] Northwestern Univ, Galter Hlth Sci Lib, Feinberg Sch Med, Chicago, IL 60611 USA.
RP Capo-Lugo, CE (reprint author), Northwestern Univ, Feinberg Sch Med, Inst Publ Hlth & Med, Ctr Educ Hlth Sci, 633 N St Clair St, 20th Floor, Chicago, IL 60611 USA.
EM carmen.capolugo@northwestern.edu
CR AcademyHealth, UPC EV
Australia and New Zealand Burn Association/Monash University, 2017, BURNS REG AUSTR NZ
Biering-Sorensen F, 2015, SPINAL CORD, V53, P265, DOI 10.1038/sc.2014.246
Center for Large Data Research & Data Sharing in Rehabilitation, 2016, ADV RES DIS Center on Knowledge Translation for Disability and Rehabilitation Research (KTDRR), 2016, ART KNOWL VAL MAPP
Centers for Medicare & Medicaid Services (CMS) Health Human Services, 2016, FED REGISTER, V81, P77008
Charlifue S, 2016, ARCH PHYS MED REHAB, V97, P1805, DOI 10.1016/j.apmr.2016.03.030
Cowley S., 2016, NY TIMES Dana-Farber/Boston Children's Cancer and Blood Disorders Center, WE WORK CENTR AM REG
Coelho FGD, 2013, ARCH GERONTOL GERIAT, V56, P10, DOI 10.1016/j.archger.2012.06.003
Erekson EA, 2015, J MINIM INVAS GYN, V22, P1124, DOI 10.1016/j.jmig.2015.07.003
Gini Rosa, 2016, EGEMS (Wash DC), V4, P1189, DOI 10.13063/2327-9214.1189
Jesus TS, 2016, ARCH PHYS MED REHAB, V97, P1853, DOI 10.1016/j.apmr.2016.06.017
Kahn MG, 2012, MED CARE, V50, P560, DOI 10.1097/MLR.0b013e318259bff4
Kronman MP, 2015, J PEDIAT INF DIS SOC, V4, P143, DOI 10.1093/jpids/piv007
Kruse CS, 2016, JMIR MED INF, V4, pe38, DOI [DOI 10.2196/MEDINFORM.5359, DOI 10.2196/MEDINFORM.5359]
Mimouni M, 2016, ARCH PHYS MED REHAB, V97, P1030, DOI 10.1016/j.jacc.2015.10.102
National Cancer Institute Surveillance, BRIEF HIST CANC REG
Nudo RJ, 1996, SCIENCE, V272, P1791, DOI 10.1126/science.272.5269.1791
Ogunyemi OI, 2013, MED CARE, V51, P45, DOI 10.1097/MLR.0b013e31829b1e0b
Overhage JM, 2012, J AM MED INFORM ASSN, V19, P54, DOI 10.1136/amiajnl-2011-000376
Parker SL, 2015, NEUROSURG FOCUS, V39, DOI 10.3171/2015.9.FOCUS15355
Ramos Hegwer L, 2016, BUILDING MEANINGFUL
Schjodt I, 2016, CLIN EPIDEMIO, V8, P497, DOI 10.2147/CLEP.S99504
Sears JM, 2016, PUBLIC HEALTH REP, V131, P791, DOI 10.1177/0033354916669358
Smith MD, 2012, BEST CAR LOW COST PA
Stucki G, 2008, EUR J PHYS REHAB MED, V44, P343
Taichman DB, 2016, LANCET, V387, P69, DOI 10.1016/S0140-6736(15)01279-9
Teresi JA, 2016, MED CARE, V55, P1035, DOI 10.1097/MCR.0000000000000662
The PLOS Medicine Editors, 2016, PLOS MED, V13
Veras M, 2016, J TELEMED TELECARE
Xu YH, 2015, DRUG SAFETY, V38, P767, DOI 10.1007/s40264-015-0322-8
For Diabetes Shared Savings Programs, 1 Year of Data Is Not Enough

AB Fee-for-service payment models are moving toward pay-for-performance designs, many of which rely on shared savings for financial sustainability. Shared savings programs divide the cost savings between health care purchaser and provider based on provider performance. Often, these programs measure provider performance as the delivery of agreed-upon clinical practice guidelines that usually are represented as evidence-based medicine (EBM). Multiyear studies show a negative relationship between total cost and EBM, indicating that long-term shared savings can be substantial. This study explores expectations for the rewards in the first year of a shared savings program. It also indicates the effectiveness of using 1 year of claims to assess cost savings from evidence-based care, especially in a patient population with high turnover. This study
analyzed 1956 adults with diabetes insured through Medicaid. Results of linear regression showed that the relationship between total cost of care and each element of evidence-based medical care during a 1-year period was positive (higher cost) or insignificant. The results indicate that diabetes EBM programs cannot expect to see significant cost savings if the evaluation lasts only 1 year or less. The study concludes that improvements in EBM incentive programs could come from investigating the length of time needed to realize cost savings from each element of diabetes EBM. Investigating other factors that could affect the expected amount of cost savings also would benefit these programs, especially factors derived from sources external to insurance program information such as the medical record and care management data.

C1 [VanArsdale, Lynne] Univ Colorado Hlth Sci, Grad Sch, Clin Sci, Aurora, CO USA.

[Currnan-Everett, Douglas] Natl Jewish Hlth, Div Biostat & Bioinformat, Denver, CO USA.

[Augen, Heather] Univ Colorado Hlth Sci, Hlth Inform Technol, Aurora, CO USA.


[Atherly, Adam] Univ Colorado Hlth Sci, Colorado Sch Publ Hlth, Aurora, CO USA.

RP VanArsdale, L (reprint author), Univ Colorado Hlth Sci, Grad Sch, Colorado Clin & Translat Sci Inst, 12401 E 17th Ave,Mail Stop B141, Aurora, CO 80045 USA.

EM Lynne.vanarsdale@ucdenver.edu

FU NIH/NCATS Colorado CTSI Grant [UL1 TR001082]

FX Ms. VanArsdale and Drs. Curran-Everett, Haugen, Smith, and Atherly declared no conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors received the following financial support: Supported by NIH/NCATS Colorado CTSI Grant Number UL1 TR001082. The contents are the authors' sole responsibility and do not necessarily represent official NIH views.


Agency for Healthcare Research and Quality, DEF THE PCMH

[Anonymous], 2015, DIABETES CARE, V38, p81, DOI 10.2337/dc15-0001

Cecchini M, 2010, LANCET, V376, p1775, DOI 10.1016/S0140-6736(10)61514-0

Centers for Disease Control and Prevention, 2014, DIAB 2014 REP CAR

Centers for Medicare & Medicaid Services, SHAR SAV PROGR

Centers for Medicare & Medicaid Services, 2012, CHRON COND MED BEN C


de Brantes F, 2011, SUSTAINING MED HOME

DeVoe JE, 2011, ANN FAM MED, V9, P351, DOI 10.1370/afm.1279

Doran T, 2013, CURR DIABETES REP, V13, P196, DOI 10.1007/s11892-012-0351-z

Eisenhandler J, COMP EXPLANATORY POW

Garfield SS, 2015, DIABETES THER, V6, P113, DOI 10.1007/s13300-015-0109-z


Hazel-Fernandez L, 2015, POPUL HEALTH MANAG, V18, P115, DOI 10.1089/pop.2014.0038

Health Care Incentives Improvement Institute, PROM PAYM MOD 3 11


HICKS J, 2003, POTENTIAL CLAIMS DAT

Huerta TR, 2016, HEALTH CARE MANAGE R, V41, P56, DOI 10.1097/HMR.0000000000000045
TRIPS and disclosure of clinical information: An intellectual property perspective on data sharing

SO JOURNAL OF WORLD INTELLECTUAL PROPERTY
Health scholars, lawyers, and social activists have greatly emphasized the social benefits of disclosure of clinical reports, that is, dossiers of drugs trials submitted to medical agencies in support of pharmaceutical authorizations. On their side, medical authorities are reluctant to divulge regulatory documents because they fear that they might contain commercial trade secrets of drug applicants. In these regards, the Agreement on Trade Related Aspects of Intellectual Property (TRIPS) prohibits trials disclosure except "where necessary to protect the public" or "unless steps are taken to ensure that the data are protected against unfair commercial use." This paper delves into the complications of the TRIPS discipline to clarify the limits imposed by the treaty on medical agencies, and it goes on to suggest meaningful ways of complying with the TRIPS obligations while retaining most of the benefits associated with trials disclosure.

C1 [Ali, Gabriele Spina] Univ Hong Kong, Fac Law, 10-F Cheng Yu Tung Tower, Centennial Campus, Hong Kong, Hong Kong, Peoples R China.
RP Ali, GS (reprint author), Univ Hong Kong, Fac Law, 10-F Cheng Yu Tung Tower, Centennial Campus, Hong Kong, Hong Kong, Peoples R China.
EM gabriele.spinaali@gmail.com

CR Abou-El-Enein M, 2016, NAT BIOTECHNOL, V34, P231, DOI 10.1038/nbt.3492
Akst J, 2013, SCIENTIST
Basheer S., 2006, PROTECTION REGULATOR
Bradford A, 2015, SCI SCI METHOD DEFIN
Correa C. M., 2002, PROTECTION DATA SUBM
Correa C. M., 2007, TRADE RELATED ASPECT
Davis C.O, 2014, WASHINGTON U LAW REV, V91, P1591
Day S., 2004, TXB CLIN TRIALS
Delimatsis P., 2014, TILBURG LAW SCH LEGA, V4, P22
Dhar B., 2006, ARTICLE 39 3 TRIPS A
Drazen JM, 2015, NEW ENGL J MED, V372, P201, DOI 10.1056/NEJMp1415160
EFPIA, 2009, JOINT POS DISCL CLIN
Eichler HG, 2012, PLOS MED, V9, DOI 10.1371/journal.pmed.1001202
Eisenberg Rebecca S., 2007, MICH TELECOMM TECH L, V13, P345
Engelberg Alfred B., 1999, IDEA, V39, P389
Evelagelatos N, 2016, PUBLIC HEALTH GENOM, V19, P211, DOI 10.1159/000446101
Fellmeth AX, 2004, HARVARD INT LAW J, V45, P443
Food and Drug Administration, 1981, FDA CONSUMER MAGAZIN
Fujimoto E., 2009, THESIS
Goffin J., 2009, CLIN TRIALS HDB
Goldacre B, 2014, GUARDIAN
Gotzsche PC, 2011, TRIALS, V12, DOI 10.1186/1745-6215-12-249
Groves T., 2014, BRIT MED J, V349, P1
HALPERIN RM, 1979, DUKE LAW J, P286
Institute of Medicine (IOM), 2015, SHAR CLIN TRIAL DAT
Kant L, 2008, INDIAN J TUBERCULOSI, V55, P42
Kapczynski A, 2014, INTERACTION OPEN TRI
Katari R., 2015, PATENT MONOPOLIES CO
Lee C.-J., 2006, CLIN TRIALS DRUGS BI
Lemmens T, 2014, EMAS PROPOSED DATA R
Lemmens T, 2012, AM J LAW MED, V38, P63
Loder E, 2013, BRIT MED J, V347, P1
Mercurio B, 2006, REGIONAL TRADE AGREE
Mestre-Ferrandiz J, 2012, R D COST NEW MED
Owoeye O. A., 2015, J LAW INFORM SCI, V23, P106
Peppercorn J., 2009, CLIN TRIALS HDB
Perehudoff K., 2013, ACCESS CLIN TRIALS E
Pires De Carvalho N., 2008, INTERPRETING IMPELE
Ratain M. J., 2003, PRINCIPLES PHARMACOK
Reddy Satwant, 2007, REPORT STEPS BE TAKE
Reichman Jerome H, 2009, Marquette Intellect Prop Law Rev, V13, P1
Roffe P., 2010, RES HDB PROTECTION I
Schricker G., 1989, GATT WIPO NEW WAYS I
Shaikh O. H, 2016, MUNICH STUDIES INNOV
Sim I, 2006, LANCET, V367, P1631, DOI 10.1016/S0140-6736(06)68708-4
Singh J, 2015, J PHARMACOL PHARMACO, V6, P185, DOI 10.4103/0976-500X.162004
Skillington L., 2003, NW J INT LAW BUS, V24, P1
Smyth D., 2012, J INTELLECTUAL PROPE, V7, P838
Sorscher S., 2009, HARV JL TECH, V23, P285
Sydes M. R., 2014, TRIALS, V16, P1
Tharyan P, 2008, NATL MED J INDIA, V21, P31
Unlu Mustafa, 2010, MICI TELECOMM TECH L, V16, P511
Van Noorden R, 2014, REPORT DISPUTES BENE
Wadlow C., 2007, INTELLECTUAL PROPERT, P350
Watal J., 2001, INTELLECTUAL PROPERT, P206
The importance of ethical, legal, and social issues (ELSI) in genomics has been recognized since the inception of the Human Genome Project. As it is medical professionals who most directly interact with, advise, and guide patients and research participants, they are de facto intermediators between the public and these scientific, ethical, and regulatory matters. As individual genotyping becomes the norm, the public will increasingly turn to medical professionals for help in making sense of how uses of genomic data are relevant to one's own interests and to the interests of others. The Global Alliance for Genomics and Health (GA4GH) is developing metadata tools to help address regulatory concerns in the increasingly non-localized data contexts into which medical research is rapidly moving. This article discusses how these metadata tools establish clarity on complex, multifaceted, regulatory issues, and thereby
improve medical professionals' ability to inform individuals, respond to concerns, and foster trust.


Dove ES, 2016, SCIENCE, V351, P1399, DOI 10.1126/science.aad5269
Dyke SOM, 2016, PLOS GENET, V12, DOI 10.1371/journal.pgen.1005772
Fuchsberger C, 2016, NATURE, V536, P41, DOI 10.1038/nature18642
Green ED, 2011, NATURE, V470, P204, DOI 10.1038/nature09764
International Rare Disease Research Consortium (IRDiRC), 2016, AUT DISC ACC MATR AD
Mitchell JS, THE DDC AND OCLC
National Institute of Health, ALL US RES PROGR
Sankar PL, GENETICS ME IN PRESS
Sterckx S, 2016, MED HEALTH CARE PHIL, V19, P177, DOI 10.1007/s11019-015-9661-6
UNESCO, UNESCO DECL BIOETH G
UNESCO, INT DECL HUM GEN DAT
UNESCO, DECL HUM GEN HUM RIG
Vayena E, 2016, J MED ETHICS, V42, P216, DOI 10.1136/medethics-2015-102663
World Medical Association, DECL TAIP ETH CONS R
Wyllys RE, OVERVIEW OF METADATA
Yafiez I, METADATA IMPLICATION
Enabled by mobile and wearable technology, personal health data delivers immense and increasing value for healthcare, benefiting both care providers and medical research. The secure and convenient sharing of personal health data is crucial to the improvement of the interaction and collaboration of the healthcare industry. Faced with the potential privacy issues and vulnerabilities existing in current personal health data storage and sharing systems, as well as the concept of self-sovereign data ownership, we propose an innovative user-centric health data sharing solution by utilizing a decentralized and permissioned blockchain to protect privacy using channel formation scheme and enhance the identity management using the membership service supported by the blockchain. A mobile application is deployed to collect health data from personal wearable devices, manual input, and medical devices, and synchronize data to the cloud for data sharing with healthcare providers and health insurance companies. To preserve the integrity of health data, within each record, a proof of integrity and validation is permanently retrievable from cloud database and is anchored to the blockchain network. Moreover, for scalable and performance considerations, we adopt a tree-based data processing and batching method to handle large data sets of personal health data collected and uploaded by the mobile platform.
Foundation of China [61402470]; research project of Trusted Internet Identity Management [2016YFB0800505, 2016YFB0800501]

This work was supported by Office of the Assistant Secretary of Defense for Research and Engineering (OASD (R & E)) agreement FA8750-15-2-0120. The work was also supported by a grant from the National Natural Science Foundation of China (No. 61402470) and the research project of Trusted Internet Identity Management (2016YFB0800505 and 2016YFB0800501).

CR

Azaria A, 2016, PROCEEDINGS 2016 2ND INTERNATIONAL CONFERENCE ON OPEN AND BIG DATA - OBD 2016, P25, DOI 10.1109/OBD.2016.11

Cachin Christian, 2016, WORKSH DISTR CRYPT C

Clippinger J. H, WHY SELF SOVEREIGNTY

Kim H, 2016, INT CONF UBIQ FUTUR, P453, DOI 10.1109/ICUFN.2016.7537069

Kish LJ, 2015, NAT BIOTECHNOL, V33, P921, DOI 10.1038/nbt.3340

Liang X., 2017, MIL COMM C MILCOM 20

Liang X., 2017, INT S CLUST CLOUD GR

McFarlane C., PATIENTORY HEALTHCAR


Nakamoto S., 2008, BITCOIN PEER TO PEER

Peterson K, 2016, BLOCKCHAIN BASED APP

T. O. of the National Coordinator for Health IT (ONC) the National Institute for Standards and T. (NIST), 2016, US BLOCKCH HEALTHC R


Zhang J., 2016, IEEE ACCESS

NR 14

TC 0

Z9 0

U1 3

U2 18

PU IEEE

PI NEW YORK

PA 345 E 47TH ST, NEW YORK, NY 10017 USA

BN 978-1-5386-3531-5

FY 2017

PG 5

WC Engineering, Electrical & Electronic; Telecommunications

SC Engineering; Telecommunications

GA BJ6WY

UT WOS:000426970901049

DA 2019-08-06

ER

PT J

AU Rake, EA

van Gelder, MMHJ

Grim, DC

Heeren, B

Engelen, LJLP

van de Belt, TH

AF Rake, Ester A.

van Gelder, Marleen M. H. J.

Grim, David C.

Heeren, Barend

Engelen, Lucien J. L. P. G.

van de Belt, Tom H.

TI Personalized Consent Flow in Contemporary Data Sharing for Medical Research: A Viewpoint

SO BIOMED RESEARCH INTERNATIONAL
Background. Health data personally collected by individuals with wearable devices and smartphones is becoming an important data source for healthcare, but also for medical research. Objective. To describe a new consent model that allows people to control their personally collected health data and determine to what extent they want to share these for research purposes. Methods. We developed, in close collaboration with patients, researchers, healthcare professionals, privacy experts, and an accredited Medical Ethical Review Committee, an innovative concept called "personalized consent flow" within a research platform connected to a personal health record. The development was an iterative process with informal meetings, semistructured interviews, and surveys. The final concept of the personalized consent flow was reviewed by patients and improved and approved by the same patients in a focus group. Results. This concept could result in optimal control for individual users, since they will answer questions about how they will share data. Furthermore, it enables users to collect data for specific studies and add expiration dates to their data. This work facilitates further discussion about dynamic and personalized consent. A pilot study with the personalized consent model is currently being carried out.

Cl [Rake, Ester A.; van Gelder, Marleen M. H. J.; Grim, David C.; Heeren, Barend; Engelen, Lucien J. L. P. G.; van de Belt, Tom H.] Radboud Univ Nijmegen, Med Ctr, Radboud REshape Innovat Ctr, Nijmegen, Netherlands.


RP van Gelder, MMHJ (reprint author), Radboud Univ Nijmegen, Med Ctr, Radboud REshape Innovat Ctr, Nijmegen, Netherlands.; van Gelder, MMHJ (reprint author), Radboud Univ Nijmegen, Med Ctr, Radboud Inst Hlth Sci, Dept Hlth Evidence, Nijmegen, Netherlands.

EM Marleen.vanGelder@radboudumc.nl

RI van Gelder, Marleen/P-9473-2015

OI van Gelder, Marleen/0000-0003-4853-4434


Erlich Y, 2014, PLOS BIOL, V12, DOI 10.1371/journal.pbio.1001983

Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71

Kirby T., 2014, LANCET, V383


Ploog T, 2015, BMJ-BRIT MED J, V350, DOI 10.1136/bmj.h2146

Rouse M., WHAT IS GAP ANAL

Safavi S, 2014, PLOS ONE, V9, DOI 10.1371/journal.pone.0114306


Weitzman ER, 2010, J MED INTERNET RES, V12, DOI 10.2196/jmir.1356


AR 7147212

DI 10.1155/2017/7147212
Nivolumab for Non-Small Cell Lung Cancer (NSCLC): An Economic Model for Risk Sharing Based on Real-Life Data

JOURNAL OF THORACIC ONCOLOGY

Meeting Abstract

Nivolumab; economic model; non-small cell lung cancer (NSCLC); risk sharing

Dudnik, Elizabeth; Goldstein, Daniel; Roisman, Laila; Zer, Alona; Peled, Nir

Davidoff Canc Ctr, Petah Tiqwa, Israel.

Hammerman, Ariel; Greenberg-Dotan, Sari

Rabin Med Ctr, Petah Tiqwa, Israel.

Bar, Jair; Daher, Sameh

Sheba Med Ctr, Ramat Gan, Israel.

Moskovitz, Mor; Shechtman, Yelena; Abu-Amna, Mahmoud; Wollner, Mira

Rambam Med Ctr, Haifa, Israel.
Secure and Privacy-Preserving Data Sharing and Collaboration in Mobile Healthcare Social Networks of Smart Cities

Mobile healthcare social networks (MHSN) integrated with connected medical sensors and cloud-based health data storage provide preventive and curative health services in smart cities. The fusion of social data together with real-time health data facilitates a novel paradigm of healthcare big data analysis. However, the collaboration of healthcare and social network service providers may pose a series of security and privacy issues. In this paper, we propose a secure health and social data sharing and collaboration scheme in MHSN. To preserve the data privacy, we realize secure and fine-grained health data and social data sharing with attribute-based encryption and identity-based broadcast encryption techniques, respectively, which allows patients to share their private personal data securely. In order to achieve enhanced data collaboration, we allow the healthcare analyzers to access both the reencrypted health data and the social data with authorization from the data owner based on proxy.
reencryption. Specifically, most of the health data encryption and decryption computations are outsourced from resource-constrained mobile devices to a health cloud, and the decryption of the healthcare analyzer incurs a low cost. The security and performance analysis results show the security and efficiency of our scheme.

C1 [Huang, Qinlong; Wang, Licheng; Yang, Yixian] Beijing Univ Posts & Telecommun, State Key Lab Networking & Switching Technol, Informat Secur Ctr, Beijing 100876, Peoples R China.
[Huang, Qinlong; Wang, Licheng; Yang, Yixian] Beijing Univ Posts & Telecommun, Natl Engr Lab Disaster Backup & Recovery, Beijing 100876, Peoples R China.; Huang, QL (reprint author), Beijing Univ Posts & Telecommun, State Key Lab Networking & Switching Technol, Informat Secur Ctr, Beijing 100876, Peoples R China.; Huang, QL (reprint author), Beijing Univ Posts & Telecommun, Natl Engr Lab Disaster Backup & Recovery, Beijing 100876, Peoples R China.
EM longsec@bupt.edu.cn
FU National Key Research and Development Program of China [2016YFB0800605]; National Natural Science Foundation of China [61572080]; CCF; Venustech Research Program [2016012]
FX This work was supported by the National Key Research and Development Program of China under Grant no. 2016YFB0800605, the National Natural Science Foundation of China under Grant no. 61572080, and the CCF and Venustech Research Program under Grant no. 2016012.
CR Au M. H., 2017, J COMPUTER SYSTEM SC
Chen L., 2011, P 54 ANN IEEE GLOB T
Chen TL, 2016, SECUR COMMUN NETW, V9, P652, DOI 10.1002/sec.1387
Guo LK, 2014, IEEE T MOBILE COMPUT, V13, P1927, DOI 10.1109/TMC.2013.84
Hossain M. S, 2017, FUTURE GENERATION CO
Huang HP, 2017, IEEE T IND INFORM, V13, P1227, DOI 10.1109/TII.2017.2687618
Huang Q., 2017, WORLD WIDE WEB, P1
Huang QL, 2017, FUTURE GENER COMP SY, V72, P239, DOI 10.1016/j.future.2016.09.021
Jiang SR, 2015, SENSORS-BASEL, V15, P22419, DOI 10.3390/s150922419
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Liang XH, 2011, J COMMUN NETW-S KOR, V13, P102, DOI 10.1109/JCN.2011.6157409
Liu Y., 2017, FUTURE GENERATION CO
Lounis A, 2016, FUTURE GENER COMP SY, V55, P266, DOI 10.1016/j.future.2015.01.009
Lynn B., PAIRING BASED CRYPTO
Tang Bo, 2017, IEEE T IND INFORM
Yeh L.-Y., 2015, IEEE T CLOUD COMPUTI
Zanella A, 2014, IEEE INTERNET THINGS, V1, P22, DOI 10.1109/JIOT.2014.2306328
Zhang AQ, 2016, SECUR COMMUN NETW, V9, P3496, DOI 10.1002/sec.1556
Zhang K, 2015, IEEE WIREL COMMUN, V22, P104, DOI 10.1109/MWC.2015.7224734
Zhang P., 2016, FUTURE GENERATION CO
Zhou J, 2013, IEEE WIREL COMMUN, V20
NR 30
PT S
AU Bouzille, G
Westerlynck, R
Defossez, G
Bouslimi, D
Bayat, S
Riou, C
Busnel, Y
Le Guillou, C
Cauvin, JM
Jacquelinet, C
Pladys, P
Oger, E
Stindel, E
Ingrand, P
Coatrieux, G
Cuggia, M
AF Bouzille, Guillaume
Westerlynck, Richard
Defossez, Gautier
Bouslimi, Dalel
Bayat, Sahar
Riou, Christine
Busnel, Yann
Le Guillou, Clara
Cauvin, Jean-Michel
Jacquelinet, Christian
Pladys, Patrick
Oger, Emmanuel
Stindel, Eric
Ingrand, Pierre
Coatrieux, Gouenou
Cuggia, Marc
BE Gundlapalli, AV
Jaulent, MC
Sharing and exploiting Health Big Data (HBD) allow tackling challenges: data protection/governance taking into account legal, ethical, and deontological aspects enables trust, transparent and win-win relationship between researchers, citizens, and data providers. Lack of interoperability: compartmentalized and syntactically/semantically heterogeneous data. INSHARE project using experimental proof of concept explores how recent technologies overcome such issues. Using 6 data providers, platform is designed via 3 steps to: (1) analyze use cases, needs, and requirements; (2) define data sharing governance, secure access to platform; and (3) define platform specifications. Three use cases - from 5 studies and 11 data sources - were analyzed for platform design.

Governance derived from SCANNER model was adapted to data sharing. Platform architecture integrates: data repository and hosting, semantic integration services, data processing, aggregate computing, data quality and integrity monitoring, Id linking, multisource query builder, visualization and data export services, data governance, study management service and security including data watermarking.

We would like to thank the French National Research Agency (ANR) for funding this work inside the INSHARE (INtegrating and Sharing Health dAta for Research) project (grant no. ANR-15-CE19-0024).
Jensen PB, 2012, NAT REV GENET, V13, P395, DOI 10.1038/nrg3208
Natter MD, 2013, J AM MED INFORM ASSN, V20, P172, DOI 10.1136/amiajnl-2012-001042
Sethi Nayha, 2013, Med Law Int, V13, P168

PT S
AU Small, SS
Peddie, D
Ackerley, C
Hohl, CM
Balka, E
AF Small, Serena S.
Peddie, David
Ackerley, Christine
Hohl, Corinne M.
Balka, Ellen
BE Nohr, C
Kuziemsky, CE
Wong, ZSY
TI Patient Perceptions About Data Sharing & Privacy: Insights from ActionADE
SO CONTEXT SENSITIVE HEALTH INFORMATICS: REDESIGNING HEALTHCARE WORK
SE Studies in Health Technology and Informatics
Information communication technologies (ICTs) may improve health delivery by enhancing informational continuity of care and enabling secondary use of health data including public health surveillance and research. ICTs also introduce concerns related to privacy. In this paper, we examine and address this tension in the context of the development and implementation of a novel platform that will enable the documentation and communication of patient-specific ADE information, titled ActionADE. We explored privacy concerns qualitatively from the perspective of patients. Our findings will inform a series of recommendations for system design that seek to balance the need to both share and protect personal health information.

CI [Small, Serena S.; Peddie, David; Ackerley, Christine; Balka, Ellen] Simon Fraser Univ, Sch Commun, Burnaby, BC, Canada.

[Saus, Serena S.; Peddie, David; Ackerley, Christine; Hohl, Corinne M.; Balka, Ellen] Ctr Clin Epidemiol & Evaluat, Vancouver, BC, Canada.


RP Small, SS (reprint author), Simon Fraser Univ, Sch Commun, Burnaby, BC, Canada.; Small, SS (reprint author), Ctr Clin Epidemiol & Evaluat, Vancouver, BC, Canada.

EM small@sfu.ca

Bowker GC, 1999, SORTING THINGS OUT C


Nissenbaum H.F., 2010, PRIVACY CONTEXT TECH

OIP CBC, 2014, SPECIAL REPORT

Peddie D., 2017, P INF TECHN COMM HLT

Peddie D, 2016, JMIR, V5

Price M., 2013, BMC HLTH SERVICES RE, V13

Reiman JH, 1995, SANTA CLARA COMPUTER, V11, P27


Spencer K, 2016, J MED INTERN RES, V18, DOI 10.2196/jmir.5011

Van den Hoven Jeroen, 2001, READINGS CYBERETHICS, P488


NR 19
An information platform for smart communities realizing data usage authentication and secure data sharing

The deployment of Information and Communication Technology in existing infrastructure has increased interest in smart communities. Smart communities provide various services such as ancillary services, road traffic information management, and health care management. Each service has distinctive characteristics such as processing delay, the need for anonymity, computational cost, and the amount of data. Therefore, to optimize the system, locations to provide these services should be organized. In addition, secondary use of personal data is assumed in smart communities. Thus, measures to provide privacy protection should be implemented. In this paper, a new information platform is proposed, which allows management of a user's privacy policy, management of data usage, smooth data sharing, and adequate service location organization by introducing the concept of "Relationship." Response time associated with organization was evaluated on the implemented platform to ensure the feasibility.
of the proposed method, and it was about 15 minutes when the number of
Relationships is 12,800.
C1 [Niwa, Akira; Nishi, Hiroaki] Keio Univ, Grad Sch Sci & Technol, 3-14-1
Hiyoshi, Yokohama, Kanagawa 2238522, Japan.
RP Niwa, A (reprint author), Keio Univ, Grad Sch Sci & Technol, 3-14-1 Hiyoshi,
Yokohama, Kanagawa 2238522, Japan.
EM niwa@west.sd.keio.ac.jp; west@sd.keio.ac.jp
OI Nishi, Hiroaki/0000-0002-6331-2947
FU MEXT/JSPS KAKENHI [JP16H04455]; SECOM Science and Technology Foundation;
MLIT Grant for development of advanced technology in housing and
buildings; R&D project "Design of Information and Communication Platform
for Future Smart Community Services" by the Ministry of Internal Affairs
and Communications of Japan; Keio Univ. Global Smart Society Creation
Project Research
FX This work was partially supported by MEXT/JSPS KAKENHI Grant (B) Number
JP16H04455, through funding received from SECOM Science and Technology
Foundation, from an MLIT Grant for development of advanced technology in
housing and buildings, by the R&D project "Design of Information and
Communication Platform for Future Smart Community Services" by the
Ministry of Internal Affairs and Communications of Japan, and from Keio
Univ. Global Smart Society Creation Project Research.
DSouza C, 2014, 2014 IEEE 15TH INTERNATIONAL CONFERENCE ON INFORMATION REUSE
AND INTEGRATION (IRI), P16, DOI 10.1109/IRI.2014.7051866
Jalali R, 2015, INT CONF INTELL NEXT, P108, DOI 10.1109/ICIN.2015.7073815
Kiyomoto S., 2013, PPM PRIVACY POLICY M, P377
Machanavajjhala A., 2007, ACM T KNOWL DISCOV D, V1, P3, DOI DOI
10.1145/1217299.1217302
Nakamura Y., 2014, INT C INT COMP BIG D, P65
Searlis Doc, 2012, INTENTION EC CUSTOME
Stojmenovic I, 2014, ACSIS-ANN COMPUT SCI, V2, P1
Su KH, 2011, 2011 INTERNATIONAL CONFERENCE ON ELECTRONICS, COMMUNICATIONS AND
CONTROL (ICECC), P1028, DOI 10.1109/ICECC.2011.6066743
Sweeney L, 2002, INT J UNCERTAIN FUZZ, V10, P557, DOI
10.1142/S0218488502001648
CLUSTER COMPUTING AND THE GRID, PROCEEDINGS, P128, DOI
10.1109/CCGRID.2002.1017120
NR 16
TC 0
Z9 0
U1 0
U2 1
FU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2379-1888
BN 978-1-5386-2087-8
J9 INT SYMPOS COMPUT NE
PY 2017
BP 119
EP 125
DI 10.1109/CANDAR.2017.73
AB With the advancements of electronic medical equipment, e-healthcare system becomes a promising paradigm to continuously monitor health conditions and remotely diagnose phenomena. However, it also generates a large volume of health data and poses several security challenges, such as access control security and privacy leakage. Furthermore, some medical devices/sensors have low battery power. In this paper, we propose a lightweight and privacy-preserving fog-assisted information sharing scheme (PFHD) for health big data. Specifically, we integrate fog computing into e-healthcare system to pre-process the raw health data and improve the efficiency of health data analysis. Specifically, we design a hierarchical attribute-based encryption method by encrypting the profile and health data with different access policies for privacy preservation. Furthermore, we achieve lightweight encryption on devices by offloading part of encryption cost from devices to fog servers. Security discussions show that PFHD can achieve fine-grained health data sharing with data privacy preservation. Performance evaluations demonstrate the efficiency of PFHD, especially in terms of encryption computation and storage costs.

C1 [Tang, Wenjuan; Ren, Ju; Zhang, Yaoxue] Cent S Univ, Dept Informat Sci & Engn, Changsha, Hunan, Peoples R China.
   [Zhang, Kuan; Shen, Xuemin (Sherman)] Univ Waterloo, Dept Elect & Comp Engn, Waterloo, ON, Canada.
   [Zhang, Kuan] Univ Nebraska Lincoln, Dept Elect & Comp Engn, Lincoln, NE USA.

EM wenjuantang@csu.edu.cn; k52zhang@uwaterloo.ca; renju@csu.edu.cn; zyx@csu.edu.cn; sshen@uwaterloo.ca

FU Innovation Foundation for Postgraduate of Central South University [2016zzts057]; Natural Science Foundation Project of Fujian Province of China [2015J01271]; Innovation-Driven Project of Central South University [2016CXS013]; Natural Sciences and Engineering Research Council of Canada

FX This work is partly supported by the Innovation Foundation for Postgraduate of Central South University under Grant Number 2016zzts057, the Natural Science Foundation Project of Fujian Province of China (No: 2015J01271), the Innovation-Driven Project of Central South University (No. 2016CXS013), and the Natural Sciences and Engineering Research Council of Canada.

CR Aranha D. F., RELIC IS EFFICIENT L
Barua M., 2013, IEEE GLOB COMM CONF, P647, DOI 10.1109/GLOCOM.2013.6831145
Beimel A., 1996, SECURE SCHEMES SECRE
Cao Y., 2015, P 2015 WORKSH MOB BI, P43
Hohenberger S., 2014, LECT NOTES COMPUT SC, V8383, P293, DOI 10.1007/978-3-642-54631-0_17
Huang C., 2016, ASIA CCS'16: PROCEEDINGS OF THE 11TH ACM ASIA CONFERENCE ON COMPUTER AND COMMUNICATIONS SECURITY, P95, DOI 10.1145/2897845.2897870
Lin XD, 2009, IEEE J SEL AREA COMM, V27, P365, DOI 10.1109/JSAC.2009.090502
Liu W., 2014, INT CONF COMPUT NETW, P982, DOI 10.1109/ICNCN.2014.6785471
Liu Y., FUTURE GENE IN PRESS
Rahmani Amir M., 2017, FUTURE GENERATION CO
Ren J., 2017, IEEE NETWOR IN PRESS
Su Z., IEEE T BIG IN PRESS
Tong Y., 2013, IEEE CONF COMM NETW, P514, DOI 10.1109/CNS.2013.6682769
Waters B., 2011, LECT NOTES COMPUT SC, V6571, P53, DOI 10.1007/978-3-642-19379-8_4
Yang K., 2016, IEEE T MULTIMEDIA, V18, P940, DOI 10.1109/TMM.2016.2535728
Zhang K., 2016, IEEE T DEPENDABLE SE
Zhang K., 2015, IEEE WIREL COMMUN, V22, P104, DOI 10.1109/MWC.2015.7224734
Zhou Y., 2017, PEER TO PEER NETWORK, P1

NR 22
TC 0
Z9 0
U1 1
U2 2
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2334-0983
BN 978-1-5090-5019-2
J9 IEEE GLOB COMM CONF
PY 2017
PG 6
WC Engineering, Electrical & Electronic; Telecommunications
SC Engineering; Telecommunications
GA BJ8DL
UT WOS:000428054305099
The emergence of a plethora of wearables and sensing technologies has enabled non-intrusive digitization of our daily physical activities. Emerging applications utilize such data to make inferences about our physiological and health states, provide health diagnosis, and contribute to wellbeing improvements. The common approach for such applications is to collect data, either using mobile applications or special hardware, e.g., wearables, and store them on a third-party storage provider. This results in many unconnected data silos of self-quantification data. Researchers and industry advocate for a common personal storage space, to conquer the myriad of small chunks of data, deemed to be lost/forgotten in the long term. The benefits of such co-located personal data are tremendous, specifically with regards to personalized medicine, treatment, and health care. However, the centralized storage of data exacerbates the privacy and security concerns that the IoT ecosystem is facing today. In this position paper, we advocate the necessity of privacy and security guarantees for the paradigm of co-located storage of personal health data. We envision two core security functionalities: true end-to-end encryption, such that only encrypted data is stored in the cloud and secure sharing of encrypted data, without disclosing data owner's secret keys. We discuss the challenges in adopting such an end-to-end encryption paradigm while preserving the cloud's basic processing functionalities over encrypted data and how to cryptographically enforce access control.
Boneh Dan, 2013, APPL CRYPTOGRAPHY NE
Boneh Dan, 2013, CRYPTO
Brakerski Zvika, 2012, INN THEOR CS C
Dredge Stuart, 2013, GUARDIAN
Garbarino Maurizio, 2014, MOBIHEALTH
Gentry Craig, 2009, ACM S THEOR COMP STO
Hithnawi Anwar, 2015, ACM C INF PROC SENS
Islam Mohammad Saiful, 2012, NDSS
Keelveedhi Sriram, 2013, USENIX SECURITY
Lazar David, 2016, USENIX OSDI
Lewi K, 2016, ACM CCS
Lodderstedt Torsten, 2013, 6819 IETF RFC
Lopez-Alt Adriana, 2012, ACM STOC
McCoy Damon, 2008, MOBISYS
Naveed Muhammad, 2015, CCS
Nikolaenko V, 2013, P IEEE S SECUR PRIV, P334, DOI 10.1109/SP.2013.30
Paillier P., 1999, EUROCRYPT
Papadimitriou Antonis, 2016, USENIX OSDI
Popa RA, 2013, P IEEE S SECUR PRIV, P463, DOI 10.1109/SP.2013.38
Popa Raluca Ada, 2011, ACM SOSP
Popa Raluca Ada, 2014, USENIX NSDI
Ren Ling, 2015, USENIX SECURITY
Sanamrad Tahmineh, 2014, DBSEC
Shafagh H., 2015, ACM SENSYS
Shafagh Hossein, 2016, ACM SENSYS
Sherry Justine, 2015, ACM SIGCOMM
Shi Elaine, 2011, NDSS
Song Dawn Xiaodong, 2000, IEEE SECURITY PRIVAC
Tanner A, 2016, SCI AM, V314, P26
Tu Stephen, 2013, VLDB
Wang Frank, 2016, USENIX NSDI

NR 44
TC 0
Z9 0
U1 0
U2 0
PU ASSOC COMPUTING MACHINERY
PI NEW YORK
PA 1515 BROADWAY, NEW YORK, NY 10036-9998 USA
BN 978-1-4503-5059-4
PY 2017
BP 25
EP 30
DI 10.1145/3097620.3097625
PG 6
WC Telecommunications
SC Telecommunications
GA BJ6RD
UT WOS:000426924600005
DA 2019-08-06
ER

PT B
AU Saha, R
Use of wearable fitness trackers is progressively increasing over the world. The raw information from these gadgets on processing produces Electronic Health Record (EHR). It has great importance since it enhances the scope of medicinal services with financially savvy nature. Despite this fact, the human health architecture are tested essentially by security and ownership of information. Securing EHR with an encoded secret key is a plausible choice. EHRs have their potential advantages in the Evidence Based Medicine (EBM). The purpose of this paper is to discuss the various ethical issues arising during use of the EHRs of fitness trackers and their possible solutions by strengthening security with gaining public trust on EHR based approach. This paper also proposes a filter system that balances the security & sharing of health data.

C1 [Saha, Renata; Sarkar, Sayan; Datta, Soumya Kanti] Natl Inst Technol, Future Tech Lab, Durgapur, India.
RP Saha, R (reprint author), Natl Inst Technol, Future Tech Lab, Durgapur, India.
EM saharenata@gmail.com
CR Buhov D, 2015, PROCEEDINGS 10TH INTERNATIONAL CONFERENCE ON AVAILABILITY, RELIABILITY AND SECURITY AREX 2015, P327, DOI 10.1109/ARES.2015.59
Frantti T, 2014, INT CONF UBIQ FUTUR, P69, DOI 10.1109/ICUFPN.2014.6876753
Hilts A, 2016, EVERY STEP YOU FAKE
Islam SMR, 2015, IEEE ACCESS, V3, P678, DOI 10.1109/ACCESS.2015.2437951
Kim BJ, 2015, INT CON ADV INFO NET, P448, DOI 10.1109/AINA.2015.220
Ozair Fouzia F., 2015, PERSPECTIVES CLIN RE, V6, P73
Posland S., 2009, UBQUITOUS COMPUTING
Rahman M., 2013, 34 IEEE S SEC PRIV I
Sarkar S., 2017, 2017 2 IEEE INT C EL
E-Healthcare system plays a major role in the society. It monitors the health condition and helps in giving appropriate medical treatments. This system aims at gathering and storing patient's details and sharing health-related information. It also has high legitimate concerns about patient's privacy and information security. This system minimizes the infrastructural barriers for the developing nations. It also extends healthcare systems to the remote and isolated areas which has limited access to medical technologies, remote health services are provided through telecommunications. Quality of the service and security are added advantage to the system. They collect the real-time personal information (PHI) and health problems from patients and transmit them to the healthcare provider for the authorized physicians to decide on the corresponding treatment. They send the PHI in terms of text and image to the cloud, and also the other personal queries related to their medical history. In cloud computing, collected PHI should match the physicians experience to judge the state of the patient and unfortunately, delegating both storage and computation to the untrusted entity would bring a series of security. This is where deduplication comes into play. It is a technique for eliminating duplicate copies of data, and has been widely used in cloud storage to reduce storage space and upload bandwidth. Attribute-based encryption (ABE) has been a preferred encryption technology to solve the challenging problem of security during data sharing in cloud computing. For every file a separate key will be provided, which is to be decrypted for using the file further.
Sharing of Big Data in Healthcare: Public Opinion, Trust, and Privacy Considerations for Health Informatics Researchers

Proceedings of the 10th International Joint Conference on Biomedical Engineering Systems and Technologies, Vol 5: HealthINF

English

Advances in technology has transformed clinical medicine; electronic patient records routinely store clinical notes, internet-enabled mobile apps support self-management of chronic diseases, point-of-care testing enables laboratory tests to be performed outside of hospital environments, patient treatment can be delivered over wide geographic areas and wireless sensor networks are able to
collect and send physiological data. Increasingly, this technology leads to the development of large databases of sensitive electronic patient information. There is public interest into the secondary use of this data; many concerns are voiced about the involvement of private companies and the security and privacy of this data, but at the same time, these databases present a valuable source of clinical information which can drive health informatics and clinical research, leading to improved patient treatment. In this position paper, we argue that for health informatics projects to be successful, public concerns over the secondary use of patient data need to be addressed in the design and implementation of the technology and conduct of the research project.


[Moss, Laura; Shaw, Martin; Piper, Ian] NHS Greater Glasgow & Clyde, Dept Clin Phys, Glasgow, Lanark, Scotland.


OI Moss, Laura/0000-0003-4968-0900

FX The CHART-ADAPT project is a collaboration between the University of Glasgow, Aridhia, NHS Greater Glasgow & Clyde, and Philips Healthcare. It has been co-funded by Innovate UK (ref: 102113). Approval for the CHART-ADAPT work was granted by the West of Scotland Research Ethics Committee (REC ref: 15/WS/0222) and local Caldicott Guardian approval has been provided. Approval for the survey (section 4) was provided by MVLs, University of Glasgow. The CHART-ADAPT project we would like to acknowledge the staff and patients of the Neurointensive care unit, Neurosciences Institute, Glasgow.

Aiken M, 2016, SCI PUBL POLICY, V43, P713, DOI 10.1093/scipol/scv075


Apache a, 2016, AP SPARK

Apache b, 2016, AP HAD

BMA, 2016, SEC US DAT PUBL WORK

Caldicott, 2016, INF SHAR NOT SHAR IN


DeepMind a, 2016, DEEPMIND AC KIDN INJ

DeepMind b, 2016, DEEPMIND MOORF EYE H


IBM a, 2016, IBM BIG DAT EXTR BUS

IBM b, 2016, THE 4 VS OF BIG DAT

IBM c, 2016, IBMS WATS SUP SPEED

Jaspers MWM, 2011, J AM MED INFORM ASSN, V18, P327, DOI 10.1136/amiajn1-2011-000094

Kaye J, 2015, EUR J HUM GENET, V23, P141, DOI 10.1038/ejhg.2014.71

Kinsella J., 2017, P SOC CRIT CAR MED C

New Scientist, 2016, REV GOOGL AI HAS ACC

Presser L., 2015, TECHNOLOGY SCI 0811

Riordan F, 2015, INT J MED INFORM, V84, P237, DOI 10.1016/j.ijmedinf.2015.01.008

Scala, 2016, SCAL PROGR LANG


van Staa TP, 2016, BMJ-BRIT MED J, V354, DOI 10.1136/bmj.i3636

van Staa TP, 2016, BMJ-BRIT MED J, V354, DOI 10.1136/bmj.i3636
Choices on selective clinical data sharing by people with Parkinson's disease

Background: Clinical data sharing and ownership are key issues in modern digital data acquisition. Data sharing is subject to influence by a range of stakeholders. Of these, patient attitudes are pivotal.

Objectives: The objective of this report was to characterize attitudes to clinical data sharing among people with Parkinson's disease (PD).

Methods: A recent survey, conducted by the Parkinson's Movement (2016) highlighted patient concerns over data sharing. This formed the basis for discussion by two focus groups at the Rallying to the Challenge meeting at the Van Andel Research Institute in September 2016.

Results: The focus groups examined issues related to the appropriateness of data sharing for different categories of data and highlighted both the value and concerns regarding data sharing.
Conclusion: At the conclusion of the session, it was proposed that a "data charter" be developed to reflect the thinking of people with PD on best practices in data acquisition, ownership, and sharing.


[Schmidt, Peter] Parkinsons Fdn, Natl Parkinson Fdn, Miami, FL USA.

[Dean, John M.] Davis Phinney Fdn, Boulder, CO USA.


EM leah@cureparkinsons.org.uk

CR Anderson M, 2016, SCI TRANSL MED, V8, DOI 10.1126/scitranslmed.aaf6730


Dubman S., CALL ACTION SHARING


The Cure Parkinson's Trust, RALL CHALL 2016 DAT

Tsai AC, 2016, SOC SCI MED, V169, P191, DOI 10.1016/j.socscimed.2016.08.004
AB Personal Health Records (PHR) is patient-centric healthcare system, which allows patients to control who can get access to their health records and which section of the record can be accessed. Hot issues such as access control, patients control degree, and privacy protection, etc. are still the challenging concerns while designing a secure PHR system.

In this paper, we propose dsPPS, a secure integrated PHR framework (from health data collection to health data sharing) that meets patients' full control of their PHR and sufficient privacy preservation. Specifically, dsPPS provides two schemes: Biometric-Based secure health data Collection (BBC) scheme and Attribute-Based health record Accessing (ABA) scheme. While BBC scheme enables patients to collect their scattered health data from multiple typical health systems securely and efficiently, the ABA scheme allows users (health systems) access to the PHR server with their sensitive attributes being protected. Comprehensive analysis is conducted to show the security of dsPPS against typical attacks. In addition, experiments in both smart phone and PC (Intel) platforms demonstrate that dsPPS produces reasonable performance in terms of storage, communication and computational overheads.

C1 [Huang, Chanying; Yan, Kedong; Wei, Songjie] Nanjing Univ Sci & Technol, Sch Comp Sci & Engn, Nanjing 210094, Jiangsu, Peoples R China.

[Huang, Chanying] Nanjing Univ Sci & Technol, Minist Educ, Key Lab Intelligent Percep & Syst High Dimens In, Nanjing 210094, Jiangsu, Peoples R China.

[Lee, Dong Hoon] Korea Univ, Grad Sch Informat Secur, Seoul 02841, South Korea.

RP Huang, CY (reprint author), Nanjing Univ Sci & Technol, Sch Comp Sci & Engn, Nanjing 210094, Jiangsu, Peoples R China.; Huang, CY (reprint author), Nanjing Univ Sci & Technol, Minist Educ, Key Lab Intelligent Percep & Syst High Dimens In, Nanjing 210094, Jiangsu, Peoples R China.

EM hcy@njust.edu.cn; yan@njust.edu.cn; swei@njust.edu.cn; donghlee@korea.ac.kr

FU China NSF [61472189]; Jiangsu Planned Projects for Postdoctoral Research Funds [1701146B]; CERNET Next Generation IT Innovation Project [NGI20160105]; State Key Laboratory of Air Traffic Management System and Technology [SKLATM201703]; Open Project Program of Key Laboratory of Intelligent Perception and Systems for High-Dimensional Information of Ministry of Education [JYB201610]

FX This work is supported by China NSF (61472189), Jiangsu Planned Projects for Postdoctoral Research Funds (1701146B), CERNET Next Generation IT Innovation Project (NGI20160105), State Key Laboratory of Air Traffic Management System and Technology (SKLATM201703), and the Open Project Program of Key Laboratory of Intelligent Perception and Systems for High-Dimensional Information of Ministry of Education (JYB201610).

CR Akinyele Joseph A., 2011, P 1 ACM WORKSH SEC P
Chen M, 2011, MOBILE NETW APPL, V16, P171, DOI 10.1007/s11036-010-0260-8
Forouzan B. A., 2011, CRYPTOGRAPHY NETWORK
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Guo LK, 2014, IEEE T MOBILE COMPUT, V13, P1927, DOI 10.1109/TMC.2013.84
Li M, 2013, IEEE T PARALL DISTR, V24, P131, DOI 10.1109/TPDS.2012.97
Lo B., 2005, 3 INT C PERV COMP, P77
Lu RX, 2013, IEEE T PARALL DISTR, V24, P614, DOI 10.1109/TPDS.2012.146
Lynn B, 2012, PAIRING BASED CRYPTO
Martin Nick, 2013, CHARTING FUTURE CAPA
Morgenthaler John, MOVING OPEN STANDARD
Seor Inmaculada Carrin, 2012, J MED INTERNET RES, V14
Sun JY, 2011, INT CON DISTR COMP S, P373, DOI 10.1109/ICDCS.2011.83

AU Bever, U.
  Tucker, K.
TI Roche-Genentech oncology trials - our experience with data sharing via CSDR
SO EUROPEAN JOURNAL OF CANCER
LA English
DT Meeting Abstract
CT 28th EORTC-NCI-AACR Symposium on Molecular Targets and Cancer Therapeutics
CY NOV 29-DEC 02, 2016
CL Munich, GERMANY
SP EORTC, Natl Canc Inst, Amer Assoc Canc Res
C1 [Bever, U.] Hoffmann La Roche AG, Biostat, Basel, Switzerland.
Sharing public health data saves lives
Data sharing in public health emergencies

The GM AHSN AF LANDSCAPE TOOL: A SHARED DATA PLATFORM TO IDENTIFY HEALTH AND ECONOMIC OPPORTUNITIES TO REDUCE INCIDENCE OF STROKE THROUGH EFFECTIVE ANTICOAGULANT MANAGEMENT OF PATIENTS WITH ATRIAL FIBRILLATION IN GREATER MANCHESTER

Infectious Diseases

Value in Health

Meeting Abstract
BIG HEALTH DATA Opt-in method is vital for data sharing
Data Sharing Agreements: How to Glue Definition, Analysis and Mapping Together

AB An electronic data sharing agreement (DSA) is a human-readable, yet machine-processable contract, regulating how organisations and/or individuals share data. Its smooth definition and fluid lifecycle management are key aspects for enabling data protection in various contexts, from e-government to the provision of business and healthcare services, for example.

C1 [Gambardella, Carmela] Hewlett Packard Enterprise Italy, Cernusco Sul Naviglio, Italy.

[Matteucci, Ilaria; Petrocchi, Marinella] CNR, IIT, I-00185 Rome, Italy.

CR Caimi C., 2015, LEGAL TECHNICAL PERS, P178

Matteucci I., 2010, P ACM S APPL COMP SA, P616

Ruiz J., 2016, LIFECYCLE D IN PRESS
TI Mapping global cancer research and control in areas of low and middle income: The need for shared data on a single, interactive platform

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
How cancer patients and oncologist assess data-sharing and the risk of re-identification in genomic research? Ethical implications for informed consent and governance.

AU Winkler, EC
   Schleidgen, S
   Schickhardt, C
   Kalle, CV
   Ose, D
   Husedzinovic, A

AF Winkler, Eva Caroline
   Schleidgen, Sebastian
   Schickhardt, Christoph
   Kalle, Christof V.
   Ose, Dominik
   Husedzinovic, Alma

TI How cancer patients and oncologist assess data-sharing and the risk of re-identification in genomic research? Ethical implications for informed consent and governance.

SO JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Meeting Abstract
CT Annual Meeting of the American-Society-of-Clinical-Oncoology (ASCO)
CY JUN 03-07, 2016
CL Chicago, IL
Sharing regulatory data as tools for strengthening health systems in the Region of the Americas

Regulatory transparency is an imperative characteristic of a reliable National Regulatory Authority. In the region of the Americas, the process of building an open government is still fragile and fragmented across various Health Regulatory Agencies (HRAs) and Regional Reference Authorities (RRAs). This study assessed the transparency status of RRAs, focusing on various medicine life-cycle documents (the Medicine Dossier, Clinical Trial Report, and Inspection Report) as tools for strengthening health systems. Based on a narrative (non-systematic) review of RRA regulatory transparency, transparency status was classified as one of two types: public disclosure of information
(intra-agency data) and data- and work-sharing (inter-agency data). The risks/benefits of public disclosure of medicine-related information were assessed, taking into account 1) the involvement and roles of multiple stakeholders (health care professionals, regulators, industry, community, and academics) and 2) the protection of commercial and personal confidential data. Inter-agency data- and work-sharing was evaluated in the context of harmonization and cooperation projects that focus on regulatory convergence.

Technical and practical steps for establishing an openness directive for the pharmaceutical regulatory environment are proposed to improve and strengthen health systems in the Americas. Addressing these challenges requires leadership from entities such as the Pan American Health Organization to steer and support collaborative regional alliances that advance the development and establishment of a trustworthy regulatory environment and a sustainable public health system in the Americas, using international successful initiatives as reference and taking into account the domestic characteristics and experiences of each individual country.

C1 [Sousa, Varley Dias; Silveira, Damaris] Univ Brasilia, Dept Pharmaceut Sci, Brasilia, DF, Brazil.
[Ramalho, Pedro I.] Agencia Nacl Vigilancia Sanit, Brasilia, DF, Brazil.
RP Sousa, VD (reprint author), Univ Brasilia, Dept Pharmaceut Sci, Brasilia, DF, Brazil.
EM varley.sousa@yahoo.com.br
OI Ramalho, Pedro Ivo Sebba/0000-0002-1710-2500; Silveira, Damaris/0000-0003-1851-5224

CR [Anonymous], 2014, PRINC COND CLIN TRIA
[Anonymous], 2013, NATURE, V495, P11
Butler D, 2012, NATURE, V490, P322, DOI 10.1038/490322a
Department of Health and Human Services Food and Drug Administration (US), 2014, INSPE CMPL ENF CRIM
Department of Health and Human Services Food and Drug Administration (US), 2011, FDA TRANSP IN IMPR T
Department of Health and Human Services Food and Drug Administration (US), 2012, FOOD DRUG ADM TRANSP
Department of Health and Human Services Food and Drug Administration (US), 2011, FOOD DRUG ADM REP GO
Department of Health and Human Services Food and Drug Administration (US), 2014, MED DEV SING AUD PRO
European Medicines Agency, 2013, EMA2408102013
European Medicines Agency, 2010, EMEA1101962006 EMA
European Medicines Agency, 2014, EMA EU MSS FDA IN IN
European Medicines Agency, 2011, EMA7179962012
European Medicines Agency, 2014, EMAMB3256382014
Freedom of information Services, 2014, FDA FOIA REC S UNPUB
Harrison C, 2012, NAT REV DRUG DISCOV, V11, P891, DOI 10.1038/nrd3907
Heads of Medicines Agencies / European Medicines Agency, 2012, HMA EMA GUID

DOC ID
Health Canada, 2014, HLTH CAN REG TRANSP
Instituto Nacional de Vigilancia de Medicamentos y Alimentos (CO), 2014, CONS

REG DOC AS
Medicines Transparency Alliance, MED TRANSP ALL REV P
Mendel T., 2013, RTI RATING DAT ANAL
MENDEL Toby, 2009, LIBERDADE INFORM EST
Nilen P, 2013, NEW ENGL J MED, V13, P4
Pan America Health Organization, 2012, PAH LAUNCH REG PLATF
The combination of signatuare and encryption techniques ensures data integrity and confidentiality in cloud. Researchers suggest the signcryption method to improve the efficiency during data signing, encrypting, verifying and decrypting procedures by integrating signature and encryption into a single function. However, the obscure use of keys and excessive cryptographical simplification reduce the system security levels. This paper proposes the identity and attribute based signcryption algorithm to enhance the security of storage and sharing of remote data. The proxy re-encryption and multi-attribute authority based signcryption techniques are used to achieve fault-tolerant attributes management and collusion-resistant system. In the Healthcare system, the attribute-based signature, encryption and signcryption methods are separately applied to scenarios of different data security levels in order to keep data access efficiency. Accordingly, the security properties and the access efficiencies of proposed algorithm are compared with known methods.

C1 [Pei, Xin; Wang, Yongjian; Yao, Wei; Lin, Jiuchuan; Peng, Ruxiang] Minist Publ Secur, Key Lab Informat Network Secur, Shanghai, Peoples R China.

[Pei, Xin; Wang, Yongjian; Yao, Wei; Lin, Jiuchuan; Peng, Ruxiang] Minist Publ Secur, Res Inst 3, Shanghai, Peoples R China.
FU Basic Scientific Research of Information Network Security of Ministry of Public Security [C16356]
FX This work was supported in part by the Special Funds for Basic Scientific Research C16356 of Information Network Security of Ministry of Public Security.
Changji Wang, 2011, Proceedings of the 2011 Seventh International Conference on Computational Intelligence and Security (CIS 2011), P905, DOI 10.1109/CIS.2011.204
Dawson J., 2009, PATIENT CTR E HLTH, P1
Goyal V., 2006, P 13 ACM C COMP COMM, P89, DOI DOI 10.1145/1180405.1180418
Herranz J, 2012, LECT NOTES COMPUT SC, V7178, P51, DOI 10.1007/978-3-642-27954-6_4
Liu Z, 2015, LECT NOTES COMPUT SC, V8957, P403, DOI 10.1007/978-3-319-16745-9_22
Maji HK, 2008, IACR CRYPTOLOGY EPRI
Maji HK, 2011, LECT NOTES COMPUT SC, V6558, P376, DOI 10.1007/978-3-642-19074-2_24
Rao Y. S., 2015, INT J INF SECUR, P1
Xu L., 2012, P 7 ACM S INF COMP C, P87
Zheng YL, 1997, LECT NOTES COMPUT SC, V1294, P165

NR 16
TC 0
Z9 0
U1 0
U2 2
PU IEEE
PI NEW YORK
PA 345 E 47TH ST, NEW YORK, NY 10017 USA
SN 2324-9013
BN 978-1-5090-3205-1
J9 IEEE TRUST BIG
PY 2016
BP 737
EP 743
DI 10.1109/TrustCom.2016.130
PG 7
WC Computer Science, Information Systems; Computer Science, Theory & Methods
SC Computer Science
GA BH6MP
UT WOS:000401929800096
DA 2019-08-06
ER
Signer-Anonymous Designated-Verifier Redactable Signatures for Cloud-Based Data Sharing

AB Redactable signature schemes allow to black out predefined parts of a signed message without affecting the validity of the signature, and are therefore an important building block in privacy-enhancing cryptography. However, a second look shows, that for many practical applications, they cannot be used in their vanilla form. On the one hand, already the identity of the signer may often reveal sensitive information to the receiver of a redacted message; on the other hand, if data leaks or is sold, everyone getting hold of (redacted versions of) a signed message will be convinced of its authenticity.

We overcome these issues by providing a definitional framework and practically efficient instantiations of so called signer-anonymous designated-verifier redactable signatures (AD-RS). As a byproduct we also obtain the first group redactable signatures, which may be of independent interest. AD-RS are motivated by a real world use-case in the field of health care and complement existing health information sharing platforms with additional important privacy features. Moreover, our results are not limited to the proposed application, but can also be directly applied to various other contexts such as notary authorities or e-government services.

C1 [Derler, David; Slamanig, Daniel] Graz Univ Technol, IAIK, Graz, Austria. [Krenn, Stephan] AIT Austrian Inst Technol GmbH, Vienna, Austria. RP Derler, D (reprint author), Graz Univ Technol, IAIK, Graz, Austria. EM david.derler@tugraz.at; stephan.krenn@ait.ac.at; daniel.slamanig@tugraz.at

O1 Slamanig, Daniel/0000-0002-4181-2561; Derler, David/0000-0002-5345-3906

CR Applebaum B., 2011, ICS

Bellare M, 2005, LECT NOTES COMPUT SC, V3376, P136
Bellare M, 2003, LECT NOTES COMPUT SC, V2656, P614
Bellare M, 2011, LECT NOTES COMPUT SC, V7073, P486, DOI 10.1007/978-3-642-25385-0_26
Brzuska Christina, 2014, Public Key Infrastructures, Services and Applications. 10th European Workshop, EuroPKI 2013, Revised Selected Papers: LNCS 8341, P12, DOI 10.1007/978-3-642-53997-8_2
Brzuska C, 2010, LECT NOTES COMPUT SC, V6056, P444
Camenisch J, 2015, LECT NOTES COMPUT SC, V9453, P262, DOI 10.1007/978-3-662-48800-3_11
Healthcare requires continuous and systematic innovation in order to provide high quality services. Cloud computing is a new model of computing that promises to provide more flexibility, less expense and more efficient IT services to end-users. Large amount of sensitive data is shared by the healthcare cloud users. Here, privacy and security of group sharing data have become two major issues.

The aim of this paper is to propose a ternary tree based TGDH protocol for dynamic group data sharing in healthcare cloud that could be used by a healthcare organization to share their data in dynamically secure groups containing other health organizations. Secure and reliable group communication in healthcare organizations is an increasingly active research area by growing popularity in group oriented and collaborative applications. Ternary tree approach covers more other healthcare members (organizations) in a subgroup and height of ternary tree will get increase when number of members in a group increase where height of tree is number of iterations required to compute group shared key.

RP Thakare, VR (reprint author), VIT Univ, Sch Informat Technol & Engn, Vellore 632014, TN, India.
EM vaishali.thakare@vit.ac.in; johnsingh.k@vit.ac.in
Koufi V., 2010, P 10 IEEE INT C INF, P1, DOI 10.1109/ITAB.2010.5687702
Li ZJ, 2011, IEEE INTELL SYST, V26, P73, DOI 10.1109/MIS.2011.10
Mell P, 2010, COMMUN ACM, V53, P50
Roman A, 2015, EXPERT SYST APPL, V42, P9512, DOI 10.1016/j.eswa.2015.07.071
Samanthula BK, 2015, INFORM SYST, V48, P196, DOI 10.1016/j.is.2013.08.004
Seo SH, 2014, IEEE T KNOWL DATA EN, V26, P2107, DOI 10.1109/TKDE.2013.138
Interoperability stands in the ability of different information systems to exchange data. Today interoperability is highly requested in several departments of healthcare organizations. Dialysis facilities register a high delay in the possibility of data exchange, because the strong lack of standards results in a huge gap in having interoperable systems. This work represents a first effort to overcome the problems of interoperability of data related to dialysis units. A Federated DataBase System (FDBS) approach has been adopted to construct a common data repository. The storage system has been built by the Dialysis Data Infrastructure (DDI), a unique multilevel standardized data structure supported by the Dialysis MATlib (DM), an embedded Matlab (R) library, that's able to convert, harmonize and query the raw data coming from the dialysis treatment units into a common interoperable format. The DDI and DM have been developed in the context of the Italy-Switzerland cooperation project INTERREG DialysIS, and currently contains 1018 dialysis sessions recorded referred to 145 patients. C1 [Vito, Domenico; Casagrande, Giustina; Bianchi, Camilla; Costantino, Maria Laura] Politecn Milan, Lab Biol Struct Mech, Dept Chem Mat & Chem Engn Giulio Natta, Milan, Italy.
Purpose - The purpose of this paper is to analyze the institutional and social forces that influence collaborative data sharing practices in cross-sector interorganizational networks. The analysis focuses on the data sharing practices between professionals in the transportation and public health sectors, areas prioritized for collaborative action to improve public health.

Design/methodology/approach - A mixed methods design is utilized. Electronic surveys were sent to 57 public health and 157 transportation professionals in a large major metropolitan area in the USA (response rate 39.7 percent). Focus
groups were held with 12 organizational leaders representing professionals in both sectors.

Findings - The application of the institutional-social capital framework suggests that professional specialization and organizational forces make it challenging for professionals to develop the cross-sector relationships necessary for cross-sector collaborative data sharing.

Research limitations/implications - The findings suggest that developing the social relationships necessary for cross-sector collaboration may be resource intensive. Investments are necessary at the organizational level to overcome the professional divides that limit the development of cross-sector relationships critical for collaborative data sharing. The results are limited to the data sharing practices of professionals in one metropolitan area.

Originality/value - Despite mandates and calls for increased cross-sector collaboration to improve public health, such efforts often fail to produce true collaboration. The study's value is that it adds to the theoretical conceptualization of collaboration and provides a deeper understanding as to why collaborative action remains difficult to achieve. Future study of collaboration must consider the interaction between professional specialization and the social relationships necessary for success.
Genome sharing projects around the world: how you find data for your research

Positioning and Power in Academic Publishing: Players, Agents and Agendas

English

Proceedings Paper

20th International Conference on Electronic Publishing

Jun 07-09, 2016

Univ Göttingen, Göttingen, Germany
Access to raw experimental research data and data reuse is a common hurdle in scientific research. Despite the mounting requirements from funding agencies that the raw data is deposited as soon as (or even before) the paper is published, multiple factors often prevent data from being accessed and reused by other researchers. The situation with the human genomic data is even more dramatic, since on the one hand human genomic data is probably the most important data to share—it lies at the heart of efforts to combat major health issues such as cancer, genetic diseases, and genetic predispositions for complex diseases like heart disease and diabetes. On the other hand, since it is sensitive and personal information, it is often exempt from data sharing requirements. DNAdigest investigates the barriers for ethical and efficient genomic data sharing and engages with all stakeholder groups, including researchers, librarians, data managers, software developers, policy makers, and the general public interested in genomics. Repositive offers services and tools that reduce the barriers for data access and reuse for the research community in academia, industry, and clinics. To address the most pressing problem for public genomic data: that of data discoverability, Repositive has built an online platform (repositive.io) providing a single point of entry to find and access available genomic research data.


EM fiona@repositive.io

CR Collection of UK funders' policies, 2015, RES DAT MAN BLOG

Richards M, 2015, COLLECTION LINKING U

Toronto International Data Release Workshop Authors, 2009, NATURE, V461, P168, DOI [10.1038/461168a, DOI 10.1038/461168A]

van Schaik TA, 2014, APPL TRANSL GENOM, V3, P100, DOI 10.1016/j.atg.2014.09.013

NR 4
TC 0
Z9 0
U1 0
U2 2

PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
BN 978-1-61499-649-1; 978-1-61499-648-4
PY 2016
BP 48
EP 50
DI 10.3233/978-1-61499-649-1-48
PG 3

WC Computer Science, Information Systems; Information Science & Library Science
SC Computer Science; Information Science & Library Science

GA BF8ZA
UT WOS:000385302800009
DA 2019-08-06
ER
The potential of ICT to address problems in modern healthcare is considerable, and an ICT-driven revolution in healthcare appears imminent. Such developments may be viewed largely in positive terms. Thus they should result in enhanced treatment and care options, empowering patients—including by permitting greater self-management of illness outside hospital, while offering economic benefits and costs savings over traditional healthcare provision. However, the new possibilities also present manifold risks, such as of data breaches, encroachments on subject autonomy, as well as of other harms. This article considers some of the key regulatory challenges against the background of the progress of the current EU Commission-sponsored 'MyHealthAvatar' project.

C1 [Dahi, Alan; Forgo, Nikolaus; Jensen, Sarah; Stauch, Marc] Leibniz Univ Hannover, Inst Legal Informat, D-30167 Hannover, Germany.
RP Stauch, M (reprint author), Leibniz Univ Hannover, Inst Legal Informat, D-30167 Hannover, Germany.
EM stauch@iri.uni-hannover.de

CR Andoulsi I., 2013, EHEALTH LEGAL ETHICA, P27
[Anonymous], 2013, PAVING WAY PERSONALI
[Anonymous], 2015, SUMMARY REPORT PUBLI, P11
[Anonymous], COM 2014 219 FINAL, P13
Baile W F, 2000, Oncologist, V5, P302, DOI 10.1634/theoncologist.5-4-302
Center for Democracy & Technology, 2012, MOBILE PLATFORMS INT

European Commission Staff, SWD 2014 135 FINAL, P4
Goldstein M., 2010, CONSUMER CONSENT OPT, P7
Ilves T. H., REDESIGNING HLTH EUR
MHRA Guidance, 2014, MHRA GUIDANCE
Vaghela M., 2015, EHEALTH LAW POLICY, P13
Vihul L., 2014, TALLIN PAPERS, V1
Vollebregt E., 2011, JHW, P4

J9 EUR J HEALTH LAW
Doctor, meet my data Web-based health info can confuse patients and frustrate GPs. A better way to store, analyse and share health data online should strengthen the doctor-patient relationship.

Sharing data to save lives

New Scientist

Nature Medicine

Multidisciplinary Sciences

Science & Technology - Other Topics
AB Journals can and should ensure that they erect no barriers to fast and wide sharing of critical data during major public health emergencies. But funders and scientists must also play a part.

TI BETTER DATA INTEGRATION AND SHARING CAN ACCELERATE RESEARCH AND POLICY FOR GLOBAL POPULATION HEALTH

SO AMERICAN JOURNAL OF TROPICAL MEDICINE AND HYGIENE

AU Van Panhuis, WG
Paul, P
Emerson, C
Wilder, R
Herbst, AJ
Heymann, D

AF Van Panhuis, Willem G.
Paul, Proma
Emerson, Claudia
Wilder, Richard
Herbst, Abraham J.
Heymann, David

C1 [Van Panhuis, Willem G.; Paul, Proma] Univ Pittsburgh, Grad Sch Publ Hlth, Pittsburgh, PA USA.
    [Emerson, Claudia] St Michaels Hosp, Toronto, ON, Canada.
    [Wilder, Richard] Bill & Melinda Gates Fdn, Seattle, WA USA.
Going mainstream: Online sharing of health data and test results with patients

Christensen K, 2013, J PARTICIPATORY MED, V5, pe38
Topol E, 2015, PATIENT WILL SEE YOU
Woods SS, 2013, J MED INTERN RES, V15, P182, DOI 10.2196/jmir.2356

Woods SS, 2013, J MED INTERN RES, V15, P182, DOI 10.2196/jmir.2356
Could networking and sharing (open) data in an international collaborative effort unravel the mechanisms of sleep disturbances in middle-aged women?

SO MENOPAUSE—THE JOURNAL OF THE NORTH AMERICAN MENOPAUSE SOCIETY

LA English

DT Editorial Material

ID POSTMENOPAUSAL WOMEN; MIDLIFE WOMEN; MENOPAUSAL TRANSITION; POOR SLEEP; SYMPTOMS; INSOMNIA; HEALTH; ACTIGRAPHY; DURATION; DISEASE

C1 [Carrier, Julie] Univ Montreal, Dept Psychol, Montreal, PQ H3C 3J7, Canada. 
Hop Sacre Coeur, Res Ctr, Ctr Adv Res Sleep Med, Montreal, PQ H4J 1C5, Canada. 
Inst Univ Geriatrie Montreal, Res Ctr, Montreal, PQ, Canada.

RP Carrier, J (reprint author), Univ Montreal, Dept Psychol, CP 6128, Montreal, PQ H3C 3J7, Canada.


de Zambotti M, 2014, FERTIL STERIL, V102, P1708, DOI 10.1016/j.fertnstert.2014.08.016


Duffy OK, 2013, MENOPAUSE, V20, P383, DOI 10.1097/gme.0b013e31827655cf


Freeman EW, 2015, CLIMACTERIC, V16, P719, DOI 10.1097/GME.0000000000000392


Hall MH, 2009, SLEEP, V32, P73

Hartz A, 2013, SLEEP MED, V14, P71, DOI 10.1016/j.sleep.2012.08.003


10.1097/GME.0000000000000183

Im EO, MENOPAUSE

Kravitz HM, 2005, ARCH INTERN MED, V165, P2370, DOI

10.1001/archinte.165.20.2370

Kravitz HM, 2003, MENOPAUSE, V10, P19, DOI 10.1097/01.GME.0000030707.35686.5A

Kravitz HM, 2008, SLEEP, V31, P979

Kravitz HM, 2015, MENOPAUSE, V22, P710, DOI 10.1097/GME.0000000000000379

Kravitz HM, 2011, SLEEP, V34, P1221, DOI 10.5665/SLEEP.1244
Mezick EJ, 2014, SLEEP MED, V15, P64, DOI 10.1016/j.sleep.2013.08.784
Monterroza-Castro A, 2013, MENOPAUSE, V20, P464, DOI 10.1097/gme.0b013e31826e7649
Polesel DN, MENOPAUSE
Regestein QR, 2012, MENOPAUSE, V19, P715, DOI 10.1097/gme.0b013e318258dd40
Sowers MF, 2008, SLEEP, V31, P1339
Taavoni Simin, 2015, J Midlife Health, V6, P21, DOI 10.4103/0976-7800.153611
Tu XD, 2012, SLEEP MED, V13, P1138, DOI 10.1016/j.sleep.2012.06.014
Vousoura E, MENOPAUSE
Yazdi Z, 2013, PSYCHIAT J, V2013

NR 34
TC 0
Z9 0
U1 0
U2 2

PU LIPPINCOTT WILLIAMS & WILKINS
PI PHILADELPHIA
PA TWO COMMERCE SQ, 2001 MARKET ST, PHILADELPHIA, PA 19103 USA
SN 1072-3714
EI 1530-0374
J9 MENOPAUSE
PD JUL
PY 2015
VL 22
IS 7
BP 691
EP 692
DI 10.1097/GME.0000000000000496
PG 2
WC Obstetrics & Gynecology
SC Obstetrics & Gynecology
GA CMICE
UT WOS:000357416700004
FM 26079970
DA 2019-08-06
ER

PT J
AU Loh, BCS
    Then, PHH
AF Loh, Brian C. S.
    Then, Patrick H. H.
TI Mobile Imagery eXchange (MIX) toolkit: data sharing for the unconnected
SO PERSONAL AND UBIQUITOUS COMPUTING
LA English
DT Article
DE Health care; Echocardiography; SMS; GSM; Image processing
This paper proposes a healthcare solution that enables the sharing of medical videos in areas without satellite, broadband or mobile internet connectivity. Rural areas often encounter issues such as shortage of electricity, poor telecommunication services and lack of health facilities which have led to a deficiency of medical care in remote areas. The deployment of mobile devices for healthcare services is vital to alleviating these concerns. A majority of mobile device owners are located in developing nations, and the number of users is continually rising. These technologies effectively support remote health care due to their low-power requirements, multiple functionalities and custom applications. The Mobile Imagery eXchange (MIX) toolkit is a software application capable of converting echocardiogram videos into text for transmission through short message service (SMS), over a global system for mobile communications network. A smartphone or computer installed with the MIX toolkit can be utilized to deliver effective medical care within rural regions. To significantly shrink data size, video, image and file processing techniques are applied for analysis, segmentation, compression and conversion. Experiments show that data size reduction rates above 60 until 95 % are achievable when transforming imagery into text. Furthermore, in optimal conditions, the average SMS per image ranges from 9 to 23 text messages.

RP Loh, BCS (reprint author), Swinburne Univ Technol, Fac Engn Comp & Sci, Sarawak Campus, Kuching, Malaysia.
EM bloh@swinburne.edu.my; pthen@swinburne.edu.my
CR Abur M, 2010, P INT C SOFTW ENG IN, P159
Back I, 2012, J INFORM TECH SOFT E, V2, P2
Chigona W, 2012, J COMMUN INFORM, V9, P1011
Contributors W, 2014, SARAWAK
Gladding PA, 2013, J PERS MED, V3, P203, DOI 10.3390/jpm3030203
Graziplene LR, 2009, CREATING TELEMEDICIN
Ifikhar M, 2010, 2010 Third International Conference on Advances in Human-Oriented and Personalized Mechanisms, Technologies, and Services (CENTRIC 2010), P83, DOI 10.1109/CENTRIC.2010.25
Khan M. F., 2011, INT J COMPUTER SCI I, V8, P357
Khan MF, 2012, ARXIV12011383
Lee Y H, 2011, VEH TECHN C VTC SPRI, P1
Mai TV, 2013, EMERG MED INT, DOI 10.1155/2013/627230
Mitra S, 2008, TENCON 2008 IEEE C, P1
Mohd-Nor R, 2013, J KOMUN, V29, P161
Shirali-Shahreza M, 2009, 11TH INTERNATIONAL CONFERENCE ON ADVANCED COMMUNICATION TECHNOLOGY, VOLS I-III, PROCEEDINGS,, P222
Sibon P, 2012, BORNEO POST
Spencer KT, 2013, J AM SOC ECHOCARDIOG, V26, P567, DOI 10.1016/j.echo.2013.04.001
Tahat A. A., 2009, WIR PERV COMP 2009 I, P1
Just like the internet, Internet of things (IoT) with right standards and technologies, will impact multiple aspects of human lives including Smart Home, Smart Car and Healthcare. Healthcare of things (HoT) would enhance healthcare using the insight provided by sensor data. Healthcare users will subscribe to HoT services that use sensors to get activity data (such as steps walked, hours
slept and so on) along with other health vitals (such as heart rate, temperature and weight) to improve user's health. Similarly Smart home users subscribe to a Smart home cloud service that will use data from home sensors. Most of these IoT scenarios have multiple producer, multiple consumer (MPMC) environments, with multiple sensors as producers of data, and multiple IoT services as consumers of data. Current literature and standards provide many protocols for data paths (data transfers) in these MPMC environments that can be used for IoT. However, data paths in MPMC environment must be easily configurable and manageable by end users in order for IoT to be more appealing to a broader user community. Multiple sensors with multiple applications from each manufacturer to control them would not be preferred by users. Also, IoT users need to be able easily choose between multiple options for service providers. In this demonstration, we highlight how user experience perspectives impact the data framework design in MPMC environments, using our drops data framework infrastructure. We hope to have these concepts included IoT standardization efforts. This demonstration was also made at CES at the IEEE booth.

C1 [Jagatheesan, Arun; Maragathavel, Senthil; Sivapurapu, Mouli; Lee, Juhan] Samsung Res Amer Silicon Valley, 75 W Plumeria Dr, San Jose, CA 95134 USA.
RP Jagatheesan, A (reprint author), Samsung Res Amer Silicon Valley, 75 W Plumeria Dr, San Jose, CA 95134 USA.
EM a.jagatheesa@samsung.com; s.maraga@samsung.com; mouli.siva@samsung.com; juhan.l@samsung.com

---

AU Alamri, FS
Lee, KD
AF Alamri, Fahad Saeed
Lee, Ki Dong
GP IEEE
TI Secure Sharing of Health Data Over Cloud
SO 2015 5TH NATIONAL SYMPOSIUM ON INFORMATION TECHNOLOGY: TOWARDS NEW SMART WORLD (NSITNSW)
LA English
DT Proceedings Paper
CT 5th National Symposium on Information Technology - Towards New Smart World (NSITNSW)
Modern information technology is increasingly used in healthcare with the goal to improve and enhance medical services and to reduce costs. In this context, the outsourcing of computation and storage resources to general IT providers (cloud computing) has become very appealing. As cloud computing is becoming more mature data outsourcing in public cloud is also gaining momentum including sensitive information like personal data, health data, media files and government documents. For sensitive data which is outsourced in public cloud, its encrypted uploads are recommended thus narrowing its utility scope in terms of processing and evaluation. To evaluate user requests obliviously on public cloud over sensitive encrypted data, we have formalized a system which protects not only the privacy of data but also the evaluation process that is carried on the public cloud. Throughout the system execution the cloud server will learn nothing useful except the reply cardinality.

C1 [Alamri, Fahad Saeed; Lee, Ki Dong] Yeungnam Univ, Comp Engn, Daegu, South Korea.

RP Alamri, FS (reprint author), Yeungnam Univ, Comp Engn, Daegu, South Korea.

EM F_ksa1987@hotmail.com; kdrhee@yu.ac.kr

Chang R. M., 2013, DECISION SUPPORT SYS
Fiengberg S. E., 2001, STAT MED, P1347
Gantz J., 2013, IDC IVIEW IDC ANAL F
Hacigumus H, 2004, LECT NOTES COMPUT SC, V2973, P125
Hans Hr L., 2010, P 1 ACM INT HLTH INF, P220, DOI DOI 10.1145/1882992.1883024
Hore B, 2004, P 30 INT C VER LARG, V30, P720
International Organization for Standardization (ISO), 2015 ISO
Iyer B, 2004, LECT NOTES COMPUT SC, V2992, P147
Kandukuri BR, 2009, 2009 IEEE INTERNATIONAL CONFERENCE ON SERVICES COMPUTING, P517, DOI 10.1109/SICC.2009.84
Kim J., 1995, AM STAT ASS P SECT S, P114
Pearson S, 2010, CLOUD COMP TECHN SCI, P693, DOI DOI 10.1109/CLOUDCOM.2010.66
Sion R., 2007, VLDDB 07, P1431
MonDossierMedical.ch: An Efficient Tool for Sharing Medical Data Between Patients and Doctors

Abstract
MonDossierMedical.ch is a project led by the canton of Geneva, making it possible for every patient to access his own electronic health record (EHR) and to share the medical files with his doctors. It was introduced across the canton in mid-2013, and provided to all patients free of charge. It is based on the first Swiss-wide eHealth-compliant pilot project "e-toile". The canton of Geneva developed "e-toile" as a public-private partnership together with Swiss Post and it was launched in 2011 in few municipalities. Back then, Geneva's EHR represented the first Swiss attempt to link all healthcare professionals in the treatment chain. Today, it serves more than 4,000 patients and 380 physicians. This number is growing regularly, as well as the health care institutions (private hospitals, labs) joining the community.

C1 [Rosemberg, Aurelie; Plaut, Olivier] Direct Gen Sante, 24 Ave Beau Sejour, CH-1206 Geneva, Switzerland.
RP Plaut, O (reprint author), Direct Gen Sante, 24 Ave Beau Sejour, CH-1206 Geneva, Switzerland.
EM information@mondossiermedical.ch; olivier.plaut@etat.ge.ch

Electronic health record; Geneva; MonDossierMedical.ch; Shared care plan; Shared medication list
The Research on the Design of Medical Data Exchange and Sharing Platform for Smart Healthcare

This paper puts forward a solution for building a data exchange and sharing platform. The platform should satisfy the need of information interconnection and intercommunication between institutions among a whole city. The paper researched on big data management, cloud storage, medical data standardize and exchange platform, and then designed the platform. After researching, the paper designed a viable solution. According to analysis, the system should have functions as data acquisition, data processing, data storage, data management, data query and data mining. Medical institutions could use it to upload their own data, the system collected data from institutions, then saved and manage the data into cloud storage platform, by the other side, institutions could share the data in the platform while the system provided data query and mining.

Finally, this paper gives an implementation for the platform.

References:
- Wang, Xiao-guo; Zhang, Dan-dan, Tongji Univ, Sch Elect & Informat, Shanghai, Peoples R China.

- RP Wang, XG (reprint author), Tongji Univ, Sch Elect & Informat, Shanghai, Peoples R China.

- CR LI Wei, 2010, CHINESE MED EQUIPMEN, V31, P79
  - [Ã…†ï½œ+Ã²: Meng Xiaofeng], 2013, [Ã§³½µ/Ã°¡â½+ï¾Œ], Journal of Computer Research and Development], V50, P146
  - PENG Shaohui, 2010, WORLD HLTH DIGEST ME, V07, P372
  - TANG Kai, 2010, CHINESE MED EQUIPMEN, V31, P35
  - YANG Lei, 2013, NETWORK SECURITY, P43
An Agent-Oriented Data Sharing and Decision Support Service for Hubei Provincial Care Platform

Abstract

Research today is often dedicated in isolation to the fields of regional clinical data sharing and clinical decision support with closed boundary. A framework has been proposed in this paper for integrating agent-oriented data sharing and agent-oriented argumentation upon shared data, for the Hubei Provincial Care Platform. This is built upon the LCC technology and CDA standard, demonstrated with a hypertension management example, and in compliant with IHE XDS standard. The agent-oriented platform services will support, in the entire province, a regional collaborative health service paradigm where the right clinical data will be available at the right place at the right time, for making the right decision.

Keywords

Agent; Clinical data sharing; Clinical decision support; CDA; LCC

References

Garg AX, 2005, JAMA-J AM MED ASSOC, V293, P1223, DOI 10.1001/jama.293.10.1223
Integrating the Healthcare Enterprise (IHE), 2007, IT INFR TECHN FRAM, V1-3
National Institute for Health and Clinical Excellence (NICE), 2015, ANT TREATM, P2
A Survey on Energy Harvesting and Integrated Data Sharing in Wireless Body Area Networks

Wireless body area networks (WBANs) are important branches of wireless sensor networks (WSNs). They promise unobtrusive ambulatory health monitoring for real-time updates of patients' medical records that have aroused extensive attention in various fields. In recent years, one can find a lot of researches related to WBANs that have appeared in these literatures. But there are still many key
issues that need to be further investigated. This paper briefly introduces the architecture and features of WBANs. In this attempt, we focus mostly on energy acquisition, data integration and data sharing, and collaboration of WBANs, from the viewpoint of energy harvesting development, the social network and smartphone application in WBANs, and the integration of WBANs and cloud system networks computing to analyze related issues of WBANs. Finally, we put forward concluding remarks with several future research directions.

Cl [Xu, Xiaoling; Shu, Lei; Liu, Mei] Guangdong Univ Petrochem Technol, Guangdong Prov Key Lab Petrochem Equipment Fault, Maoming 525000, Peoples R China.

[Guizani, Mohsen] Qatar Univ, Doha, Qatar.

RP Shu, L (reprint author), Guangdong Univ Petrochem Technol, Guangdong Prov Key Lab Petrochem Equipment Fault, Maoming 525000, Peoples R China.

EM lei.shu@live.ie
OI Shu, Lei/0000-0002-6700-9347

FU Guangdong University of Petrochemical Technology [2012RC0106]; Educational Commission of Guangdong Province, China [2013JJCX0131]; Top Level Talents Project in "Sailing Plan" of Guangdong Province; Guangdong University [512030]; Science and Technology Program of Maoming City [0010041110629036]; Special Fund of Guangdong Higher School Talent Recruitment

FX This work is supported by the Guangdong University of Petrochemical Technology's Internal Project no. 2012RC0106, Educational Commission of Guangdong Province, China, Project no. 2013KJCX0131, 2013 Top Level Talents Project in "Sailing Plan" of Guangdong Province, 2013 Special Fund of Guangdong Higher School Talent Recruitment, Fault Diagnosis of Petrochemical Process and Informatization Control Engineering Open Fund in Guangdong University no. 512030, and the Science and Technology Program of Maoming City no. 0010041110629036.

Anton SR, 2007, SMART MATER STRUCT, V16, pR1, DOI 10.1088/0964-1726/16/3/001
Bahga A, 2013, IEEE J BIOMED HEALTH, V17, P894, DOI 10.1109/JBHI.2013.2257818
Botts N., 2010, P 43 ANN HAW INT C S
Caldeira JMLP, 2013, IEEE SENS J, V13, P4339, DOI 10.1109/JSEN.2013.2267729
Cao HS, 2009, IEEE COMMUN MAG, V47, P84, DOI 10.1109/MCOM.2009.5350373
Challa V., 2008, SMART MATER STRUCT, V75, P1
Chang Ko Wei, 2011, 2011 IEEE Conference on Sustainable Utilization and Development in Engineering and Technology, P165, DOI 10.1109/STUDENT.2011.6089346
Cui XY, 2007, IEEE 2007 INTERNATIONAL SYMPOSIUM ON MICROWAVE, ANTENNA, PROPAGATION AND EMC TECHNOLOGIES FOR WIRELESS COMMUNICATIONS, VOLS I AND II, P178
An empirical study on the performance evaluation of scientific data sharing platforms in China

Purpose - The purpose of this paper is to conduct performance evaluation of eight main scientific data sharing platforms in China and find existing problems, thus providing reference for maximizing the value of scientific data and enhancing scientific research efficiency.

Design/methodology/approach - First, the authors built an evaluation indicator system for the performance of scientific data sharing platforms. Next, the analytic hierarchy process was employed to set indicator weights. Then, the authors use experts grading method to give scored for each indicator and
calculated the scoring results of the scientific data sharing platform performance evaluation. Finally, an analysis of the results was conducted.

Findings - The performance evaluation of eight platforms is arranged by descending order by the value of F: the Data Sharing Infrastructure of Earth System Science (76.962), the Basic Science Data Sharing Center (76.595), the National Scientific Data Sharing Platform for Population and Health (71.577), the China Earthquake Data Center (66.296), the China Meteorological Data Sharing Service System (65.159), the National Agricultural Scientific Data Sharing Center (55.068), the Chinese Forestry Science Data Center (56.894) and the National Scientific Data Sharing & Service Network on Material Environmental Corrosion (Aging) (52.528). And some existing shortcomings such as the relevant policies and regulation, standards of data description and organization, data availability and the services should be improved.

Originality/value - This paper is mainly discussing about the performance evaluation system covering operation management, data resource, platform function, service efficiency and influence of eight scientific data sharing centers and made comparative analysis. It reflected the reality development of scientific data sharing in China.

C1 [Si, Li] Wuhan Univ, Ctr Studies Informat Resources, Wuhan 430072, Peoples R China.

[Li, Yueting; Zhuang, Xiaozhe; Li, Xin; Xin, Juanjuan] Wuhan Univ, Sch Informat Management, Dept Lib Sci, Wuhan 430072, Peoples R China.


[Hua, Xiaqin] Zhejiang Inst Hydraul & Estuary, Hangzhou, Zhejiang, Peoples R China.

RP Si, L (reprint author), Wuhan Univ, Ctr Studies Informat Resources, Wuhan 430072, Peoples R China.

EM lsiwu@163.com

FU Ministry of Education of P.R. China [13YJA870016]

FX This paper is one of the research outcomes of a Humanities and Social Sciences Project supported by the Ministry of Education of P.R. China (Project Name: Study on the Guarantee of Scientific Data Integration and Sharing in China, Project No. 13YJA870016).

CR Alexander M., 2010, DECISION MAKING USIN

Basic Science Data Sharing Center, 2009, EV IND SYST SHAR SER

Fan X. E., 2009, CHINESE J PUBLIC HLT, V8, P179

Jiang H., 2009, LIB DEV, P19

Jiang H., 2009, LIB DEV, P25

Li H. Y., 2009, WORLD SCI TECHNOLOGY, V11, P578

Lu X. C., 2010, ACTIVATION SOURCE IN

Saaty T., 1988, MATH MODELS DECISION, V48, P109


The Data Center of National Scientific Data Sharing Platform for Population and Health, 2009, EV IND SYST NAT MED

The Ministry of Science and Technology, 2011, OP SERV PERF EV IND

Tu Y., 2007, FORUM SCI TECHNOLOGY, P74

Zhao W., 2013, DIGITAL LIB FORUM, P58

NR 13

TC 0

Z9 0

U1 1

U2 61

FU EMERALD GROUP PUBLISHING LIMITED

PI BINGLEY

PA HOWARD HOUSE, WAGON LANE, BINGLEY BD16 1WA, W YORKSHIRE, ENGLAND

SN 0737-8831
A privacy enhanced search approach for cloud-based medical data sharing

With the development of healthcare industry, healthcare informatization provides great potential for the health-care improvement. The cloud computing platform, which is an important infrastructure for the inter(intra)-organization collaboration, provides a shared storage space to the medical data.
sharing. For the privacy protection of medical data, sensitive data has to be encrypted before being transmitted to the cloud, which makes it more challenging to use these data in the cloud. For strengthening the utilization of encrypted cloud data, various encrypted search technologies are widely studied. However, these existing searchable encryption schemes may not enforce users' demands well. This paper proposes a privacy enhanced search approach for cloud-based medical data sharing. The proposed solution implements a hybrid search approach, where the search process is conducted across plaintext and ciphertext. Moreover, the enhanced access control can ensure the privacy protection of cloud data. The empirical experiments illustrate the effectiveness of our solution.

C1 [Liu, Lu; Sun, Jingchao; Li, Jianguo; Li, Rong; Li, Juan] Beijing Univ Technol, Sch Software Engg, Beijing, Peoples R China.
[Meng, Xi] Peoples Publ Secur Univ China, Dept Counter Terrorism, Beijing, Peoples R China.
RP Liu, L (reprint author), Beijing Univ Technol, Sch Software Engn, Beijing, Peoples R China.
FU Beijing Natural Science Foundation [4152007, 7142014]; China National Key Technology Research and Development Program [2013BAH19F01]
FX This work is supported by Beijing Natural Science Foundation (4152007, 7142014) and China National Key Technology Research and Development Program project with no. 2013BAH19F01.

CR Ahson SA, 2011, CLOUD COMPUTING AND SOFTWARE SERVICES: THEORY AND TECHNIQUES, P1
Ballard L, 2005, LECT NOTES COMPUT SC, V3783, P414
Boneh D, 2004, ADV CRYPTOLOGY EUROCRYPT, P506
Brunette G., 2009, SECURITY GUIDANCE CR, P1
Chang YC, 2005, LECT NOTES COMPUT SC, V3351, P442
Fridsma D, 2012, COMPUTER, V45, P24, DOI 10.1109/MC.2012.371
Garets D, 2006, ELECT MED RECORDS VS
Hwang YH, 2007, LECT NOTES COMPUT SC, V4575, P2
Kuo AMH, 2011, J MED INTERNET RES, V13, DOI 10.2196/jmir.1867
Li JQ, 2013, ENTERPR INF SYST-UK, V7, P272, DOI 10.1080/17517575.2012.688223
Lori M., 2009, DATA SECURITY WORLD, P61
Narudkar M. A. D., SURVEY SEARCHING TEC
Robertson S. E., 1993, Text REtrieval Conference (TREC-1) (NIST-SP-500-207), P21
Schloeffel P., 2002, 18308 ISO TS
Song DXD, 2000, P IEEE S SECUR PRIV, P44, DOI 10.1109/SECPRI.2000.848445
Stansfield S, 2005, B WORLD HEALTH ORGAN, V83, P562
Tian Y., 2009, COMM WORKSH 2009 ICC, P1
Wang C, 2010, DISTR COMP SYST ICDC, P253
Wang LZ, 2013, COMPUT ELECTR ENG, V39, P3, DOI 10.1016/j.compeleceng.2012.05.001
Witten Ian H., 1999, MANAGING GIGABYTES C
Yang JJ, 2015, COMPUT IND, V69, P3, DOI 10.1016/j.compind.2015.01.012
Yang JJ, 2015, FUTURE GENER COMP SY, V43-44, P74, DOI 10.1016/j.future.2014.06.004
Zerr S., 2009, P 12 INT C EXT DAT T, P439
Zhao JQ, 2014, J COMPUT SYST SCI, V80, P994, DOI 10.1016/j.jcss.2014.02.006
NR 28
AB The power of interoperable systems with data/information integration, central to achieving the goals of Telehealth, is illustrated through mutually beneficial sharing between Labor & Delivery (L&D) and Obstetrics (OBs) Clinics. Data shared between L&D and OB brought improved practice patterns and outcomes, and increased satisfaction at both. Staffing and skillsets were significantly improved by knowing complications arriving and anticipated volumes. OBs increased clinic efficiencies and improved patient-direct care time with improved clinical and cost outcomes.

C1 [Shaha, Steven H.] Ctr Policy & Publ Adm, Detroit, MI 48201 USA.

[Shaha, Steven H.; Gilbert-Bradley, Diane] Allscripts, Chicago, IL USA.

RP Shaha, SH (reprint author), Ctr Policy & Publ Adm, Detroit, MI 48201 USA.

EM steve.shaha@allscripts.com
Brailer D. J., 2005, HLTH AFFAIRS MILLWOO, V24, P5
Fichman RG, 2011, INFORM SYST RES, V22, P419, DOI 10.1287/isre.1110.0382
Hawkins JL, 1997, OBSTET GYNECOL SURV, V52, P408
Johnston R, 2000, TELEMED J E-HEALTH, V6, P341, DOI 10.1089/153056200750040192
Mackey D. S., 1996, UALR LJ, V19, P465
Murray-Weir M, 2014, HSS J
Rosenthal MS, 2006, SOCIOl PERSPECT, V49, P369, DOI 10.1525/sop.2006.49.3.369
Shah S, 2013, RIV PUBL SER INNOV, P121
Shaha HS, 2015, IMPROVING HLTH MANAG
Shaha SH, 2013, HIMSS EUROPE INSIGHT, V1, P9
Shah SH, 2013, HISA HIC 2013 P, P122
Suleiman AB, 2001, INT J MED INFORM, V61, P103, DOI 10.1016/S1386-5056(01)00132-0
Vissers J, 2005, HLTH OPERATIONS MANA
Walker Jan, 2005, Health Aff (Millwood), VSuppl Web Exclusives, pW5

NR 27
TC 0
Z9 0
U1 1
U2 1
PU IOS PRESS
PI AMSTERDAM
PA NIEUWEN HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
EI 1879-8365
BN 978-1-61499-505-0; 978-1-61499-504-3
J9 STUD HEALTH TECHNOL
PY 2015
VL 209
BP 147
EP 155
DI 10.3233/978-1-61499-505-0-147
PG 9
WC Health Care Sciences & Services; Medical Informatics
SC Health Care Sciences & Services; Medical Informatics
GA BL6LQ
UT WOS:000454396300021
PM 25980718
 TI A Global Analysis of Approaches to Sharing Clinical Data with Patients
SO MEDINFO 2015: EHEALTH-ENABLED HEALTH
SE Studies in Health Technology and Informatics
LA English
CT 15th World Congress on Health and Biomedical Informatics (MEDINFO)
CY AUG 19-23, 2015
HO Int Med Informat Assoc, Brazilian Hlth Informat Soc, Sao Paulo, BRAZIL
DE Personal Health Records; Consumer Health Information; Health Information Technology; Patients; International Perspectives
AB 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. To investigate on an international scale the current state of approaches for providing patients with access to their own clinical information, individuals from 16 countries, across six continents, participated in cross-sectional semi-structured interviews. 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. Substantive initiatives for providing information to patients in the majority of countries interviewed are present; however, these initiatives were diverse in nature and stage of implementation. 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.
[Kuperman, Gilad J.; Tiase, Victoria; Vawdrey, David K.] NewYork Presbyterian Hosp, New York, NY USA.
[Collins, Sarah A.] Partners Healthcare, Boston, MA USA.
[Collins, Sarah A.] Partners Healthcare, Boston, MA USA.
RP Prey, JE (reprint author), Columbia Univ, DBMI, 622 W 168th St PH 20,WS 14, New York, NY 10032 USA.
EM jep2175@cumc.columbia.edu
OI Kuperman, Gilad/0000-0002-4130-1577
FU National Library of Medicine [T15LM007079]; Agency for Healthcare Research and Quality [R01HS21816]
FX This work was supported by grants from the National Library of Medicine (T15LM007079 - Hripcsak) and the Agency for Healthcare Research and
Quality (R01HS21816 - Vawdrey).
CR Giardina TD, 2014, J AM MED INFORM ASSN, V21, P737, DOI 10.1136/amiajnl-2013-002239
NR 1
TC 0
Z9 0
U1 0
U2 0
PU IOS PRESS
PI AMSTERDAM
PA NIEUWE HEMWEG 6B, 1013 BG AMSTERDAM, NETHERLANDS
SN 0926-9630
EI 1879-8365
BN 978-1-61499-564-7; 978-1-61499-563-0
J9 STUD HEALTH TECHNOL
PY 2015
VL 216
BP 907
EP 907
DI 10.3233/978-1-61499-564-7-907
PG 1
WC Computer Science, Interdisciplinary Applications; Health Care Sciences & Services; Medical Informatics
SC Computer Science; Health Care Sciences & Services; Medical Informatics
GA BL7ZK
UT WOS:000455836700211
PM 26262209
DA 2019-08-06
ER

PT S
AU Burgun, A
Oksen, DV
Kuchinke, W
Prokosch, HU
Ganslandt, T
Buchan, I
van Staa, T
Cunningham, J
Gjerstorff, ML
Dufour, JC
Gibrat, JF
Nikolski, M
Verger, P
Cambon-Thomsen, A
Masella, C
Lettieri, E
Bertele, P
Salokannel, M
Thiebaut, R
Persoz, C
Chene, G
Ohmann, C
AF Burgun, Anita
Oksen, Dina V.
Kuchinke, Wolfgang
Prokosch, Hans-Ulrich
Ganslandt, Thomas
In Europe, health and medical administrative data is increasingly accumulating on a national level. Looking further than re-use of this data on a national level, sharing health and medical administrative data would enable large-scale analyses and European-level public health projects. There is currently no research infrastructure for this type of sharing. The PHRIMA consortium proposes to realise the Public Health Research Infrastructure for Sharing of health and Medical Administrative data (PHRIMA) which will enable and facilitate the efficient and secure sharing of healthcare data.

C1 [Burgun, Anita; Oksen, Dina V.; Persoz, Charles; Chene, Genevieve] AVIESAN, Inst Themat Multiorganisme Sante Publ, Paris, France.
[Burgun, Anita] Univ Paris 05, Sorbonne Paris Cite, INSERM UMR 1138, Team 22, Ctr Rech Cordeliers, Paris, France.
[Kuchinke, Wolfgang] Heinrich Heine Univ, Dusseldorf, Germany.
[Prokosch, Hans-Ulrich; Ganslandt, Thomas] Friedrich Alexander Univ Erlangen Nuremberg, Chair Med Informat, Erlangen, Germany.
[Gjerstorff, Marianne L.] Statens Serum Inst, Forsker Serv, Copenhagen, Denmark.
[Dufour, Jean-Charles; Verger, Pierre] Aix Marseille Univ, AMU INSERM IRD AMSE, SESSTIM UMR 912, Marsaille, France.
[Gibrat, Jean-Francois] CNRS, UMS 3601, Gif Sur Yvette, France.
[Salokannel, Marjut] Univ Bordeaux, CNRS LabRI, Talence, France.
[Cambon-Thomsen, Anne] Univ Toulouse III Paul Sabatier, UMR Inserm 1027, Toulouse, France.
[Masella, Cristina; Lettieri, Emanuele; Bertele, Paolo] Politecn Milan, Dept Management Econ & Ind Engn, Milan, Italy.
Novel data sharing between a comprehensive cancer center and a private
payer to better understand care at the end of life

SO JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Meeting Abstract
CT American-Society-of-Clinical-Oncology (ASCO) Quality Care Symposium
CY OCT 17-18, 2014
CL Boston, MA
SP Amer Soc Clin Oncol
CI Dana Farber Canc Inst, Boston, MA 02115 USA.
   Blue Cross & Blue Shield Massachusetts, Boston, MA USA.

PT J
AU [Anonymous]
AF [Anonymous]
TI Pharma firms pool and share cancer trial data
SO NATURE REVIEWS DRUG DISCOVERY
LA English
DT News Item
CR 2010, NATURE REV DRUG DIS, V9, P499
A Robust Watermarking Technique for Secure Sharing of BASN Generated Medical Data

As remote health monitoring BASN technology matures and begins to proliferate, several issues related to the secure sharing of the resulting medical electronic data have come to the fore. This includes 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 between these various stakeholders. In this paper, we focus on three secure sharing use-cases: proof of ownership, wherein the data owner must prove that she/he is the originator of the data; data tracking, wherein the data owner must trace unauthorized sharing of her/his biosignal data; and content authentication, wherein the data owner must prove whether the biosignal data has been maliciously altered. To address these use-cases, we develop a robust watermarking technique to embed security information into biosignal data such that the semantic fidelity of the data is unaffected, the bio-signal waveforms are altered imperceptibly, and the watermark 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.

C1 [Goudar, Vishwa; Potkonjak, Miodrag] Univ Calif Los Angeles, Dept Comp Sci, Los Angeles, CA 90024 USA.
RP Goudar, V (reprint author), Univ Calif Los Angeles, Dept Comp Sci, Los Angeles, CA 90024 USA.
CR Anemaet WK, 1999, TOP GERIATR REHABIL, V15, P66
Cox I T., 2008, DIGITAL WATERMARKING
Goudar V, 2013, INT WORKS POW TIM, P75, DOI 10.1109/PATMOS.2013.6662158
A proposal of architecture to share patients data out of healthcare settings for research purposes

2014 IEEE-EMBS INTERNATIONAL CONFERENCE ON BIOMEDICAL AND HEALTH
The emerging of new Information and Communications Technologies (ICT), the aging population and the increased number of people suffering from chronic diseases are changing the health structure of developed countries. Given this situation, it is crucial that research based on demographics data is promoted and researchers can access large amounts of patient data, having this information validated by medical institutions. Currently, there are some platforms and web applications available that allow patients the self-management and control of their health and wellness information. Other platforms allow managing large amounts of patient data (demographic, diagnostic, laboratory and medication) and share patient cohorts considering different criteria of inclusion and exclusion. This paper proposes to use a selection of these platforms and it defines how to relate them to obtain a framework where the information provided by patients and medical institutions can be safely used and validated by researchers. Furthermore, the system will enable clinical researcher to share the results of their research in a controlled and safe environment.

C1 [Hernandez, Liss; Fico, Giuseppe; Cancela, Jorge; Arredondo, Maria T.] Univ Politecn Madrid, LST Grp, E-28040 Madrid, Spain.
-Dagliati, Arianna; Sacchi, Lucia; Bellazzi, Riccardo] Univ Pavia, Comp & Biomed Engn, Dept Elect, Pavia, Italy.
-Bucalo, Mauro] BIOMERIS s r l, Pavia, Italy.

EM lhernandez@lst.tfo.upm.es; gfico@lst.tfo.upm.es;
jcancela@lst.tfo.upm.es; arianna.dagliati@unipv.it;
mauro.bucalo@biomeris.com; lucia.sacchi@unipv.it;
riccardo.bellazzi@unipv.it; mta@lst.tfo.upm.es

RI dagliati, arianna/1-7119-2019; Fico, Giuseppe/K-3640-2017
OI Fico, Giuseppe/0000-0003-1551-4613; dagliati,
arianna/0000-0002-5041-0409

FU CEI Moncloa; European Commission [600914]

FX Research supported by CEI Moncloa and European Commission through the
7th Framework Programme project MOSAIC (Grant Agreement 600914).

-Creeger M., 2009, QUEUE, V7, P3
-Frost JH, 2008, J MED INTERNET RES, V10, DOI 10.2196/jmir.1053
-Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
-Pisani E, 2010, SHARING HLTH DATA GO
-Qian L, 2009, LECT NOTES COMPUT SC, V5931, P626, DOI 10.1007/978-3-642-10665-1_63
-SAPENA A. F., 2011, PROF INFORM, V20, P259
Weitzman ER, 2011, PLOS ONE, V6, DOI 10.1371/journal.pone.0019256

FU IEEE
AB One of the most important infrastructure requirements in the domain of remote health monitoring BASNs is the secure collection and dissemination of the user's medical data. Data security desiderata in this application domain are not limited to ensuring the confidentiality and integrity of medical data that has been logged to a data sink. Requirements also arise from the need to provide the data owner (BAN user / patient) and the data consumers (healthcare providers, insurance companies, medical research facilities) secure control over the data as it is shared between these various stakeholders. Here, we study a robust watermarking technique to embed security information into biosignal data such that the semantic fidelity of the data is unaffected, while simultaneously ensuring that the watermark is not easily erased or corrupted by malicious data consumers. In doing so, we address three use-cases: proof of ownership, wherein the data owner can prove that she/he is the originator of the data; data tracking, wherein the data owner can trace unauthorized sharing of her/his biosignal data; and content authentication, wherein the data owner can prove whether the biosignal data has been maliciously altered. Based on experimentally collected datasets from a gait-stability monitoring BASN, we show that the embedding of 800 bit watermarks can be achieved robustly and effectively, with near-imperceptible changes to the signal waveform and no loss in the the signal's diagnostic quality.

C1 [Goudar, Vishwa; Potkonjak, Miodrag] Univ Calif Los Angeles, Dept Comp Sci, Los Angeles, CA 90024 USA.
The aim of the Nu. Sa. project is the definition of national level data standards to collect data coming from General Practitioners' Electronic Health Records and to allow secure data sharing between them. This paper introduces the Nu. Sa. framework and is mainly focused on security issues. A solution for secure data sharing and service interoperability is presented and implemented in the actual system used around Italy. The solution is strongly focused on privacy and correct data sharing with a complete set of tools devoted to authorization, encryption and decryption in a data sharing environment and a distributed architecture. The implemented system with more than one year of experiences in thousands of test cases shows a good feasibility of the approach and a future scalability in a cloud based architecture.

Frontoni, Emanuele; Baldi, Marco; Zingaretti, Primo

University Politecn Marche, Dipartimento Ingn Informaz, Ancona, Italy.

[Landro, Vincenzo; Misericordia, Paolo] Netmed Italia, FIMMG, Rome, Italy.

EM e.frontoni@univpm.it; m.baldi@univpm.it; p.zingaretti@univpm.it;
v.landro@netmedicaitalia.it; p.misericordia@netmedicaitalia.it

CR [Anonymous], 2001, FED INF PROC STAND P

ASTM international, 2010, E2211 ASTM

Back A., 2002, P 3 C SEC COMM NETW

Baldi M., 2014, P 2014 HIGH PERF COM

Implementation of chemotherapy treatment plans (CTP) in a large comprehensive cancer center (CCC): The key roles of infrastructure and data sharing

Sahama T., P 2013 IEEE 15 INT C, P249
Song DXD, 2000, P IEEE S SECUR PRIV, P44, DOI 10.1109/SECPRI.2000.848445
Tong Y, 2014, IEEE J BIOMED HEALTH, V18, P419, DOI 10.1109/JBHI.2013.2294932
Trappe W., 2005, INTRO CRYPTOLOGY COD
Trombetta A., 2006, P ICDE 06 ATL US APR
Zhang J, 2010, COMP APPL SYST MOD I, pV8
Zhu Jinzhi, 2010, SMARTER CLOUD COMPUT

AU Bryar, JM
Dalby, CK
Anastas, S
Brady, L
Hassett, MJ
Shulman, LN
Jacobson, JO

AF Bryar, Julie M.
Dalby, Carole Kathleen
Anastas, Susan
Brady, Lauren
Hassett, Michael J.
Shulman, Lawrence N.
Jacobson, Joseph O.

TI Implementation of chemotherapy treatment plans (CTP) in a large comprehensive cancer center (CCC): The key roles of infrastructure and data sharing

SO JOURNAL OF CLINICAL ONCOLOGY
LA English
DT Meeting Abstract
CT ASCO's Quality Care Symposium
CY NOV 01-02, 2013
CL San Diego, CA
SP ASCO
TI Integrative analysis of genomic and transcriptomic data reveals the presence of a novel molecular class of biomarkers shared by all cancer entities

SO EUROPEAN JOURNAL OF CANCER

LA English

DT Meeting Abstract
Semantic Prerequisites for Data Sharing in a Biomedical Research Network

Studies in Health Technology and Informatics
English
Proceedings Paper
14th World Congress on Medical and Health Informatics (MEDINFO)
AUG 20-23, 2013
We investigated for a research network on liver cancer semantic prerequisites for successful data sharing. To support collaboration with information technology, it is important to annotate research data with metadata. Ideally, all data handled are described ontologically to allow for automated reasoning. However, a complete ontology is hard to define. As a preliminary step we acquired a project wide common vocabulary by interviewing project partners. The vocabulary contains terms for describing the projects' processes and related data. Where the vocabulary intersects with Unified Medical Language System (UMLS) terms, the terms will be replaced by UMLS-terms. Cell line data are a subclass of the data handled in our research network. For these data we reviewed existing ontologies and developed a new ontology for cell lines. The Cell Culture Ontology (CCONT) reuses existing ontologies and enhances those with more specific cell line related properties to achieve a comprehensive description of cell lines. The results of our work can be transferred to other research networks with a similarly limited biomedical scope.
The Internet of things is widespread concerned by the whole society now. As an important component of the Internet of things, wireless sensor network has wide application prospect in various fields such as medical and health, military defense. The traditional data privacy protection technology of PKI system used in the WSN networks has its own weakness. This paper presents the secret key sharing mechanism to protect data privacy. The secret key, remote node and base station used to communicate, was divided into multiple secrets. The multiple secrets were distributed in the nodes which connect directly to the base station node. Only through collect more than threshold number of multi-secret that can decrypt the communication data between the base station and the remote node. To be safer, we used digital watermarking technology to protect the data transmission between the base station and the aggregate node. These techniques combined with the data slice, homomorphism encryption technology to protect data privacy, construct a safe and efficient wireless sensor networks.

C1 [Zhou, Jun; Yang, Zhenyu] Qilu Univ Technol, Sch Informat, Jinan, Peoples R China.
RP Zhou, J (reprint author), Qilu Univ Technol, Sch Informat, Jinan, Peoples R China.
EM zhoujun@spu.edu.cn; yzy@spu.edu.cn
[任丰原 Ren Fengyuan], 2003, [软件学报, Journal of Software], V14, P1282
Rosen E., 2001, RFC3031 IETF
Sun L., 2005, WIRELESS SENSOR NETW
Visualization of Privacy Filters for Sharing Sensor-based Health Data

This research explores interactive data visualization techniques for understanding how privacy filters in an electronic personal health record system govern the sharing of sensed health data. The research is intended to reveal insight into how well users can grasp the concepts of privacy and manipulate graphical entities to control how much and what aspects of their personal health records they are willing to share with family, friends, medical teams, and others.

Klein, Edward L.; Heines, Jesse M. Univ Massachusetts, Dept Comp Sci, Lowell, MA 01854 USA.
Klein, EL (reprint author), Univ Massachusetts, Dept Comp Sci, Lowell, MA 01854 USA.
edward_klein@student.uml.edu; heines@cs.uml.edu

[Fry, Craig L.] Univ Melbourne, Ctr Appl Philosophy & Publ Eth, Melbourne, Vic, Australia.

RP Coory, MD (reprint author), Murdoch Childrens Res Inst, Melbourne, Vic, Australia.

EM Michael.Coory@mccri.edu.au

OI Fry, Craig/0000-0001-7867-4388


COAG Reform Council, 2011, NAT HEALTHC AGR PERF


Heritage Provider Network, 2011, HLTH PRIZ COMP

Holman CDJ, 2008, MED J AUSTRALIA, V188, P435

National Collaborative Research Infrastructure Strategy, POP HLTH RES NETW

National Health and Medical Research Council, 2007, NAT STAT ETH COND HU

National Statistical Service, VIS STAT

O'Keefe CM, 2010, MED J AUSTRALIA, V193, P537


Pullman Daryl, 2009, Healthc Policy, V4, P61


The Centre for Health Record Linkage, 2009, CTR HLTH REC LINK 1


NR 16

TC 0

Z9 0

U1 0

U2 0

PU AUSTRALASIAN MED PUBL CO LTD

PI PYRMONT

PA LEVEL 2, 26-32 PYRMONT BRIDGE RD, PYRMONT, NSW 2009, AUSTRALIA

SN 0025-729X

J9 MED J AUSTRALIA


PD APR 16

FY 2012

VL 196

IS 7

BP 438

EP 439

DI 10.5694/mja11.11238

PG 2

WC Medicine, General & Internal

SC General & Internal Medicine

GA 930WO

UT WOS:000303175600006

PM 22509866

DA 2019-08-06

ER

PT B

AU Goldstein, AD

Hillman, RE

AF Goldstein, Anatoly D.

Hillman, Robert E.
AB This paper describes a set of software tools which facilitate the automated processing of clinical voice (laryngeal) evaluation results, thus assisting doctors in voice disorder diagnostics, treatment and related research. The software tools include a website and a number of client/server applications developed by the authors at the Massachusetts General Hospital (MGH) for patient voice data entry, storage, retrieval, reporting, reuse and sharing on the web in de-identified form. The website software is integrated with existing commercial clinical software to support multi-institutional research collaboration. Design of the client/server applications includes automatic reuse of standard MGH outpatient and surgical schedules. An additional application has been developed to facilitate the remote retrieval and review of recorded clinical endoscopic examinations based on the reuse of commercial viewer software and database. A new general model is suggested for web-based sharing and mining of research data processed by means of a specific desktop computer program.

CR [Anonymous], 1994, MASS EYE EAR INF VOI
[Anonymous], 2006, CLASS MAN VOIC DIS 1
Diaz J.M., 1993, ASHA, P183
Hillman R.E., 2011, OCC VOIC S 2011 ASS
Murphy SN, 2010, J AM MED INFORM ASSN, V17, P124, DOI 10.1136/jamia.2009.000893
Perry AR, 2000, J LARYNGOL OTOL, V114, P605
Sack J, 2008, SQL SERVER 2008 TRAN
Saenz-Lechon N, 2006, BIOMED SIGNAL PROCES, V1, P120, DOI 10.1016/j.bspc.2006.06.003
Szpuszta M., 2009, PRO ASP NET 3 5 C 20
Zeitels SM, 1998, ANN OTO RHINOL LARYN, V107, P2
Healthgrids, the SHARE Project, Medical Data and Agents: Retrospect and Prospect

SO PRINCIPLES AND PRACTICE OF MULTI-AGENT SYSTEMS
SE Lecture Notes in Artificial Intelligence
LA English
DT Proceedings Paper
CT 13th International Conference on Principles and Practice of Multi-Agent Systems
CY NOV 12-15, 2010
CL Kolkata, INDIA
SP Smart Serv CRC
DE Healthgrids; cloud computing; electronic patient records; data protection; medical knowledge; agents
AB The application of grid computing to biomedical research domains in the early years of the century has opened up promising prospects for the extension of this philosophy to translational medicine and hence to personalized healthcare. As the business side of the healthcare 'enterprise' also moves to take advantage of the related technology of cloud computing, the management of personal healthcare data on one hand, and of medical knowledge on the other, come to the fore as the principal challenges for successful adoption. We conclude by exploring the potential role of agents to address this and related challenges.
C1 [Solomonides, Tony] HealthGrid, F-63430 Pont Du Chateau, France.
RP Solomonides, T (reprint author), HealthGrid, 36 Rue Charles de Montesquieu, F-63430 Pont Du Chateau, France.
EM tony.solomonides@gmail.com
CR Del Frate C, 2006, STUD HEALTH TECHNOL, V120, P305
Rahmouni H.B., 2011, THESIS U W ENGLAND B
A publication process model to enable privacy-aware data sharing

As the Internet continues to permeate and connect communities, businesses, and things, there is an increasing demand for new approaches and technologies to analyze and synthesize data generated from diverse and distributed sources. In addition, this data must be accessible to a set of users having different analytic objectives and viewpoints. We examine these topics in light of the growing number of data consortia in sectors such as finance and healthcare, whose role is to share data among a set of contributing members. We address the need for data consortia to apply data customization and context-alignment services to make heterogeneous data relevant for its subscribers. Such services include record linkage, record selection, and scaling and homogeneity analysis. In addition, the often personal or business-sensitive nature of such data requires that privacy-preservation methods be employed to avoid improper disclosures. We provide a publication process model for data consortia that allow users to extract the maximum amount of information from these heterogeneous databases in a privacy-aware manner. We describe the Operational Riskdata eXchange (ORX) as a successful case study to illustrate these concepts.

RP Gkoulalas-Divanis, A (reprint author), IBM Corp, Div Res, Zurich Res Lab, Saumerstr 4, CH-8803 Ruschlikon, Switzerland.
EM agd@zurich.ibm.com; erc@zurich.ibm.com
Agrawal R, 2000, SIGMOD RECORD, V29, P439
[Anonymous], 2006, BASEL 2 INT CONV CAP


Hastie T., 2009, ELEMENTS STAT LEARNI

Hosking J.R.M., 1997, REGIONAL FREQUENCY A

HUNTSBERGER DV, 1955, ANN MATH STAT, V26, P734, DOI 10.1214/aoms/117728431
KIEFER J, 1959, ANN MATH STAT, V30, P420, DOI 10.1214/aoms/1177706261
Kifer D., 2006, P 2006 ACM SIGMOD IN, P217, DOI DOI 10.1145/1142473.1142499
Koenker R., 2005, QUANTILE REGRESSION


Lipsey MW, 2000, PRACTICAL METAANALYS

Machanavajjhala A., 2006, P 22 INT C DAT ENG I, P24, DOI DOI 10.1109/ICDE.2006.1

NEWCOMBE HB, 1959, SCIENCE, V130, P954, DOI 10.1126/science.130.3381.954
Ponemon Institute, 2009, ANN STUD GLOB COST D


Terrovitis M., 2008, P VLDB ENDOWMENT, V92, P115

UKKONEN E, 1992, THEOR COMPUT SCI, V92, P191, DOI 10.1016/0304-3975(92)90143-4

Verykios VS, 2000, INFORM SCIENCES, V126, P83, DOI 10.1016/S0020-0255(00)00013-X

NR 33
TC 0
Z9 0
U1 0
U2 7

PU IBM CORP
PI ARMONK
PA 1 NEW ORCHARD ROAD, ARMONK, NY 10504 USA
SN 0018-8646
J9 IBM J RES DEV
JI IBM J. Res. Dev.
PD SEP-OCT
PY 2011
VL 55
IS 5
AR 8
DI 10.1147/JRD.2011.2163279
PG 10

WC Computer Science, Hardware & Architecture; Computer Science, Information Systems; Computer Science, Software Engineering; Computer Science, Theory & Methods
SC Computer Science
GA 908PA
UT WOS:000301501100008
DA 2019-08-06
ER
Over the last years, the Internet has become the backbone of the information processing environments. The peer to peer concept is ideal for the development of a healthcare data sharing system because it respects the internal autonomy of each of the participating agencies (e.g., physicians, clinics, pharmacies, laboratories, etc). In this paper we introduce interoperability and data sharing settings considering a healthcare data management system where two parties or peers exchange and share data without any middleware data management system. We assume that databases in peers or data sources are created independently and may have semantic inter-dependencies with regards to data. Each peer specifies pairwise data sharing settings/mappings with acquainted peers for sharing and exchanging related data.

CR Arenas M., 2003, SIGMOD REC, V32, P53
Arenas M., 1999, P PODC
BERNSTEIN P., 2002, P WEBDB
Bertossi L., 2008, P 1 INT C DAT MAN GR
Kementsietsidis A., 2004, P VLDB
KEMENTSIETSIDIS A., 2003, P SIGMOD
Lenzerini M., 2002, P ACM SIGMOD SIGACT
Serafini L., 2003, LOCAL RELATIONAL MOD
The potential of data sharing radial proton echo planar spectroscopic imaging (rPEPSI) for TE-averaged glutamate mapping

First International Symposium on Bioengineering (ISOB 2011), Proceedings

AB Glutamate (Glu) is a major primary excitatory neurotransmitter of the central nervous system. Recently, a TE-averaged MRS is proposed to simplify the quantification of the Glu peak using successive shift echo time in scan parameter at the expense of prolonged scan time. Here we propose to map the 2D Glu distribution in the brain using radial Proton Echo Planar Spectroscopic Imaging (rPEPSI). The radial readout trajectory is superior in possible data...
sharing property which makes it more flexible in combination with TE-averaged technique.

C1 [Tsai, Shang-Yueh; Ho, Hsiang-Wei] Chang Gung Univ, Tao Yuan 333, Taiwan.
RP Tsai, SY (reprint author), Chang Gung Univ, 259 Wen Hwa 1st Rd, Tao Yuan 333, Taiwan.

Dager SR, 2004, ARCH GEN PSYCHIAT, V61, P450, DOI 10.1001/archpsyc.61.5.450
Dale B, 2001, IEEE T MED IMAGING, V20, P207, DOI 10.1109/42.918471

Tsai SY, 2008, MAGN RESON MED, V59, P989, DOI 10.1002/mrm.21545
The survey bringing biometric data in the Survey of Health Ageing and Retirement in Europe (SHARE)
The development of tools and technologies to facilitate appropriate and effective data sharing is becoming increasingly important in many academic disciplines. In particular, the 'data explosion' problem associated with the Life Sciences has been recognised by many researchers and commented upon widely, as have the associated data management problems. In this paper we describe how a middleware framework that supports the secure sharing and aggregation of data from heterogeneous data sources developed initially to underpin the sharing of healthcare-related data is being used to support Systems Biology research at the University of Oxford. As well as giving an overview of the framework and its application, we attempt to set our work within the wider context of the emerging challenges associated with data sharing within the Life Sciences.

C1 [Simpson, Andrew; Slaymaker, Mark; Gavaghan, David] Univ Oxford, Comp Lab, Oxford OX1 3QD, England.


OI gavaghan, david/0000-0001-8311-3200

Bowers S, 2004, LECT N BIOINFORMAT, V2994, P1
Coulet A, 2006, LECT NOTES COMPUT SC, V4075, P82
Halevy A. Y., 2003, P 12 INT WORLD WID W, P556
Ives Z.G., 2005, 2 BIENN C INN DAT SY, P107
Ives ZG, 2009, LECT NOTES COMPUT SC, V5647, P1, DOI 10.1007/978-3-642-02879-3_1
Kim JH, 2007, LECT N BIOINFORMAT, V4544, P3
Kirsten T, 2006, LECT NOTES COMPUT SC, V4075, P124
LENZERINI M, 2002, DATA INTEGRATION THE, P233
Leser U., 2005, 2 BIENN C INN DAT SY, P131
Ng WS, 2003, PROC INT CONF DATA, P633, DOI 10.1109/ICDE.2003.1260827
Paton NW, 2008, LECT N BIOINFORMAT, V5109, P8, DOI 10.1007/978-3-540-69828-9_3
Pettifer S, 2007, LECT N BIOINFORMAT, V4544, P59
Russell D, 2009, PROCEEDINGS OF THE 2009 SIXTH INTERNATIONAL CONFERENCE ON INFORMATION TECHNOLOGY: NEW GENERATIONS, VOLS 1-3, P1676, DOI 10.1109/ITNG.2009.21
The problem addressed in this paper is how to ensure data privacy concerns when data is shared between multiple organisations. In domains such as healthcare, there is a need to share privacy-sensitive data among autonomous but cooperating organisations. However, security concerns and compliance to privacy regulations requiring confidentiality of the data renders unrestricted access to organisational data by others undesirable. The challenge is how to guarantee privacy preservations for the owners of the information that are willing to share information with other organisations while keeping some other information secret. Therefore, there is a need for privacy preserving database operations for querying data residing at different parties. To address this challenge, we propose a new computationally efficient framework that enables organisations to share privacy-sensitive data. The proposed framework is able to answer queries without revealing any useful information to the data sources or to the third parties.

CI [Al-Neyadi, Fahed; Abawajy, Jemal] Deakin Univ, Sch Informat Technol, Geelong, Vic 3217, Australia.
RP Al-Neyadi, F (reprint author), Deakin Univ, Sch Informat Technol, Geelong, Vic 3217, Australia.
EM fmal@deakin.edu.au; jemal@deakin.edu.au
RI Abawajy, Jemal/A-1802-2008
CR AGGARWAL G, 2005, CIDR, P186
Agrawal R., 2000, P SIGMOD
ALNAYADI F, 2007, INT C MULT UB ENG MU, P299
Chen B.-C., 2009, FDM TRENDS DATABASES, V2, P1, DOI DOI 10.1561/1900000008
Dwork C, 2004, LECT NOTES COMPUT SC, V3152, P528
EMEKCI F., 2006, P 22 INT C DAT ENG I
HACIGUMUS H, 2002, SIGMOD C
HORE B, 2004, VLDB, P720
HU N, 2009, 2009 6 INT C FUZZ SY, V1, P590
LEFEVRE K, 2004, VLDB, P108
Machanavajjhala A, 2006, ICDE, DOI DOI 10.1109/ICDE.2006.1
Mitra P., 2006, P ACM C COMP COMM SE, P66
Siegenthaler M, 2009, 2009 8TH IEEE INTERNATIONAL SYMPOSIUM ON NETWORK COMPUTING AND APPLICATIONS, P82, DOI 10.1109/NCA.2009.33

NR 18
TC 0
Z9 0
U1 0
U2 0
FU SPRINGER-VERLAG BERLIN
PI BERLIN
PA HEIDELBERGER PLATZ 3, D-14197 BERLIN, GERMANY
SN 0302-9743
BN 978-3-642-17568-8
J9 LECT NOTES COMPUT SC
PY 2010
A Knowledge-Management Architecture to Integrate and to Share Medical and Clinical Data, Information, and Knowledge

AB Data, information, and knowledge in medicine is varied, changing, interrelated, and for diverse purposes. Medical and Clinical care depends on the correct and efficient combined application of these elements to concrete health care situations as prophylactics, screening, diagnosis, therapy, and prognosis. In this paper, we propose a Knowledge Management Architecture (KMA) to allow the integration of medical and clinical data, information and knowledge in a consistent and incremental way. The components of KMA are described and the already implemented parts are provided with references to papers where they are explained in more detail. For the first time, we present the conceptual integration of the isolated works performed in the research group of artificial intelligence of the Rovira i Virgili University and in collaboration with the Clinical Hospital of Barcelona, and the SAGESSA health care organization.

C1 Univ Rovira & Virgili, Res Grp Artificial Intelligence Banzai, Tarragona 43007, Spain.

RI Riano, D (reprint author), Univ Rovira & Virgili, Res Grp Artificial Intelligence Banzai, Av Paisos Catalans 26, Tarragona 43007, Spain.

EM david.riano@urv.net; david.riano@urv.net

CR Abidi SR, 2009, LECT NOTES ARTIF INT, V5651, P81, DOI 10.1007/978-3-642-02976-9_10

BUIST A, 2007, GLOBAL INITIATIVE CH


Donaldson M, 1994, DEFINING PRIMARY CAR

Field MJ, 1990, CLIN PRACTICE GUIDEL

Isern D, 2009, LECT NOTES COMPUT SC, V5626, P134, DOI 10.1007/978-3-642-03262-2_11

A Privacy Preserved Model for Medical Data Sharing in Telemedicine
In the converged Information and Communication Technology (ICT) era, medical data sharing has emerged as an important element in the healthcare industry. Hospitals within a Telemedicine system would like to share their private local databases with other hospitals. However, they do not agree to keep a copy of their database into a central server. The central repository (data warehouse) model is not secure because too much control will be granted to the central site. In order to fully utilize the distributed and heterogeneous resources, a secure and privacy preserved model should be used to reach the balance between knowledge discovery and data privacy protection at the same time. We proposed a privacy preserved model to securely share the data for Telemedicine system.


SP Wong, W.K. (reprint author), Soongsil Univ, Dept Comp, 156-743 Sangdo Dong, Seoul, South Korea.

EM kswnong@ssu.ac.kr; kmh@ssu.ac.kr; rosli@mmu.edu.my; fazly.salleh.abas@mmu.edu.my

RI Wong, W.K. /Besar, Rosli /E-3541-2010

OI Wong, W.K. /Rosli-0000-0002-2029-7644

FU Soongsil University Research Fund

FX This work was supported by the Soongsil University Research Fund.

CR AERAWAL R, 2003, 22 ACM SIGMOD INT C, P86

Agrawal R, 2006, LECT NOTES COMPUT SC, V3896, P240

Ajmani S, 2001, MITLCSTR847 MIT

Brickell J, 2005, LECT NOTES COMPUT SC, V3788, P236

Cilfton C, 2004, 9 ACM SIGMOD WORKSH, P19


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

Freedman MJ, 2004, LECT NOTES COMPUT SC, V3027, P1

Goldreich O., 2004, FDN CRYPTOGRAPHY, P2


Jefferies N, 1996, LECT NOTES COMPUT SC, V1029, P98


Kissner L, 2005, LECT NOTES COMPUT SC, V3621, P241

Naor M, 1999, 31 STOC, P245

Stefan B, 2008, J SOFTWARE, V3, P9

Wiederhold G, 1993, ACM SIGMOD C MAN DAT, P434

Yao A. C., 1986, 27th Annual Symposium on Foundations of Computer Science (Cat. No.86CH2354-9), P162, DOI 10.1109/SFCS.1986.25

NR 18

TC 0

Z9 0

U1 0

U2 0
An Attempt to Forecast Hospital Market Share Using Admission Data

The purpose of this study was to develop a model to forecast market share before actual market share data become available to a hospital system. The typical data lag is about six to nine months, and market share information is often based on incomplete admissions data. Therefore, this exploratory analysis of admissions for all hospitals in a Texas hospital system was performed as an attempt to improve the accuracy and timeliness of market share data.

We used four data sources: (1) Texas Health Care Information Council Public Use Data File, (2) Solucient, (3) internal data on admissions for three small nearby hospitals not reporting to the state, and (4) population growth data based on the U.S. census. Data analysis was performed using STATA 9 and SAS statistical software. Six prediction models were chosen and evaluated that best predicted present and future market share using historical market share data, historical and current admissions data, and population growth data. These included models for the total market area; the core cluster; and the eastern, western, northern, and southern market clusters.

Only two of the six forecasting equations were useful, with a relatively high prediction value. Overall, the attempt to predict market share based on historical and current admissions data while controlling for demographic factors and seasonality was of limited success. Future research should consider additional factors associated with market share; these factors could include changes in physician referral patterns and third-party-payer contracts. The value of this type of research for management is explored here as well.

Cl [Kash, Bita A.; Ohsfeldt, Robert L.; Gamm, Larry D.] Texas A&M Univ, Hlth Sci Ctr, Sch Rural Publ Hlth, Dept Hlth Policy & Management, College Stn, TX 77843 USA.
In today's collaborative environments such as bioinformatics and healthcare, the 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 Web Service Management System (WSMS) that is used to exchange data through Data-Providing Web Services. In our system we employ a novel approach 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. Our WSMS is very useful in domains such as bioinformatics and healthcare where web services are used extensively to exchange data.

[Barhamgi, Mahmoud; Benslimane, Djamal] Univ Lyon 1, LIRIS Lab, F-69622 Villeurbanne, France.

[Ouksel, Aris M.] Univ Illinois, Dept Comp Sci, Chicago, IL 60680 USA.

Barhamgi, M (reprint author), Univ Lyon 1, LIRIS Lab, F-69622 Villeurbanne, France.

barhamgi@gmail.com; djamal.benslimane@liris.cnrs.fr; aris@uic.edu

Halevy AY, 2000, SIGMOD RECORD, V29, P40

Maamar Z, 2005, IEEE INTERNET COMPUT, V9, P79, DOI 10.1109/MIC.2005.91
Martin D., 2004, BRINGING SEMANTICS W


RIZVI S, 2004, SIGMOD C, P551

WU D, 2003, INT SEM WEB C, P195

Yerneni R, 1999, SIGMOD RECORD, VOL 28, NO 2 - JUNE 1999, P443
It is very significant for the medical and health enterprises to develop an efficient medical information grid to achieve sufficient medical data share and integration. In order to access heterogeneous data resources transparently, a front agent is built on heterogeneous databases or medical systems, the same as the unified data models and mapping rules with grid services to communicate with upper grid middleware, so that users can query or access medical data conveniently. Two medical application instances, medical information integration and content-based image diagnosis or retrieval of emphysema disease, are introduced and realized with these technologies.

C1 [Zheng, Ran; Jin, Hai; Zhang, Qin; Liu, Yingshu; Chu, Pan] Huazhong Univ Sci & Technol, Sch Comp Sci & Technol, Cluster & Grid Comp Lab, Serv Comp Technol & Syst Lab, Wuhan 430074, Peoples R China.

RP Zheng, R (reprint author), Huazhong Univ Sci & Technol, Sch Comp Sci & Technol, Cluster & Grid Comp Lab, Serv Comp Technol & Syst Lab, Wuhan 430074, Peoples R China.

EM hjin@hust.edu.cn


Formbuilder: A tool for promoting data sharing and reuse within the cancer community.
To offer the best possible care for their patients, family physicians need coordinated data obtained from the physician's own patient database, from other physicians' databases, pharmacies, and drug reference databases. P2P-based sharing systems have been actively researched to enable resource sharing between multiple heterogeneous healthcare enterprises. Unfortunately, P2P system introduces a whole new class of privacy and security threats and in order to enable resource sharing between multiple heterogeneous healthcare enterprises, a policy management framework is required. To solve these problems in a loose-coupling way, we propose a dynamic, distributed, and heterogeneous policy management framework for sharing medical information among autonomous and disparate healthcare information systems.
Comparisons of case-selection approaches based on allele sharing and/or disease severity index: application to the GAW14 simulated data

For mapping complex disease traits, linkage studies are often followed by a case-control association strategy in order to identify disease-associated genes/single-nucleotide polymorphisms (SNPs). Substantial efforts are required in selecting the most informative cases from a large collection of affected individuals in order to maximize the power of the study, while taking into consideration study cost. In this article, we applied and extended three case-selection strategies that use allele-sharing information method for families with multiple affected offspring to select most informative cases using additional information on disease severity. Our results revealed that most significant associations, as measured by the lowest p-values, were obtained from a strategy that selected a case with the most allele sharing with other affected sibs from linked families ("linked-best"), despite reduction in sample size resulting from discarding unlinked families. Moreover, information on disease severity appears to be useful to improve the ability to detect associations between markers and disease loci.

Boston Univ, Sch Publ Hlth, Dept Neurol, Boston, MA 02215 USA.
Boston Univ, Sch Publ Hlth, Dept Biostat, Boston, MA USA.

Dupuis, Josee/0000-0003-2871-3603; Cupples, L. Adrienne/0000-0003-0273-7965

Abecasis GR, 2002, NAT GENET, V30, P97, DOI 10.1038/ng786
Fingerlin TE, 2004, AM J HUM GENET, V74, P432, DOI 10.1086/381652
GOLDSTEIN AM, 1987, JNCI-J NATL CANCER I, V71, P455
Kong A, 1997, AM J HUM GENET, V61, P1179, DOI 10.1086/301592
The Integrated Health Log demonstrator shows how multimedia can be used in collaborative settings in healthcare. Patient data can be shared, annotated, discussed, and processed by medics involved with a patient. Special emphasis is put on protecting the privacy of patients and allowing medics to keep responsibility for their patient data. In particular, grid technology is used to decouple services and service providers so that services can be executed under the control of the data owner. The system will be piloted in a gait analysis...
laboratory and in a network of physiotherapists involved in treating children with movement disorders.

C1 Telemat Inst, NL-7500 AN Enschede, Netherlands.
RP Brussee, R (reprint author), Telemat Inst, POB 589, NL-7500 AN Enschede, Netherlands.
EM Rogier.Brussee@telin.nl; Paul.Porskamp@telin.nl;
Leon.vandenOord@nl.ibm.com; Erik@nl.ibm.com; H.Bloo@rrd.nl;
V.Erren@rrd.nl; L.Schaake@rrd.nl

DAYHOFF RE, 2003, P AMIA ANN S, P1063
Foster I., 2001, INT J SUPERCOMPUTER, V15
GEORGIADIS CK, 2001, SACMAT 2001
Lowe HJ, 1999, ACAD MED, V74, P146, DOI 10.1097/00001888-199902000-00014
NICTIZ, 2004, ARCHITECTUURONTWERP
199707150-00008
SHIRY C, CONNECTING HEALTH
Wang SS, 2000, J AM MED INFORM ASSN, P898

NIH data and resource sharing, data release and intellectual property policies for genomics community resource projects

SO EXPERT OPINION ON THERAPEUTIC PATENTS

LA English

DE community resource project; database; data release; data sharing; genomics; HapMap; human genome project (HGP); intellectual property (IP); Human Genome Sequencing Consortium (IHGSC); International Sequencing Consortium (ISC); licensing; Mammalian Gene Collection (MGC); National Human Genome Research Institute (NHGRI); open access; patent; policy; research tool; Trans-NIH Mouse Initiative; The SNP Consortium (TSC); US National Institutes of Health (NIH)
The rationale behind the development and adoption of various data release, data and research resource sharing, and patent policies for 'pre-competitive' biological information and critical reagents, notably DNA sequence information, genomic data and research tools generated by National Institutes of Health (NIH) partners and deposited in open access databases and repositories, is described. Specifically covered are the relevant policies implemented by NIH-supported public-private consortia efforts such the International Human Genome Sequencing Consortium (IHGSC), the Trans-NIH Mouse Initiative, the Mammalian Gene Collection (MGC) and the International Haplotype Map Project (HapMap). All of these research initiatives are considered to be community resource projects. In addition, a few key genomics research-related intellectual property (IP) concerns are discussed in conjunction with some proposed possible policy and legal remedies. The hope is that the knowledge gained from the use of the biological resources and the analysis of data generated from these large-scale genomics; projects will be a catalyst for future innovative research including the commercial development of new medicines.

C1 NHGRI, Technol Transfer Off, NIH, US Dept HHS, Bethesda, MD 20892 USA.
RP Driscoll, CT (reprint author), NHGRI, Technol Transfer Off, NIH, US Dept HHS, 12 South Dr MSC 5612, Bethesda, MD 20892 USA.
CR ABATE T, 2002, PATENTS WRAP RES RED
Bentley DR, 1996, SCIENCE, V274, P533, DOI 10.1126/science.274.5287.533
Collins FS, 2003, NATURE, V422, P835, DOI 10.1038/nature01626
Dennis C, 2003, NATURE, V423, P105, DOI 10.1038/423105a
*DNA, 2002, NUFF COUNC BIOETH
Eisenberg RS, 2003, SCIENCE, V299, P1018, DOI 10.1126/science.1081790
Gibbs RA, 2003, NATURE, V426, P789, DOI 10.1038/nature02168
*NHGRI, POL REL HUM GEN SEQ
NHGRI, 2003, INT CONS COMP HUM GE
*NIIH, 1998, ADV COMM DIR 0604
*SHAR DAT LARG SCA, 2003, WELLC TRUST REP FORT
*UBMTA, UN BIOL MAT TRANSF A
*US PHS, US PUBL HLTH SERV TE, pCH200
2004, FED REG, V69, P67747
1996, SUMM PRINC AGR INT S
1996, EU DATABASE DIRECTIV
NR 20
TC 0
Z9 0
U1 0
U2 5
PU TAYLOR & FRANCIS LTD
PI ABINGDON
PA 2-4 PARK SQUARE, MILTON PARK, ABINGDON OR14 4RN, OXON, ENGLAND
SN 1354-3776
EL 1744-7674
J9 EXPERT OPIN THER PAT
JI Expert Opin. Ther. Patents
PD JAN
PY 2005
VL 15
IS 1
BP 1
Data needed for research and policy in ageing societies - Contribution of the survey of health, ageing and retirement in Europe (SHARE project)

DISEASE-BASED COMPARISON OF HEALTH SYSTEMS: WHAT IS BEST AND AT WHAT COST?

Population ageing raises many issues of public policy at the cross roads of economics, sociology, psychology and medicine. While the OECD Ageing-Related Diseases project pointed to variations between countries in treatments and outcomes for common diseases, most European countries lack the necessary data to understand the reasons and the impact of such variations. The Survey of Health, Ageing and Retirement in Europe (SHARE) is designed to produce comparative, longitudinal, multidisciplinary data collected at an individual level and will further our understanding of the issues raised by population ageing.

C1 Univ Lausanne, Inst Social & Prevent Med, Lausanne, Switzerland.

Anderson GF, 1999, HEALTH AFFAIR, V18, P178, DOI 10.1377/hlthaff.18.3.178
Browning M, 1996, J ECON LIT, V34, P1797
Cavelaars AEJM, 1998, J EPIDEMIOL COMMUN H, V52, P219, DOI 10.1136/jech.52.4.219

DISNEY R, 1997, CAN WE AFFORD GROW O
Dwyer DS, 1999, J HEALTH ECON, V18, P173, DOI 10.1016/S0167-6296(98)00034-4
Evans JG, 2000, J INTERN MED, V247, P159
GRUBER J, 2001, NBER WORKING PAPER W, V8103
*I MED, 2001, CROSS QUAL CHASM
Lloyd-Sherlock P, 2000, SOC SCI MED, V51, P887, DOI 10.1016/S0277-9536(00)00068-X
Norton EC, 2000, HANDB ECON, V17, P955
Rice DP, 1992, World Health Stat Q, V45, P61
SCHOEN CE, 2000, ELDERLYS EXPERIENCES

NR 25
TC 0
Z9 0
U1 0
U2 0
PU ORGANIZATION ECONOMIC COOPERATION & DEVELOPMENT
PI PARIS
PA 2, RUE ANDRE PASCAL, CEDEX 16, 75775 PARIS, FRANCE
BN 92-64-09981-6
PY 2003
BP 181
EP 191
PG 11
WC Health Care Sciences & Services; Health Policy & Services
SC Health Care Sciences & Services
GA BX11X
UT WOS:000184328200011
DA 2019-08-06
ER
PT S
AU Le Duff, F
  Happe, A
  Burgun, A
  Levionnois, S
  Bremond, M
  Le Beux, P
AF Le Duff, F
  Happe, A
  Burgun, A
  Levionnois, S
  Bremond, M
  Le Beux, P
BE Patel, VL
  Rogers, R
  Haux, R
TI Sharing medical data for patient path analysis with data mining method
SO MEDINFO 2001: PROCEEDINGS OF THE 10TH WORLD CONGRESS ON MEDICAL
  INFORMATICS, PTS 1 AND 2
SE Studies in Health Technology and Informatics
LA English
DT Proceedings Paper
CT 10th World Congress on Medical Informatics (MEDINFO 2001)
CY 2001
CL LONDON, ENGLAND
SP McGill Univ, Ctr Med Educ, Columbia Univ, Dept Med Informat
DE Intranet; health care process; low back pain; confidentiality; health
  information system
ID PRIMARY-CARE
The Agora Data project started in October 1997 in France. The objective was to share medical data between several medical institutions to analysis medical care pathways for patients that suffer from low back pain. The analysis of the medical records decomposed in three steps allowed us to produce knowledge on medical contacts of patients with the health care system. In order to study the relations between these contacts, we created medical path of patients within the framework of the possible contacts we had isolated. This work relates the implementation and the first results of the pilot study.

C1 Fac Med, Lab Informat Med, F-35043 Rennes, France.
EM Franck.LeDuff@univ-rennes1.fr
OI Burgun, Anita/0000-0001-6855-4366
CR Clark D E, 1995, Proc Annu Symp Comput Appl Med Care, P397
Fetter RB, 1980, MED CARE S, V18, P1
Kendrick SW, 1998, METHOD INFORM MED, V37, P64
Nigrin DJ, 1998, J AM MED INFORM ASSN, P957
Walker C, 1998, PC WEEK, V15, P28
WONG ML, 1999, P IEEE SYST MAN CYB, V5, P936
World Health Organization, 1993, INT STAT CLASS DIS R
Experimental evidence and clinical experience suggest that non-immunologic factors are important predictors of long-term renal allograft survival. It has been suggested that chronic allograft failure may in some cases be mediated by non-immunologic factors implicated in the pathobiology of other forms of progressive renal disease. Donor age, sex, and race may influence the 'dose' of nephrons delivered in cadaveric renal transplantation. The United Network of Organ Sharing 1994 Public Use Data Tape was used to evaluate these and other risk factors in more than 31,000 recipients of cadaver allografts followed between 1987 and 1992. Female sex and African American race of the donor were important predictors of allograft failure. There was a markedly increased risk of allograft failure at both extremes of donor age. Recipients of large body size had accelerated graft loss. Stratified analyses suggested an interaction between donor and recipient race; nevertheless, all non-immunologic factors examined expressed independent associations with allograft survival. In sum, antigen-independent factors appear to be important determinants of allograft performance. Additional multivariable analyses are required to assess the relative importance of these factors compared with other known immunologic factors, such as HLA antigen mismatch. These findings may have important biomedical and health care policy implications.
Interinstitutional evaluations of molecular markers for the diagnosis and staging of cancer are highly dependent on strict standardization of assays to make clinical comparisons valid. New assays for cancer markers depend on discoveries of biochemical or cellular functions coupled with technologies suitable for making relevant measurements. Transfer of these technologies from the research laboratory to the diagnostic laboratory requires method validation that consists of specific information regarding assay principle, reagents, calibration, sensitivity, assay behavior, specimen requirements, clinical and method correlations, reference range, quality control, proficiency testing, critical steps, and guidelines for interpretation. Fulfillment of all the components of method validation will guarantee the fastest and most accurate implementation of new diagnostic assays in clinical studies and practice.

RP MCPHERSON, RA (reprint author), SCRIPPS CLIN & RES FDN, SCRIPPS IMMUNOL REFERENCE LAB, 11107 ROSELLE ST, SAN DIEGO, CA 92121, USA.

ARNOLD A, 1983, NEW ENGL J MED, V309, P1594
COSSMAN J, 1988, ARCH PATHOL LAB MED, V112, P117
NUOVO GJ, 1988, LAB INVEST, V59, P720