

Contents IMIA Yearbook of Medical Informatics 2018

President's Statement	C. U. Lehmann President's Statement	1
Obituary	C. A. Kulikowski, R. Haux, N. M. Lorenzi, O. Rienhoff In Memoriam: Diarmuid Ua Conaill	3
Editorial	J. H. Holmes, L. F. Soualmia, B. Séroussi A 21st Century Embarrassment of Riches: The Balance Between Health Data Access, Usage, and Sharing	5
IAHSI Paper	R. Haux Visions for IAHSI, the International Academy of Health Sciences Informatics	7
Keynote	C. Petersen Through Patients' Eyes: Regulation, Technology, Privacy, and the Future	10

**Special Section:
Between Access and Privacy:
Challenges in Sharing Health Data**

Survey	P. Shankar, N. Anderson Advances in Sharing Multi-sourced Health Data on Decision Support Science 2016-2017	16
Working Group Contributions	A. Georgiou, F. Magrabi, H. Hyppönen, Z. Shui-Yee Wong, P. Nykänen, P. J. Scott, E. Ammenwerth, M. Rigby The Safe and Effective Use of Shared Data Underpinned by Stakeholder Engagement and Evaluation Practice	25
	M. Househ, R. Grainger, C. Petersen, P. Bamidis, M. Merolli Balancing Between Privacy and Patient Needs for Health Information in the Age of Participatory Health and Social Media: A Scoping Review	29
	E.-H. Kluge, P. Lacroix, P. Ruotsalainen Ethics Certification of Health Information Professionals	37
	S. Kobayashi, T. B. Kane, C. Paton The Privacy and Security Implications of Open Data in Healthcare	41
	C. E. Kuziemsky, S. B. Gogia, M. Househ, C. Petersen, A. Basu Balancing Health Information Exchange and Privacy Governance from a Patient-Centred Connected Health and Telehealth Perspective	48
Synopsis	B. Malin, K. Goodman Between Access and Privacy: Challenges in Sharing Health Data	55
Best Paper Selection	Content summaries of: Gilbert M, Bonnell A, Farrell J, Haag D, Bondyra M, Unger D, Elliot E. Click yes to consent: incorporating informed consent into an internet-based testing program for sexually transmitted and blood-borne infections. <i>Int J Med Inform</i> 2017;105:38-48 Humbert M, Ayday E, Hubaux JP, Telenti A. Quantifying interdependent risks in genomic privacy. <i>ACM Transactions on Privacy and Security</i> 2017;20(1):3 Ohno-Machado L, Sansone SA, Alter G, Fore I, Grethe J, Xu H, Gonzalez-Beltran A, Rocca-Serra P, Guraraj AE, Bell E, Soysal E, Zong N, Kim HE. Finding useful data across multiple biomedical data repositories using DataMed. <i>Nat Genet</i> 2017;49(6):816-9	59

Wan Z, Vorobeychik Y, Xia W, Clayton EW, Kantarcioglu M, Malin B. Expanding Access to large-scale genomic data while promoting privacy: a game theoretic approach. <i>Am J Hum Genet</i> 2017;100(2):316-22	59
Yuan J, Malin B, Modave F, Guo Y, Hogan WR, Shenkman E, Bian J. Towards a privacy preserving cohort discovery framework for clinical research networks. <i>J Biomed Inform</i> 2017;66:42-51	59

Section 1: Health Information Management

Survey	L. L. Kloss, M. S. Brodnik, L. A. Rinehart-Thompson	60
	Access and Disclosure of Personal Health Information: A Challenging Privacy Landscape in 2016-2018	60
Synopsis	M. Bloomrosen, E. S. Berner	67
	Findings from the 2017 on Health Information Management	67
Best Paper Selection	Content summaries of:	
	Roehrs A, da Costa CA, da Rosa Righi R. OmniPHR: A distributed architecture model to integrate personal health records. <i>J Biomed Inform</i> 2017 Jul;71:70-81	71
	Klein DM, Pham K, Samy L, Bluth A, Nazi KM, Witry M, Klutts JS, Grant KM, Gundlapalli AV, Kochersberger G, Pfeiffer L, Romero S, Vetter B, Turvey CL. The Veteran-Initiated Electronic Care Coordination: A Multisite Initiative to Promote and Evaluate Consumer-Mediated Health Information Exchange. <i>Telemed J E Health</i> 2017 Apr;23(4):264-27	71
	Bockvar KS, Ho W, Pruskowski J, DiPalo KE, Wong JJ, Patel J, Nebeker JR, Kaushal R, Hung W. Effect of health information exchange on recognition of medication discrepancies is interrupted when data charges are introduced: results of a cluster-randomized controlled trial. <i>J Am Med Inform Assoc</i> 2017 Nov 1;24(6):1095-101	72
	Downing NL, Adler-Milstein J, Palma JP, Lane S, Eisenberg M, Sharp C; Northern California HIE Collaborative, Longhurst CA. Health information exchange policies of 11 diverse health systems and the associated impact on volume of exchange. <i>J Am Med Inform Assoc</i> 2017 Jan;24(1):113-22	72

Section 2: Human Factors and Organizational Issues

Survey	K. A. Siek	74
	Expanding Human Computer Interaction Methods to Understand User Needs in the Design Process of Personal Health Systems	74
Synopsis	S. Pelayo, J. Kaipio	79
	Findings from the 2018 Yearbook Section on Human Factors and Organizational Issues	79
Best Paper Selection	Content summaries of:	
	Ancker JS, Edwards A, Nosal S, Hauser D, Mauer E, Kaushal R, with the HITEC Investigators. Effects of workload, work complexity, and repeated alerts on alert fatigue in a clinical decision support system. <i>BMC Med Inform Decis Mak</i> 2017 Apr 10;17(1):36	82
	Blijlevens V, Koelemeijer K, Wetzels M, Jaspers M. Workarounds emerging from electronic health record system usage: consequences for patient safety, effectiveness of care, and efficiency of care. <i>JMIR Hum Factors</i> 2017 Oct 5;4(4):e27	82
	Cresswell KM, Mozaffar H, Lee L, Williams R, Sheikh A. Safety risks associated with the lack of integration and interfacing of hospital health information technologies: a qualitative study of hospital electronic prescribing systems in England. <i>BMJ Qual Saf</i> 2017 Jul;26(7):530-41	82
	Dufendach KR, Koch S, Unertl KM, Lehmann CU. A randomized trial comparing classical participatory design to VandAID, an interactive crowdsourcing platform to facilitate user-centered design. <i>Methods Inf Med</i> 2017 Oct 26;56(5):344-9	82
	Luna DR, Rizzato Lede DA, Otero CM, Risk MR, González Bernaldo de Quirós F. User-centered design improves the usability of drug-drug interaction alerts: experimental comparison of interfaces. <i>J Biomed Inform</i> 2017 Feb;66:204-13.	82

Section 3: Clinical Information Systems

Survey	M. M. Islam, T. Nasrin Poly, Y.-C. Li Recent Advancement of Clinical Information Systems: Opportunities and Challenges	83
Synopsis	W. O. Hackl, A. Hoerbst On the Way to Close the Loop in Information Logistics: Data from the Patient – Value for the Patient	91
Best Paper Selection	Content summaries of: Andersen B, Kasparick M, Ulrich H, Franke S, Schlamelcher J, Rockstroh M, Ingenerf J. Connecting the clinical IT infrastructure to a service-oriented architecture of medical devices. <i>Biomed Tech</i> 2018;63(1):57–68. Nguyen P, Tran T, Wickramasinghe N, Venkatesh S. Deepr: A Convolutional Net for Medical Records. <i>IEEE J Biomed Health Inform</i> 2017;21(1):22–30 Olchanski N, Dziadzko MA, Tiong IC, Daniels CE, Peters SG, O'Horo JC, Gong MN. Can a Novel ICU Data Display Positively Affect Patient Outcomes and Save Lives? <i>J Med Syst</i> 2017;41:171. Plastiras P, O'Sullivan DM. Combining Ontologies and Open Standards to Derive a Middle Layer Information Model for Interoperability of Personal and Electronic Health Records. <i>J Med Syst</i> 2017;41:195	96

Section 4: Sensor, Signal and Imaging Informatics

Survey	N. Ganapathy, R. Swaminathan, T. M. Deserno Deep Learning on 1-D Biosignals: a Taxonomy-based Survey	98
Synopsis	W. Hsu, T. M. Deserno, C. E. Kahn Jr. Sensor, Signal, and Imaging Informatics in 2017	110
Best Paper Selection	Content summaries of: Bote JM, Recas J, Rincon F, Atienza D, Hermida R. A modular low-complexity ECG delineation algorithm for real-time embedded systems. <i>IEEE J Biomed Health Inform</i> 2018;22(2):429–41 Grossmann P, Stringfield O, El-Hachem N, Bui MM, Rios Velazquez E, Parmar C, Leijenaar RT, Haibe-Kains B, Lambin P, Gillies RJ, Aerts HJ. Defining the biological basis of radiomic phenotypes in lung cancer. <i>ELife</i> 2017;6 Larson DB, Chen MC, Lungren MP, Halabi SS, Stence NV, Langlotz CP. Performance of a deep-learning neural network model in assessing skeletal maturity on pediatric hand radiographs. <i>Radiology</i> 2018;287(1):313–22 Satija U, Ramkumar B, Manikandan MS. Automated ECG noise detection and classification system for unsupervised healthcare monitoring. <i>IEEE J Biomed Health Inform</i> 2018;22(3):722–32	113

Section 5: Decision Support

Survey	I. Cho, D. W. Bates Behavioral Economics Interventions in Clinical Decision Support Systems	114
Synopsis	V. Koutkias, J. Bouaud Contributions from the 2017 Literature on Clinical Decision Support	122
Best Paper Selection	Content summaries of: Chen JH, Alagappan M, Goldstein MK, Asch SM, Altman RB. Decaying relevance of clinical data towards future decisions in data-driven inpatient clinical order sets. <i>Int J Med Inform</i> 2017 Jun;102:71-9 Ebadi A, Tighe PJ, Zhang L, Rashidi P. DisTeam: A decision support tool for surgical team selection. <i>Artif Intell Med</i> 2017 Feb;76:16-26 Fung KW, Kapusnik-Uner J, Cunningham J, Higby-Baker S, Bodenreider O. Comparison of three commercial knowledge bases for detection of drug-drug interactions in clinical decision support. <i>J Am Med Inform Assoc</i> 2017 Jul 1;24(4):806-12 Mikalsen KØ, Soguero-Ruiz C, Jensen K, Hindberg K, Gran M, Revhaug A, Lindsetmo RO, Skrøvseth SO, Godtliebsen F, Jenssen R. Using anchors from free text in electronic health records to diagnose postoperative delirium. <i>Comput Methods Programs Biomed</i> 2017 Dec;152:105-14	127

Section 6: Knowledge Representation and Management

Survey	O. Bodenreider, R. Cornet, D. J. Vreeman Recent Developments in Clinical Terminologies – SNOMED CT, LOINC, and RxNorm	129
Synopsis	F. Dhombres, J. Charlet As Ontologies Reach Maturity, Artificial Intelligence Starts Being Fully Efficient: Findings from the Section on Knowledge Representation and Management for the Yearbook 2018	140
Best Paper Selection	Content summaries of: Boudellioua I, Mahamad Razali RB, Kulmanov M, Hashish Y, Bajic VB, Goncalves-Serra E, Schoenmakers N, Gkoutos GV, Schofield PN, Hoehndorf R. Semantic prioritization of novel causative genomic variants. <i>PLoS Comput Biol</i> 2017;13(4):e1005500 Galeota E, Pelizzola M. Ontology-based annotations and semantic relations in large-scale (epi) genomics data. <i>Brief Bioinform</i> 2017;18(3):403-12 Khan Y, Saleem M, Mehdi M, Hogan A, Mehmood Q, Rebholz-Schuhmann D, Sahay R. SAFE: SPARQL Federation over RDF Data Cubes with Access Control. <i>J Biomed Semantics</i> 2017;8(1):5 Notaro M, Schubach M, Robinson PN, Valentini G. Prediction of Human Phenotype Ontology terms by means of hierarchical ensemble methods. <i>BMC Bioinformatics</i> 2017;18(1):449 Petegrosso R, Park S, Hwang TH, Kuang R. Transfer learning across ontologies for phenome-genome association prediction. <i>Bioinformatics</i> 2017;33(4):529-36	144

Section 7: Consumer Health Informatics and Education

Survey	J. Huh, J. Koola, A. Contreras, A. KP. Castillo, M. Ruiz, K. G. Tedone, M. Yakuta, M. K. Schiaffino Consumer Health Informatics Adoption among Underserved Populations: Thinking beyond the Digital Divide	146
Working Group Contribution	H. Liyanage, S.-T. Liaw, E. Konstantara, F. Mold, R. Schreiber, C. Kuziemsky, A. L. Terry, S. de Lusignan Benefit-risk of Patients' Online Access to their Medical Records: Consensus Exercise of an International Expert Group	156
Synopsis	P. Staccini, A. Y. S. Lau Findings from 2017 on Consumer Health Informatics and Education: Health Data Access and Sharing	163
Best Paper Selection	Content summaries of: Bender JL, Cyr AB, Arbuckle L, Ferris LE. Ethics and Privacy Implications of Using the Internet and Social Media to Recruit Participants for Health Research: A Privacy-by-Design Framework for Online Recruitment. <i>J Med Internet Res</i> 2017 Apr 6;19(4):e104 Sanderson SC, Brothers KB, Mercaldo ND, Clayton EW, Antommaria AHM, Aufox SA, Brilliant MH, Campos D, Carrell DS, Connolly J, Conway P, Fullerton SM, Garrison NA, Horowitz CR, Jarvik GP, Kaufman D, Kitchner TE, Li R, Ludman EJ, McCarty CA, McCormick JB, McManus VD, Myers MF, Scrol A, Williams JL, Shrubsole MJ, Schildcrout JS, Smith ME, Holm IA. Public Attitudes toward Consent and Data Sharing in Biobank Research: A Large Multi-site Experimental Survey in the US. <i>Am J Hum Genet</i> 2017 Mar 2;100(3):414-27 Peacock S, Reddy A, Leveille SG, Walker J, Payne TH, Oster NV, Elmore JG. Patient portals and personal health information online: perception, access, and use by US adults. <i>J Am Med Inform Assoc</i> 2017 Apr 1;24(e1):e173-e177 Walker DM, Johnson T, Ford EW, Huerta TR. Trust Me, I'm a Doctor: Examining Changes in How Privacy Concerns Affect Patient Withholding Behavior. <i>J Med Internet Res</i> 2017 Jan 4;19(1):e2	167 167 168 168

Section 8: Clinical Research Informatics

Survey	N. C. Lea, J. Nicholls, N. K. Fitzpatrick Between Scylla and Charybdis: Charting the Wicked Problem of Reusing Health Data for Clinical Research Informatics	170
Synopsis	C. Daniel, D. Kalra Clinical Research Informatics: Contributions from 2017	177
Best Paper Selection	Content summaries of: Caron A, Chazard E, Muller J, Perichon R, Ferret L, Koutkias V, Beuscart R, Beuscart JB, Ficheur G. IT-CARES: an interactive tool for case-crossover analyses of electronic medical records for patient safety. <i>J Am Med Inform Assoc</i> 2017;24(2):323-30 Girardeau Y, Doods J, Zapletal E, Chatellier G, Daniel C, Burgun A, Dugas M, Rance B. Leveraging the EHR4CR platform to support patient inclusion in academic studies: challenges and lessons learned. <i>BMC Med Res Methodol</i> 2017;17(1):36 Huang J, Duan R, Hubbard RA, Wu Y, Moore JH, Xu H, Chen Y. PIE: A prior knowledge guided integrated likelihood estimation method for bias reduction in association studies using electronic health records data. <i>J Am Med Inform Assoc</i> 2017 Dec 1 Jackson RG, Patel R, Jayatilleke N, Koliakou A, Ball M, Gorrell G, Roberts A, Dobson RJ, Stewart R. Natural language processing to extract symptoms of severe mental illness from clinical text: the Clinical Record Interactive Search Comprehensive Data Extraction (CRIS-CODE) project. <i>BMJ Open</i> 2017;7(1):e012012 Kim H, Bell E, Kim J, Sitapati A, Ramsdell J, Farcas C, Friedman D, Feupe SF, Ohno-Machado L. iCONCUR: informed consent for clinical data and bio-sample use for research. <i>J Am Med Inform Assoc</i> 2017;24(2):380-7	181

Section 9: Natural Language Processing

Survey	M. Filannino, Ö. Uzuner Advancing the State of the Art in Clinical Natural Language Processing through Shared Tasks	184
Synopsis	A. Névéol, P. Zweigenbaum Expanding the Diversity of Texts and Applications: Findings from the Section on Clinical Natural Language Processing of the International Medical Informatics Association Yearbook	193
Best Paper Selection	Content summaries of: Castro SM, Tseytlin E, Medvedeva O, Mitchell K, Visweswaran S, Bekhuis T, Jacobson RS. Automated annotation and classification of BI-RADS assessment from radiology reports. <i>J Biomed Inform</i> 2017 May;69:177-87 Pérez A, Weegar R, Casillas A, Gojenola K, Oronoz M, Dalianis H. Semi-supervised medical entity recognition: A study on Spanish and Swedish clinical corpora. <i>J Biomed Inform</i> 2017 Jul;71:16-30 Tapi Nzali MD, Bringay S, Lavergne C, Mollevi C, Opitz T. What Patients Can Tell Us: Topic Analysis for Social Media on Breast Cancer. <i>JMIR Med Inform</i> 2017 Jul 31;5(3):e23	198

Section 10: Public Health and Epidemiology Informatics

Survey

R. Gamache, H. Kharrazi, J. P. Weiner

Public and Population Health Informatics: The Bridging of Big Data to Benefit Communities

199

Synopsis

R. Thiébaut, F. Thiessard

Artificial Intelligence in Public Health and Epidemiology

207

Best Paper Selection

Content summaries of:

Choi S, Lee J, Kang MG, Min H, Chang YS, Yoon S. Large-scale machine learning of media outlets for understanding public reactions to nation-wide viral infection outbreaks. *Methods* (2017) 129:50–59

210

Dernoncourt F, Lee JY, Uzuner O, Szolovits P. De-identification of patient notes with recurrent neural networks. *J Am Med Inform Assoc* (2017) 24:596–606

210

Section 11: Cancer Informatics

Survey

E. Mathé, J. L Hays, D. G. Stover, J. L. Chen

The Omics Revolution Continues: The Maturation of High-Throughput Biological Data Sources

211

Synopsis

J. L. Warner, D. A. Patt

Cancer Informatics in 2017: A New Beginning and a Bright Future

223

Best Paper Selection

Content summaries of:

Chakravarty D, Gao J, Phillips SM, Kundra R, Zhang H, Wang J, Rudolph JE, Yaeger R, Soumerai T, Nissan MH, Chang MT, Chandarlapaty S, Traina TA, Paik PK, Ho AL, Hantash FM, Grupe A, Baxi SS, Callahan MK, Snyder A, Chi P, Danila D, Gounder M, Harding JJ, Hellmann MD, Iyer G, Janjigian Y, Kaley T, Levine DA, Lowery M, Omuro A, Postow MA, Rathkopf D, Shoushtari AN, Shukla N, Voss M, Paraiso E, Zehir A, Berger MF, Taylor BS, Saltz LB, Riely GJ, Ladanyi M, Hyman DM, Baselga J, Sabbatini P, Solit DB, Schultz N. OncoKB: a precision oncology knowledge base. *JCO Precis Oncol* 2017 Jul;2017

226

Newton Y, Novak AM, Swatloski T, McColl DC, Chopra S, Graim K, Weinstein AS, Baertsch R, Salama SR, Ellrott K, Chopra M, Goldstein TC, Haussler D, Morozova O, Stuart JM. TumorMap: exploring the molecular similarities of cancer samples in an interactive portal. *Cancer Res* 2017 Nov 1;77(21):e111-e114

226

Seyednasrollah F, Koestler DC, Wang T, Piccolo SR, Vega R, Greiner R, Fuchs C, Gofer E, Kumar L, Wolfinger RD, Winner KK, Bare C, Neto EC, Yu T, Shen L, Abdallah K, Norman T, Stolovitzky G, Soule HR, Sweeney CJ, Ryan CJ, Scher HI, Sartor O, Elo LL, Zhou FL, Guinney J, Costello JC, and Prostate Cancer DREAM Challenge Community. A DREAM Challenge to build prediction models for short-term discontinuation of docetaxel in metastatic castration-resistant prostate cancer. *JCO Clin Cancer Inform* 2017;1:1-15

226

Grémy Award Papers

F. González Bernaldo de Quirós, C. Otero, D. Luna

Terminology Services: Standard Terminologies to Control Health Vocabulary

227

K. C. Lun

The Datafication of Everything – Even Toilets

234

Research & Education

C. U. Lehmann, A. V. Gundlapalli, J. J. Williamson, D. B. Fridsma, W. R. Hersh, M. Krousel-Wood, C. J. Ondrula, B. Munger

Five Years of Clinical Informatics Board Certification for Physicians in the United States of America

237

History of Medical Informatics

G. I. Mihalas, L. Stoicu-Tivadar

History of Romanian Medical Informatics: Learning from the Past to Reshape the Future

243

Information on IMIA	Welcome to IMIA	252
	Honorary Fellows	255
	IMIA Member Societies	256
	Institutional Members	257
	Addresses of IMIA Member Societies	259
Information on IMIA Regions	Information on APAMI (Asia Pacific Association for Medical Informatics)	275
	Information on Helina (African Region)	281
	Information on IMIA-LAC (Federation of Health Societies in Latin America)	283
	Information on MENAHIA (Middle East and North African Association for Health Informatics)	286
	Information on NAMI (North-American Medical Informatics)	292
	Information on EFMI (European Federation For Medical Informatics)	296
National Contribution	P. Knaup, T. M. Deserno, H.-U. Prokosch, U. Sax Implementation of a National Framework to Promote Health Data Sharing	302
<hr/>		
Miscellaneous	Contributors	305
	Reviewers	306
	IMIA Yearbook Special Topics	307