Transforming Data into Knowledge: How to Improve the Efficiency of Clinical Care?

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Summary

Objectives: To provide an introduction to the 2017 IMIA Yearbook of Medical Informatics by the editors.

Methods: We present a brief overview of the 2017 special topic "Learning from experience: Secondary use of patient data". We review our choice of special topic section editors, present the new section "Health Information Management", and discuss transitions in the editorial team.

Results: In this edition of the Yearbook, we focused on one of the most important issues for the medical informatics community: The secondary use of clinical data. With the ubiquitous adoption of electronic health records (EHRs) and the increasing availability of genomic and environmental data, as well as the accessibility of unstructured data in social media, issues related to data integration, storage, and management, as well as the need for novel analytic approaches are clear challenges. The paradigm of Learning Health Systems (LHSs) is presented in the keynote paper and survey papers review the significant developments in allied fields such as clinical research, clinical systems, translational informatics, and public health over the past two years. IMIA Working Groups also contributed to this topic.

Conclusion: The 2017 issue of the IMIA yearbook focuses on the secondary use of patient data and presents the difficulties that still need to be solved before witnessing the actual development of LHSs.

Learning from Experience and Patient Data Reuse Challenges

The current rate of health data generation is increasing almost exponentially. While the growing adoption of Electronic Health Records (EHRs) plays a role in this massive production of digitized clinical data, health-related data also exist outside health information systems. Indeed, the widespread generalization of personal computing technology, the availability of personal health records, and the utilization of various forms of social media and mobile Apps have contributed to the explosion of patient generated health data stored outside traditional health systems. Further, smart wearable body sensors for patient self-assessment and monitoring could be the greatest contributors to Big Data in healthcare in a very near future.

The use of data for reasons other than originally intended when initially collected is broadly termed *secondary use,* or *reuse.* The reuse of clinical data is not new. Data has long been reused to create new knowledge and potentially improve clinical care. This is a basis for progress in the science of medicine and the processes of health care. However, in the era of digitization, patient data could be massively reused. Could we expect an impact of the same magnitude on care quality and clinical outcomes? Recently, the availability of digital big health data has allowed the emergence of a new paradigm, the *Learning Health System* (LHS). The broad vision of the LHS model implies that we can use the data collected as a by-product of clinical care to improve the performance of health care systems. Such data can be used to facilitate phenotyping and hypothesis generation to foster clinical research. They can also be used for prediction and clinical decision support by allowing the accurate classification of disease cohorts to identify predictive features that could lead to interventions that prevent disease, hospital re-admissions, and adverse events associated with drugs. Finally, these data can be used to provide individual patients with the best possible information about their diagnostic and treatment choices. Repositories of clinical data may also serve for direct patient care to support the identification of similar patients and the proposition of the treatment that offers the best clinical outcome. Increasingly, traditional sources of health-related data, such as claims databases, have been linked with clinical data from EHRs to enlarge the volume of data and provide extended and more robust conclusions to the problems to be solved, for example, to improve the detection of weak signals in pharmacovigilance.

However, barriers to clinical data reuse have also been reported: Most data in EHRs are unstructured and, to date, natural language processing methods are not sufficiently reliable to analyze this wealth of data. Furthermore, the quality and accuracy of data collected for a given goal have often been criticized when reused for another goal. Data are often stored in a way that does not easily support downstream reuse; specifically, aggregation from multiple settings though

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necessary is difficult because of syntactic and semantic interoperability issues. Besides, additional barriers include ownership or rights to use data, issues of privacy and re-identification of personal information, and the legal context for data analysis.

For these reasons, the editorial committee of the International Medical Informatics Association (IMIA) Yearbook has chosen to devote the special topic of its 2017 edition to "Learning from experience: Secondary use of patient data". Because of the numerous issues related to data reuse and learning from experience, including data representation, aggregation, and analysis, the choice of common data models, natural language processing techniques, the lack of legal framework to preserve patients rights while promoting the access and reuse of patient data, the need for specific technical infrastructures, we aimed to illuminate the reflections and thoughts on the subject with the contribution of senior researchers in different fields of Biomedical Informatics. The keynote paper was written by Charles Friedman et al. on Learning Health Systems and describes the characteristics of a fully functional learning system and the role of the infrastructure to serve multiple simultaneous learning cycles. Grégoire Ficheur and Daniel R. Schlegel guided the review of the literature and the selection of the best papers for the special topic section. The survey paper of the special topic section written by Charles Safran focuses on data reuse. The Yearbook generally tries to offer a worldwide vision in the different fields of the Biomedical Informatics domain. Therefore, we have this year two contributions in the Public Health and Epidemiology Informatics (PHEI) section - one US-centered and one Europe-centered - to describe the main trends of the works conducted in PHEI in conjunction with the special topic. As in previous years, the contributions of voluntary working groups are included in this edition of the Yearbook. The best papers published in 2016 in the different fields of Biomedical Informatics are presented in each section. They are the result of the reviews conducted on the more than 10,000 papers initially returned by the queries used in each section by the 24 section editors, trough MEDLINE/PubMed, Web of Sciences, and some specific journals.

New Sections in 2017 and 2018

Health Information Management (HIM) is information management applied to health and health care. It is the practice of acquiring, analyzing, and protecting digital and traditional medical information necessary to provide quality patient care. The tools of health informatics and health information technology are continually improving to bring greater efficiency to information management in the health care sector. The field of Health Information Management is thus dedicated to the development of methods to ensure the availability, accuracy, and protection of the clinical information that is needed to deliver healthcare services and to make appropriate healthcare-related decisions. Traditional areas addressed in HIM are diagnostic and procedure coding, as well as privacy and security of health information; both areas are closely connected to health information exchange. Biomedical Informatics and HIM have interests in common but they were traditionally working on separate domains. Recently, it was obvious to the Yearbook editorial committee that HIM was providing a complementary vision to the usual fields of Biomedical Informatics and, as a consequence, it was important to add this field as a new section in the Yearbook. This has been done from 2017, and we are pleased to introduce Eta Berner and Meryl Bloomrosen, the HIM's section editors of the IMIA Yearbook.

The American Society of Clinical Oncology (ASCO) has launched a new clinical journal, JCO Clinical Cancer Informatics (JCO CCI), to advance the field of clinical cancer informatics. JCO CCI, an online-only journal, publishes clinically relevant research based on biomedical informatics methods and processes applied to cancer-related data, information, and images. The interest of a collaboration between ASCO and IMIA to promote each other's informatics offerings was then obvious, and we are pleased to announce the introduction of a new Yearbook section entitled "Cancer Informatics" beginning in 2018. We welcome in the Yearbook editorial committee the two section editors of this new section,

Dr. Debra Patt (founding Editor-in-Chief of ASCO's JCO Clinical Cancer Informatics) and Dr. Jeremy Warner from Vanderbilt University.

A New Editorial Committee

For the 2017 edition, the Yearbook team has been renewed with two new editors Lina F. Soualmia, PhD, who is an Assistant Professor at the French University of Rouen, France (she is not new in the editorial committee since she has been serving as a section editor of the Yearbook since 2013), and John H. Holmes, PhD, FACE, FACMI, who is a Professor of Medical Informatics in Epidemiology, at the Perelman School of Medicine at the University of Pennsylvania. We are also very pleased that Martina Hutter, who has served as the Yearbook Editorial Assistant since 2000, and was planning to leave the Yearbook, has relented and accepted to remain in charge of the typesetting of all the articles of the Yearbook. We are also happy to welcome Adrien Ugon, PhD, Assistant Professor at ESIEE (School of Engineers in Electronics and Electrical Engineering), who managed the selection of best papers. Brigitte Séroussi who used to be editor is now also the IMIA Vice President for Services.

Undoubtedly so much change will require that every one reuses previous data and learns from experience! We are convinced that the new team will bring some fresh blood with new ideas, new perspectives, and new skills to make the Yearbook even more successful.

The International Academy of Health Sciences Informatics

IMIA has decided to create an International Academy of Health Sciences Informatics (IAHSI). The Academy will serve as an honor society that recognizes expertise in biomedical and health informatics internationally. As an international forum for peers in biomedical and health informat-

ics, the Academy will play an important role in exchanging knowledge, providing education and training, and producing policy documents, e.g., recommendations and position statements. Leaders in health informatics worldwide have been selected through a multistep election process led by Drs. Ted Shortliffe and Patrice Degoulet, as well as IMIA's President Dr. Hyeoun-Ae Park and President-Elect Dr. Christoph U. Lehmann. This edition of the Yearbook provides a presentation of IAHSI as well as the description of the inaugural class of IAHSI members.

A New Anniversary: IMIA is 50!

IMIA was originally established in 1967 as the Technical Committee 4 of the International Federation for Information Processing (IFIP). In 1979, IFIP-TC4 evolved from a Special Interest Group to its current status as a fully independent organization under the leadership of Professor Francois Grémy and became the direct precursor of IMIA. At the meeting of the IMIA Board in 2009 in Hiroshima, an IMIA 50th Anniversary History Project was approved. A Taskforce was organized under the direction of Dr.

Casimir Kulikowski and the IMIA History Working Group (WG) was approved in 2014 to document and write about the history of the field and its organizations. This edition of the Yearbook includes a paper that describes how the IMIA History WG arose and developed, including its meetings and projects, leading to the forthcoming 50th Anniversary of IMIA that will be celebrated in 2017 at the World Congress of Medical Informatics in China (MEDINFO 2017). After the 25th Anniversary of the Yearbook celebrated in 2016, let's come to Hangzhou for MEDINFO 2017 and celebrate IMIA!