IMIA Working Group on Health Record Banking – Workshop on Health Information Exchange Challenges

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Abstract: This workshop is a business meeting of the IMIA Working Group on Health Record Banking, aiming at discussion of updates on approaches to resolving the problem of health information fragmentation. In principle, we challenge the current paradigm of keeping medical records where they were created and discuss an alternative approach in which an individual's health data can be maintained by new entities whose sole responsibility is the sustainability of individual-centric health records. In particular, we will discuss the unique characteristics of the European health information landscape and promote the suggestion to establish a European alliance for citizen health records under the umbrella of the IMIA HRB group and possibly within EFMI.

Keywords. Health Record Banking, Health Information Exchange, Health Information Systems, Health Information Infrastructure

Introduction of the topic

Large-scale regional, national and international efforts around the globe targeted at developing health information exchange and making available a patient-centric and comprehensive health record to the clinicians at the point of care have not been successful as expected. The health information landscape has remained extremely fragmented and as a result patient records are not complete, seldom semantically interoperable, and more importantly, cannot be put together into a longitudinal and cross-institutional electronic health record. The implication of this fragmentation is that there is no complete and coherent health record available for medical care, population health, research, or policy. In addition, there is no way to facilitate patient’s access and control of their own health records.

Disappointment from large-scale interoperability projects led to lowering expectations of semantic interoperability and therefore scope of recent projects have been narrowed down to specific use cases with limited requirements such as electronic scheduling and prescriptions, or sparse medical summaries at best. In addition, the bulk

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of the exchanged information is not sufficiently complete or structured for machine processability, which makes it hard for decision-support applications to provide meaningful advice and the promised power of health analytics is hindered.

1. Aim of the discussion

The discussion aims at comparing alternative approaches of health information exchange and integration, contrasting common approaches currently in use, with the health record banking (HRB) approach. Workshop speakers will present different aspects of HRB and will strive to develop active discussion with the audience on HRB and other approaches.

In particular, workshop speakers will describe (1) legal and ethical issues of HRB including legislation changes enabling Independent Health Record Banks; (2) informatics considerations of ways HRB organizations communicate with other stakeholders in the healthcare arena such as healthcare provider information systems; (3) privacy issues and challenge in access control of data releases from HRBs and (4) the business structure of the HRB organization that best fits their job.

A few of the above considerations are described in the following venues and publications of the IMIA HRB Working Group: a panel discussion on HRB held in MedInfo 2013; an HRB Focus Theme of the Methods of Information in Medicine Journal; HRB workshop at MIE 2014 in Istanbul; and an ‘IMIA HRB Day’ at WCIT 2014 in Guadalajara. Thus, the proposed workshop will build on results of these discussions and describe HRB state-of-the-art through lessons learned from ongoing implementations.

2. Contribution from each speaker

Amnon Shabo will focus on ethical and legal considerations of HRB, based on his recent HRB publication, which is the editorial of the HRB Focus Theme in Methods. In addition, Amnon will add a new proposal on developing international guiding legislation model, which could then be brought to the various countries for enacting concrete legislation following this model. In particular, a two-phase legislation will be presented where the first phase requires healthcare providers to send out electronic and standardized copies of medical records they create. In the second phase, health record banks will be designated as the sole keepers of the medico-legal record.

Reinhold Haux will describe the Braunschweig Bank of Health and their approach to exchange of patient data with healthcare providers while keeping the independency of the bank and its benefits to all stakeholders.

Alfred Winter will focus on privacy challenges and discuss how methods related to digital rights management may not only provide privacy but empower patients and all HRB’s clients to effectively control usage of their data in- and outside the HRB.

Ernst Hafen will focus on the midata.coop efforts in Europe. For the new medicine to become a reality, millions of personal health data sets have to be aggregated. The value of such aggregated personal data has been recognized as a new asset class and many commercial entities are competing for this new asset. The primary source and
beneficiary of personal health data is the individual. As a collective, society should be the beneficiary of both the economic and health value of these aggregated data and (health) information. Empowering citizens by providing them with a platform to safely store, manage and share their health related data will be a necessary element in the transformation towards a more effective and efficient precision medicine. Such health data platforms should be organized as cooperatives that are solely owned and controlled by their members and not by shareholders. Members determine which data they want to share for example with doctors or to contribute to research for the benefit of their health and that of society. Members will also decide how the revenues generated by granting third parties access to the anonymized data that they agreed to share, should be invested in research, information or education. In the Health Data Cooperative model, the citizens with their data would take the center stage in the healthcare system and society would benefit from the health-related and financial benefits that aggregation of these data brings [4].

3. Expected results

Workshop results will further inform the public discussion on medico-legal and socio-economic constellations of health information exchange and integration, in order to overcome the extreme data fragmentation of the individual’s health history, which hinders its availability at the point of care.

In particular, workshop results will combine the various considerations in implementing HRB, as will be articulated by the workshop speakers, into a more cohesive view on HRB in contrast to the other health record sharing paradigms. In addition, input from other members of the HRB Working Group as well as from the audience will be combined into the workshop results.

In order to engage the audience beyond the usual discussion taking place after the speakers’ presentations, we will shorten significantly the frontal presentations, preceded by an introduction that summarizes the agreed-upon principles of health record banking, so that each speakers can focus on the unique ideas he brings to the table. During the workshop, participants will be able to write their comments/questions/ideas on cards handed out at the beginning of the workshop, and those cards will initiate an active discussion after ending the speakers’ presentations.

References