It’s Time for Health Record Banking!

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Keywords
Health record banking, electronic health records, health information integration, health information fragmentation, case-based reasoning, health information systems, health records sustainability

Summary
This article is part of a Focus Theme of Methods of Information in Medicine on Health Record Banking. This Focus Theme aims at describing the Health Record Banking (HRB) paradigm, which offers an alternative constellation of health information exchange and integration through sustainability of health records over the lifetime of individuals by independent and trusted organizations.

It also aims at describing various approaches to HRB and reporting on the state-of-the-art HRB through actual implementations and lessons learned, as described in articles of this Focus Theme.

Methods Inf Med 2014; 53: 63–65

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doi: 10.3414/ME13-02-0048

1. Introduction

In the past decade we have witnessed several large-scale national and international efforts around the globe targeted at developing health information exchange and integration mechanisms, in order to make available a patient-centric, cross-institutional and longitudinal health record to the clinicians at the point of care. However, despite these endeavors, the health information landscape has remained extremely fragmented, and the current status is that the aforementioned type of health record is practically nonexistent. When integrating data across several providers, patient data sets are often not semantically interoperable and more importantly, cannot be put together into a single and coherent health record [1]. As a result, current use cases of health information exchange have been narrowed down to electronic prescriptions or sparse medical summaries [2]. In more advanced efforts, federated medical records are accessible merely for human viewing while the bulk of the exchanged information is not sufficiently structured and standardized for machine processability, which makes it hard for decision-support applications to provide meaningful advice [3] and thus the promised power of health analytics is hindered.

This editorial article starts with reviewing the evolvement of the HRB paradigm, as well as describing different approaches to the realization of HRB. The conclusion of this review is that the key principles underlying most approaches to HRB are as follows:

- HRB is carried out by independent and trusted organizations that curate and manage health records on behalf of individuals and make it available to all authorized parties;
- the records of each individual are logically aggregated in one place, but not all records of some population are in the same place (thanks to availability of multiple banks);
- greater control and privacy for individuals over their own records with no need for globally unique patient’s identification assigned by governmental authorities.

2. HRB Evolvement

Several HRB ideas were raised in the past decades and contributed to the evolvement of the HRB paradigm.
Szolovits et al. suggested in a technical report [4] in 1994 that software agents (called Guardian Angels) could integrate all health-related information about an individual over a lifetime, thus "providing a comprehensive medical record that is often impossible to reconstruct in a timely manner". This report assumed that "exhaustive long-term records" will be handled by hospitals and focused on use cases of capturing data from home care devices and conveying them to the hospital.

In 1997, Dodd suggested to the UK National Health Service that citizens could benefit if a "non-profit-making Health Information Bank" will be established along with two more organizations – “Health Information Academy” and “commercially-oriented Health Information Corporation” [5]. Dodd described the relations between these three organizations where the Academy supervises the Bank as well as the commercial exploitation of data deposited in the Bank by the Corporation. Protti revisited Dodd’s idea [6] and emphasized that the detailed records are not held in the bank: "the bank, and so the patient, would facilitate and control the sharing of the wider ‘birth to death’ longitudinal health record – it would be the Electronic Health Record (EHR) while the detailed records maintained by the health professionals would be the Electronic Patient Records (EPR)."

Ramsaroop and Ball described in 2000 the Bank of Health [7] and emphasized the personal aspects of health records (e.g., patient empowerment) through banking of certain subsets of the provider health records, while keeping the full-blown records where they were created ("…they would not include access to physician notes or hospital records, as does a complete CPR"). This approach has evolved along the years to the Personal Health Record (PHR) concept, which is related to HRB. While PHR initiatives of the nature of Google Health [8] are closer to HRB, most of the existing PHR systems are actually ‘tethered’ to healthcare provider health record systems [9] and are mainly extensions of institutional systems that aim at improving the ‘user experience’ in the context of healthcare transformation to contain its rising costs.

Shabo was motivated by the importance of case-based reasoning to HRB, which is an alternative reasoning methodology suitable to domains where the unknown is greater by far than the known and thus it is extremely hard to represent the known knowledge with explicit and formal rules. Shabo assumed that the ultimate case for case-based reasoning in health is the lifetime health record (including items of currently unknown significance), and to that end it is essential to have health record banking, which is the inevitable approach to get to lifetime health record. He established Bankomied in 1998 [10] but lack of cooperation on the providers’ side led him to the vision of Independent Health Record Banks (IHRB), which has at its core a slight but fundamental change in medical records legislation. IHRB has been described in various venues, e.g. [11] and in most detail in two articles of Methods of Information in Medicine [12, 13] on a Global Socio-economic-medico-legal Model for the Sustainability of Longitudinal Electronic Health Records.

The IHRB vision is a ‘top-down’ approach to health record banking and can be explored as a long-term goal in policy making and legislation planning related to national and international approaches to an individual’s health record. It varies from other approaches to HRB in the following aspects: First and foremost, it suggests a change in current legislation so that the copy of a legally-authenticated medical record stored in an IHRB is the sole medically-legal record and healthcare providers are no longer required by the law to hold archives of medical records. In this way, duplication of data as in PHR systems is avoided and integrity could be achieved. Medical records are consolidated into a coherent health record that will be sustained for the lifetime of an individual by new players in the healthcare arena – IHRBs. These new entities function as a custodian/trustee on behalf of individuals and are 1) operationally and ethically independent of current stakeholders such as healthcare providers, insurers, government agencies and even the patients themselves and 2) regulated by new legislation, allowing multiple competing banks to be established by private entities. IHRBs are obligated to allow all authorized parties access to the consolidated health record or to any of its attested medical record source constituents. On the macroeconomic level, healthcare providers could reduce their costs of medical records archiving as this function is carried out by the IHRBs, thus there is no additional cost to the health sector, which already suffers from rising costs.

In summary, HRB has evolved during the past decades with different flavors varying mainly in these dimensions: 1) the approach to current legislation: is a legislation change prerequisite to HRB realization or successful HRB efforts could reach a tipping point and change the market in a bottom-up manner; 2) the extent to which the HRB record consists of all detailed medical records; 3) the type of HRB organizations: for-profit versus nonprofit, cooperative ownership versus private corporation, etc.; and 4) differences in HRB business models, e.g., who is paying for the new HRB operation and how is it accomplished in a way that could let HRB organizations be viable. Nevertheless, as mentioned in the introduction, all HRB approaches share the key principles of HRB independency and trustworthiness as well as aggregation, curation, preservation and provision of individual’s data as its major tasks.

Regarding privacy, HRB organizations utilize best practices in privacy protection since it is one of their main missions and specializations. In addition, HRB makes redundant globally-unique identifications, which are needed in any non-HRB constellation where they might be misused to get to other sensitive personal information. The privacy risk in aggregating all individual data in one logical place should be weighed against the availability of a complete health history at the point of care as well as in emergency cases and analytics for decision support. As for ‘population privacy’, HRB is not limited by geographical boundaries and thus is international in nature even if a specific HRB organization is operationally-based in a specific country. In this way, each HRB organization could potentially consist of health records of individuals from different populations and communities, thus reducing the risk of abusing the data, as in the extreme example of ethnic cleansing.
3. **State-of-the-art HRB**

The articles in this Focus Theme describe three pilot implementations of health record bank that represent the state-of-the-art in HRB.

Yasnoff and Shortliffe [14] describe an attempt to operate a health record bank in the USA and focus on the business challenges of the HRB model. A health record bank was introduced in the greater Phoenix community, with the goal to engage 200,000 individuals as members in the first year. It was also intended to evaluate a business model that was based on early adoption by consumers and physicians, followed by additional revenue streams related to incremental services and secondary uses of clinical data.

Pilschke et al. [15] describe the Lower Saxony Bank of Health (LSBH) and focus on the challenges of working with healthcare provider information systems. The LSBH was established as an entrepreneurial company, undertaking the role of a neutral third party information broker. The bank does not store medical documents itself but offers a document registry, granting access to authorized health care providers. To implement its services, LSBH uses internationally-recognized standard technical frameworks for the data federation of medical records of participating patients.

Hafen et al. [16] describe health data cooperatives based in Switzerland and focus on the structure of the health record bank organization by arguing that it has to be a cooperative type of organization in order to best serve its members. In this way, citizen-owned personal data cooperatives would efficiently unleash the huge value of personal data and result in democratization of healthcare and of the global economy at the same time. Their success depends on an entirely democratic process that is initiated by citizens and could lead to trust and transparency, which in turn are crucial for rapid adoption.

4. **Discussion**

This Focus Theme followed a Panel Discussion in MedInfo 2013 titled “Defragmenting Individual’s Health Data: It’s Time for Health Record Banking” [17] and described an alternative approach to resolving the problem of health information fragmentation. In particular, contributors have challenged the current paradigm of keeping individual health data sets where they were created and discussed an alternative approach in which the data can be maintained by new entities whose sole responsibility is the sustainability of individual-centric health records, possibly for the lifetime of the individual. Given the known challenges of traditional ways of handling health records, as well as major limitations to recent health information exchange and integration efforts around the globe [1], it is suggested that Health Record Banking (HRB) should be seriously discussed by policy makers as a viable alternative, which significantly benefits all health stakeholders.

The main benefit of HRB is that medical records could be curated, analyzed and summarized by advanced information technologies and analytics, presenting topical summaries (e.g., disease/event summary or integrative care plan) at the point of care. Effective and accurate summaries based on all available raw medical records and other sources of data (e.g., self-generated data, home care & wearable devices, genetic data, etc.) cannot be efficiently done through the current paradigm of peer-to-peer exchange or data federation of heterogeneous data from source information systems that are not always available.

The time has come for HRB to be considered in national and international healthcare and wellbeing endeavors. To that end, readers are welcome to get involved in the proposed new IMIA Working Group on HRB where these issues will be discussed by HRB proponents from all IMIA regions.

**References**