

## **Health Record Banks and Personal Health Records**

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### **History of the Health Record Banking Alliance**

The Health Record Banking Alliance ([www.healthbanking.org](http://www.healthbanking.org)) is a 501(c)(6) non-profit organization founded in 2006. We are supported by membership dues from individuals, small companies, and corporations. We have been and continue to be an education, discussion, and advocacy group. With new attention being paid to health record banks, personal health records, individual health records, and unified health records (all the same thing), we are seeing many new companies entering this arena. We will continue to do education, discussion, and advocacy, and now we are beginning to evaluate the personal health record offerings of these companies. We do this to bring attention to and understanding of this sector of health information technology and to help individuals, organizations, companies, and communities become more comfortable with the concept of an individual health record. With the coming regulations related to the 21st Century Cures Act, we believe that this is a good time to influence national policy and contribute to better care and less expensive care.

### **A Ten Year Vision of Individual, Lifetime, Unified Health Record Accounts**

A consumer goes to their office provider and displays their ID card, their insurance card, and a third card with a QR code. The receptionist scans the QR code and that office electronic medical record (EMR) has immediate access to that patient's lifetime longitudinal health record. At the close of the visit, the office EMR automatically uploads all the data generated at that visit to the patient's health record bank account.

- At home, the consumer can see a complete audit trail of every person that has accessed their record and what parts of their record were accessed.
- The consumer can designate what other providers and family members can see what parts of their record for how long.
- Each consumer's data are stored in a trusted account in the cloud. Each consumer's data are stored under a separate key managed only by the consumer, so that a breach of a login and password to that database exposes data for only one person, instead of thousands or millions of people.
- Emergency providers can always get access to the consumer's account without explicit permission of the consumer. This easy access is balanced by all members of the consumer's family getting an email notice that their loved one's record was accessed.
- Over time, the consumer's health record bank account accumulates all their diagnostic images, retail and healthcare genomics data, microbiomics data, personal device data, and data entered into personal mobile apps. Any authorized provider can view those data and download those data to their EMR.
- When the consumer changes insurance, providers, or geographically moves, their record stays with them.
- Any authorized telemedicine provider can now advise the consumer with the benefit of seeing their entire healthcare record.

- The consumer can buy or use apps that run against all the data in their health record bank account and get advice from those apps on health, wellness, symptom triage, and chronic condition management.
- The consumer can make their de-identified or identified data available to research or commercial interests that they are interested in and even receive compensation for the use of their data.
- If a consumer wishes to change personal health record companies, then just like a financial retirement account, the consumer directs their agent to move all their data from one company to another, leaving none of their data with the first company.

The most important factor for the establishment of an individual health record ecosystem is the consumer's trust. That trust could be earned by a private cloud company, by an insurance company, by a health system, by a financial bank, or by others.

### **Why Health Record Banks Are Needed**

To obtain the greatest optimization of their health, to the degree they can and are willing to participate, individuals need to be engaged in their self-care and their provider's care of them. Having all their data in one place, under their control, is crucial to attaining the best clinical, financial, and consumer satisfaction outcomes. Family caregivers need health record banks to collect and manage all the records of their loved one so that they can provide information to the provider whenever the information is needed for care. Nationally, in order to track the efficacy of all diagnosis and treatment, we need consumer-generated health data from personal device data and personally-entered app data. An individual health record bank account is the best way to manage those data.

### **Helpful Policies to Promote Health Record Banks**

The most important thing for helping consumers take charge of their health is mobilizing data from providers' EMRs. Helpful future governmental policies include the following:

- Have providers' receptionists inform their patients at each visit that they are entitled to all their data (this is already specified by HIPAA – The Health Insurance Portability and Accountability Act of 1996, and amended in 2003).
- Have providers' receptionists ask their patients at each visit where they want the data from that visit sent.
- Financially incentivize providers to send patients their data.
- Require EMRs to have a place within their tethered patient portal for the consumer to enter an address (preferably a Direct address) where their complete record should be sent each time the EMR receives new data on them.xz
- Require EMR vendors and providers to use all the currently available information exchange standards to send all the consumer's data to the consumer's account when requested by the consumer or his or her agent.