



Introduction

The Health Record Banking Alliance (HRBA), founded in 2006 and headquartered in Portland, Oregon, is recognized as a business league by the Internal Revenue Service under Section 501(c)(6) of the Internal Revenue Code. HRBA promotes technology to enable consumer-owned and -controlled accounts held in secure private sector repositories. Repository accounts allow patients to aggregate medical records from a variety of doctors' offices, hospitals, and other sources; compile and analyze the consolidated records; control access to them; analyze the compiled data in them; and use the consolidated records in a wide variety of ways, including for treatment and participation in medical research projects.

HRBA Vision

Every consumer can own a secure, consolidated, digital lifetime health record that they may share with doctors, researchers, and others for better health and health care.

HRBA Mission

The non-profit Health Record Banking Alliance advocates for a trusted network of private sector organizations that offer accounts to solve the problem of scattered health information plaguing consumers today.

HRBA Principles

Consumer Ownership and Control of Health Records

1. Health record banks protect the individual consumer's right to health information privacy and confidentiality by acting as trusted legal custodians of consumers' health records.
2. Health record banks are repositories for trustworthy copies of health information selected or submitted by the consumer from various sources.
3. Health information in a health record bank is owned by the consumer and is not an asset of the health record bank.
4. Consumers may authorize someone else to manage their health record bank account.
5. Health record banks provide consumers and others they authorize with immediate electronic access to their health information.
6. Consumers control all disclosures of their health information by a health record bank unless otherwise required by law.
7. With consumer consent based on advance disclosure appropriate to the circumstances, health record banks enable secondary use of health information, such as for public health and research purposes.



HRBA Principles (continued)

Operation of Health Record Banks

8. Health record banks are governed in an open, accountable, and transparent manner.
9. All access and updates to information in health record banks are recorded as they occur in an appropriately detailed audit trail database, and each health record bank shall maintain those unaltered audit records at least during the time that a consumer's health record is kept at the bank and make those audit records immediately accessible to consumers.
10. Health record banks have established processes for correcting errors by updating, amending, and sequestering data, including mechanisms for notification of parties who have received such data.
11. Health record banks promptly disclose breaches of privacy, confidentiality, or security to consumers.

Operation of the Health Record Banking Alliance

12. The Health Record Banking Alliance seeks to maintain neutrality among vendors that agree to adhere to the above principles.

Definitions Used in the Statement of Principles

Health information privacy refers to an individual's right to control the acquisition, use, or disclosure of his or her identifiable health data. Confidentiality refers to the obligations of those who receive information to respect the privacy interests of those to whom the data relate. Security refers to the physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access, disclosure, or loss.

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, and even internationally, 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.



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.