



Principles for Health Record Banking

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Questions to be discussed

- What is Health Record Banking
- Why is it important
- What are the Health Record Banking Alliance (HRBA) “principles”
- How should the HRBA principles be applied

Financial model inspiration

- Deposits and withdrawals are medical record information
- Consumers control accounts
- Security and privacy
- Infrastructure
- Sustainability

HRBA design advantages

- An alternative to the “record locator” (“pointer” or “federated”) model
- Inherent accommodation of security, privacy and control issues
- Better handling of regulatory and liability demands
- More manageable governance

HRBA principles

- Developed by the Health Record Banking Alliance (www.healthbanking.org)
- Subject areas
 - Consumer ownership and control
 - Bank's custodial role
 - Consumer-directed access (primary and secondary uses)
 - Bank's security and privacy duties
 - Data handling procedures
 - Neutrality of application to health record bank operators

Context for the principles

- The HRBA is neither:
 - a regulatory agency nor
 - a certifying authority
- The HRBA expects adherence to the principles to be:
 - voluntary and
 - a condition for membership in the HRBA

Reflections on HRBA principles

- A consumer-controlled health record heralds a significant social shift
- Trust is essential for health record banking, and consumer control is essential to trust
- The HRBA principles fit the existing framework of federal and state laws that already apply to health record banking

Evolution of HRBA principles

- The product of many weeks of discussions and drafts
- Participation by members of many stakeholder organizations across the spectrum of the industry
- Simplicity and clarity trumped technobabble and legalese
- Some things were easier than others

Privacy and confidentiality

Principle 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

Consumer control of content

Principle 2

- Health record banks are repositories for trustworthy copies of health information selected or submitted by the consumer from various sources

Ownership of information

Principle 3

- Health information in a health record bank is owned by the consumer and is not an asset of the health record bank

Granting agency

Principle 4

- Consumers may authorize someone else to manage their health record bank account

Timeliness of access

Principle 5

- Health record banks provide consumers and others they authorize with immediate electronic access to their health information

Consumer control of use

Principle 6

- Consumers control all disclosures of their health information by a health record bank unless otherwise required by law

Leveraging information value

Principle 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

Transparent governance

Principle 8

- Health record banks are governed in an open, accountable, and transparent manner

Meticulous auditing

Principle 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

Handling errors

Principle 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

Prompt disclosures

Principle 11

- Health record banks promptly disclose breaches of privacy, confidentiality, or security to consumers

Neutrality toward vendors

Principle 12

- The HRBA seeks to maintain neutrality among vendors that agree to adhere to the above principles

Summary

- Health Record Banks should allow consumers to manage their healthcare information in a secure and technically sophisticated manner
- Principles drafted by the Health Record Banking Alliance are already being used to help communities and private-sector companies thoughtfully plan for such activities