



Health Record Banking Alliance

October 14, 2009

Office of the National Coordinator for Health Information Technology
Attention: Requirements Document Team
Mary Switzer Building
330 C Street, S.W. Suite 1100
Washington, DC 20201

Comments on Consumer Preferences Draft Requirements Document

The Health Record Banking Alliance (<http://www.healthbanking.org>), consistent with our principles (attached on the following page), expresses its strongest possible support for consumers' rights to control all access to their own health information as compiled in personal health records. Personal health records maintained in health record banks allow consumers to establish (and modify) individual customized privacy policies, consistent with their own individual circumstances and preferences. Personal health records in health record banks also avoid the political conundrum, and insoluble technical and legal obstacles, of trying to obtain agreement on a uniform personal health record privacy policy for everyone. In short, enabling individualized consumer control is essential to the success of any effort to transition our health records from paper to electronic form.

We at the Alliance emphasize the inherent capacity of health record banks to implement consumer access preferences more easily, conveniently, and securely than alternative system architectures being proposed for the National Health Information Network. Health record banks are consumer-controlled repositories holding consumers' copies of their health records as compiled from diverse clinical sources. In health record banks (analogous to financial banks), each consumer's individual privacy preferences for access to all of their health information can be expressed and maintained in secure bank accounts under individual ownership and control. Health record bank repository architecture therefore is an efficient, convenient, technologically realistic, and financially sustainable solution to the personal health record needs of both consumers and the clinicians and others who need access to their health information.

Sincerely,

/s/ William A. Yasnoff

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Attachment (HRBA Principles)



Health Record Banking Alliance

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.

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.