



Health Record Banking Alliance White Paper

**A Proposed National Infrastructure for HIE
Using
Personally Controlled Records**

January 4, 2013

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Executive Summary

Under the HITECH legislation of 2009, the U.S. committed billions of dollars for health information infrastructure (HII), with the goal of ensuring the availability of comprehensive electronic patient records when and where needed. There are two important aspects of this initiative: 1) all providers need to adopt electronic health record systems (EHRs); and 2) systems must be implemented to aggregate the records for each patient into a comprehensive whole. To accomplish the latter, efforts are currently underway to build health information exchanges (HIEs) in communities across the nation. Most communities have chosen an institution-centric architecture for these systems, leaving patient records wherever they are created (Figure 1).

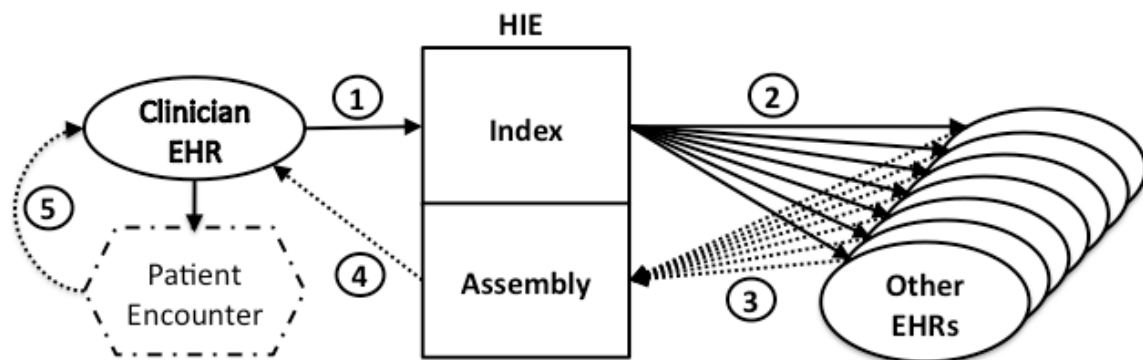


Figure 1. Institution-centric Community HII Architecture.

1. The clinician EHR requests prior patient records from the HIE; this clinician's EHR is added to the index for future queries for this patient (if not already present)
2. Queries are sent to EHRs at all sites of prior care recorded in the HIE Index; patient consent is verified at each "other" EHR prior to release of information
3. EHRs at each prior site of care return records for that patient to the HIE; the HIE must wait for all responses
4. The returned records are assembled and sent to the clinician EHR; any inconsistencies or incompatibilities between records must be resolved in real time
5. After the care episode, the new information is stored in the clinician EHR only

This choice of architecture has serious drawbacks that make it unsuitable for meeting the stated goals. It is complex, expensive, and unreliable (Lapsia et al, 2012). It also imposes substantial processing burdens on provider EHRs to be available to respond to queries around the clock. The most recent comprehensive survey of HIEs (Adler-Milstein, 2011) found that of the 179 systems reporting, only 13 could meet the requirements of Meaningful Use Stage 1, and only 6 of those systems were reported to be financially sustainable. Even worse, *none* of the 179 HIEs met the authors' definition of a comprehensive HIE, leading them to conclude in the abstract that, "*These findings call into question whether RHIOs [Regional Health*

Information Organizations] in their current form can be self-sustaining and effective in helping U.S. physicians and hospitals engage in robust HIE to improve the quality and efficiency of care.” Similarly, in 2010, the President’s Council of Advisors on Science and Technology (PCAST) observed that “HIEs have drawbacks that make them ill-suited as the basis for a national health information architecture” (PCAST, 2010). Among the drawbacks mentioned were administrative burdens (data sharing agreements to ensure stakeholder cooperation), financial sustainability, interoperability, and an architecture that cannot be scaled effectively.

In this white paper, we present an alternative patient-centric HII architecture (Figure 2), known as health record banking, and show how this approach can address the challenges and obstacles communities are currently facing in building successful, sustainable HIEs. A health record bank (HRB) or trust is an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records from multiple sources while assuring that the individual always has control over who accesses the information (to the maximum extent allowed by law).

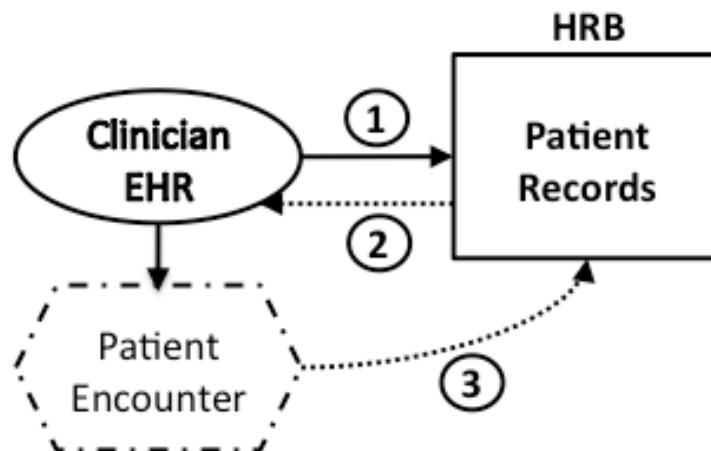


Figure 2. Patient-centric Community HII Architecture.

1. The clinician EHR requests prior patient records from the HRB
 2. The prior patient records are immediately sent to the clinician EHR
 3. After the care episode, the new information is stored in the clinician EHR and sent to the HRB; any inconsistencies or incompatibilities with prior records in the HRB need to be resolved before that patient’s records are requested again (but not in real time)
- (Note: This process is repeated whenever care is provided, resulting in the accumulation of each patient’s records from all sources in the HRB)

We then go on to describe how a national system of health record banks can provide a fully capable health information infrastructure for the nation that is simpler, less expensive, more secure, and can provide lifetime patient records. An infrastructure comprised of health record banks can meet the key requirements of comprehensive electronic patient information when and where needed, protection of privacy with dynamic patient access control, and financial sustainability. Since a separate HRBA white paper (HRBA, 2012) deals in detail with the issues around financial sustainability, only a brief overview of that issue will be provided here.

I. Overview

Each health record bank would provide individual accounts containing copies of medical records and additional information that optionally may be added by the consumer. The consumer explicitly controls who may access which parts of the information in the account. Health record banks may be local, regional, or national, and multiple competing banks are anticipated.

Each health record bank provides a secure internet-based interface for viewing and or downloading records. Also, each bank accepts deposits in one or more of a small range of standardized forms, for example, Clinical Document Architecture (CDA) via the Direct protocol. The source of each data item deposited is recorded, may not be changed, and is accessible to users.

A system of health record banks allows each person's comprehensive record to be in a single account in a single bank. Access permissions for the information in the account are stored so consumers do not have to be contacted to authorize each access. Furthermore, consumers can change their access permissions anytime in a single location, i.e., their health record bank account. Health record banks can provide a superset of anticipated health information exchange (HIE) functions including access to individual records, aggregation of records into reports (with consumer permission for use of data), quality reporting, and reporting to public health, all while protecting individual privacy by allowing each person to dynamically establish and maintain their own customized privacy policy.

II. Architectural Elements and Functional Capabilities

A. Administrative functions

1. Authentication. Patients are authenticated by their own health record bank to access their own account. This could be done, for example using a third-party open standard for authorization (e.g., OAuth). Providers must also authenticate using a standard procedure, which ideally would involve at least two factors.

2. Authorization. Authorization for viewing records is given by the consumer by logging into their health record bank account and setting or changing permissions. Authorization credentials would be sent electronically to providers that are allowed to access any portion of the patient's account. The level of granularity of information subject to patient permission is determined by each health record bank, but at a minimum allows differentiations of classes of information (e.g., medications, labs, problems). Provider directories are available to assist patients in transmitting authorizations. In an emergency, a provider could find a patient health record bank account with an account locator service (ALS), which could be operated by a neutral party such as the Health Record Banking Alliance. The provider could then connect to that patient's health record bank account using a secure Web connection and either an authorization token from the patient or from the ALS in an emergency (assuming prior patient authorization for emergency access).

3. Certification. It is anticipated that health record banks will regularly have their operations reviewed by independent third parties and receive both privacy

and security certification. Ultimately, this certification process would be subject to government oversight.

B. Deposits

Provider deposits are made securely to the health record bank (for example, using CDA via Direct protocols). The health record bank can function as the patient's Direct protocol secure e-mail provider, thereby receiving Direct messages on the patient's behalf and storing any attached information automatically in the patient's account. Patients may enter information through an interactive web interface or the health record bank may arrange for submission of documents via a file upload or other methods. Patients may also arrange for direct deposits of information from medical devices they are using, such as pedometers. For data integrity, all deposits are marked with the source of the data.

C. Communication

Health record banks would support patient-provider messaging through Direct. The patient would login and compose a message, which may include information from the record or permission to access information, and send the message to the provider. Since the health record bank would be the source of the patient's direct e-mail box, the bank would then transmit this message to the provider via Direct protocols. Any responses from the provider would be accessible to the patient, and providers may originate messages including attachments with information that would be deposited automatically in the patient's account. Both patients and providers may choose to be notified when messages are available via other non-secure channels, such as e-mail or text message (without any message content).

D. Access to records with permission

Providers or other authorized users can access patient information via credentials supplied by the patient or from the ALS, which is used to find patient health record bank accounts if the patient does not have or is unable to present information about their account (e.g., in an emergency). Exports or downloads of information from a health record bank account may be done by a provider or other authorized user. This can be accomplished using an XML payload with Web portal protocols so that the information can be incorporated in the provider's EHR system. All access to health record bank accounts is recorded in an audit trail that is accessible in an easily understandable form to the account holder.

E. Searching records with patient permission

Health record banks can be used to find subjects for clinical trials (search with notification). A neutral organization, such as the Health Record Banking Alliance, could distribute clinical trial subject request queries to multiple health record banks. Patients with the desired characteristics would receive notification that they are qualified for the trial, including contact information for the researchers. The organization requesting the search would only be notified of the number of eligible subjects that received such notifications.

Health record banks can also be used to generate anonymized reports for researchers and public health (search with reporting). A neutral organization, such as the Health Record Banking Alliance, could aggregate query results from multiple health record banks. These results would represent summary counts of patient characteristics and would be subject to statistical disclosure control to minimize the possibility of re-identification of individual patients.

III. Key Advantages of Health Record Banks Compared to the HIE

“scattered” Approach

- A. Patient permissions are more easily set or changed based on available stored data.
- B. Stakeholder cooperation is assured because patients request their records, invoking the HIPAA requirement for all providers to supply them in electronic form (U.S. 45 CFR 164.524(c)(2)).
- C. Retrieval of an individual’s comprehensive record is simple/fast because information is immediately available (no need for repeated queries to every source of patient data each time information is needed).
- D. Real-time patient matching not necessary; matching deposits to patient accounts occurs as information is received, not when it is immediately needed (avoids need for universal identifier).
- E. Record retrieval only requires each provider to have a single connection to HRB (vs. connection to every potential source of patient data).
- F. Searching is feasible as data for each patient is available in one place.
- G. Each patient’s longitudinal records are available (regardless of whether underlying records are retained).
- H. Decision support and filtering of data are facilitated by availability of comprehensive information.
- I. Scales infinitely with economies of scale (i.e., cost per account decreases as the number of accounts increase).

IV. Financial Sustainability

Each health record bank may be established and operated much more cost-effectively than an institution-centric HIE -- the estimated cost of an HRB is less than \$8/year/account (at scale). The low cost enables a number of potential business models for sustainability (HRBA, 2012). Holders of medical information only need to establish a single interface to a health record bank or to clearinghouse connected to the various health record banks serving that community, eliminating the cost of multiple interfaces. The health record bank approach avoids the costly real-time assembly of records from multiple sources since the comprehensive record for each patient is stored and immediately available for use. Queries (with patient permission) are easily accomplished and may provide an additional, potentially significant, source of revenue. Thus, a system of health record banks can provide health information exchange capabilities for the nation.

V. Conclusion

Our existing internet, telecommunications, and banking infrastructure can be used to facilitate health record bank development and operation. Health record banks meet the requirements for making comprehensive electronic patient information available when and where needed while fully protecting individual privacy and making information available for public health and research.

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