Chapter 20

The Health Record Banking Model for Health Information Infrastructure

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Abstract The goal of health information infrastructure (HII) is to assure the availability of comprehensive electronic patient records when and where needed. An effective HII must overcome the challenges of privacy, stakeholder cooperation, incomplete information, and financial sustainability. The recent increased adoption of electronic health records by providers has created a real opportunity for HII implementation. Attempts to implement HII with systems that attempt real-time aggregation of institution-centric records stored in multiple locations for each person has been unsuccessful. The high implementation costs, incomplete data that inevitably results from lack of availability of all relevant information sources, and the difficulty of assuring ongoing stakeholder cooperation are key factors. A network of health record banks, community repositories of electronic health records with access controlled by patients, can address the key HII challenges. Privacy is protected by patient control, allowing each individual to establish and maintain their own privacy policy. Stakeholder cooperation can be accomplished by having individuals request their own data, invoking the legal requirement for providers to supply digital copies of their records on patient request. To achieve interoperability, ongoing financial incentives to providers can ensure that data supplied uses acceptable standardized formats. Financial sustainability can be achieved through new value created by the information itself when utilized for innovative applications for both patients and other health care stakeholders that are only possible when comprehensive records of individuals are available. Health record banking can therefore unlock the potential of HII to simultaneously lower costs and improve the quality of care.

Keywords Health information infrastructure • Health record bank • Electronic health records • Privacy • Interoperability • Financial sustainability

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20.1 Introduction

Longitudinal patient data of individuals has great value for medical care and prevention as well as public health and research. Accessing such information is currently impossible, since the records for any given patient are fragmented over multiple locations, providers and formats (i.e., paper/electronic). The goal of universal access to comprehensive and lifetime patient data requires an electronic record and data model that (a) can aggregate all data for an individual in a usable, efficient and timely fashion, (b) maintains information assurance (confidentiality, integrity, availability), (c) aligns the interests of all stakeholders, and (d) is financially sustainable.

Design of an infrastructure to successfully support this vision requires consideration of the interdependent issues of information architectures, business models and standards that can overcome the flaws in current approaches. In addition to these considerations are the pragmatic issues of policy and governance (and modifications required to realize the vision) as well as the identification and monitoring of metrics to accurately assess progress in achieving a working health information infrastructure.

20.2 Need for Longitudinal, Patient-Centric Health Information Infrastructure (HII)

Healthcare data from individual patients is essential for medical care, the management and improvement of population health, and research. At present, longitudinal, lifetime health records of individuals are effectively unavailable. An additional challenge comes from the increasing use of personal monitoring devices, such as glucometers and pedometers that produce growing amounts of individual health data that have no natural “home” and are not easily combined with other health data to produce actionable information. The need to include genomic and other types of data (e.g. patient location data over time to assess environmental exposures) adds further complexity.

As a consequence, health care providers routinely utilize unpredictably incomplete patient information resulting in varying combinations of undertreatment, overtreatment, and inappropriate treatment producing both adverse outcomes and unnecessary costs [1]. A health information infrastructure (HII) that ensures the availability of comprehensive electronic patient information when and where needed could effectively address these issues.

Further exacerbating the problem of incomplete information is the complexity of current medical practice, which depends upon the “clinical decision-making capacity and reliability of autonomous practitioners for classes of problems that routinely exceed the bounds of unaided human cognition” [2]. Electronic health information systems could help address this problem with decision support to alert practitioners about recommended actions at the point of care. Many research studies have shown that such reminders improve safety and reduce costs [3, 4]. One study showed that medication errors could be reduced by 55 % [5]. A widely cited study by the Rand Corporation found that only 55 % of U.S. adults were receiving recommended care [6]. The same decision support methods used to reduce medical errors with electronic health information systems can also help ensure that needed care is provided. The importance of this grows as the population ages and the prevalence of chronic diseases increases.

HII has the potential to reduce the costs of healthcare. Inefficiencies as well as duplication in today's healthcare system are well documented and common. One estimate of anticipated nationwide savings from implementing advanced computerized physician order entry (CPOE) systems in the outpatient environment is $44 billion per year, [7] while another study [8] predicted $78 billion in additional savings from health information exchange (HIE) (for a total of $112 billion per year). Growing use of electronic prescribing has decreased the administrative costs of outpatient paper prescriptions and reduced transcription errors. More savings are possible in the inpatient setting – many hospitals have documented large net cost reductions from implementation of EHRs. A widely cited study anticipated that the patient safety and efficiency cost reductions from HII would be from $142 to 371 billion each year [9], and a literature survey found predominantly positive benefits from HII [10]. Of course, much of the predicted savings requires not only the widespread adoption of EHRs, but the effective electronic exchange of EHR data to ensure that comprehensive, lifetime medical records for every patient are readily available regardless of care setting.

20.2.1 Key Applications of HII

20.2.1.1 Decision Support

Guidelines and reminders also can accelerate the dissemination and routine adoption of new research results. At present, it is estimated that widespread clinical use of new research findings takes an average of 17 years [11]. Decision support that generates reminders about new research results at the point of care could substantially accelerate this process.

20.2.1.2 Research

An effective HII could also improve the efficiency of clinical trials. Today, most large clinical trials are supported by their own custom-built information infrastructure to ensure protocol compliance and collect research data. Comprehensive longitudinal records from an HII would allow clinical trials to be deployed via the dissemination of decision support guidelines that encoded the research protocol. Data collection could then occur automatically in the course of care, reducing time and costs. In addition, an HII would be able to support the analysis of de-identified aggregate patient care data to evaluate the outcomes of various treatments, as well as monitor the health of the population.

20.2.1.3 Public Health Surveillance

HII is also a valuable tool for early detection of disease patterns, especially outbreaks of newly virulent microorganisms or even bioterrorism. Our current system of disease surveillance, based on alert clinicians diagnosing and manually reporting unusual conditions, is both unreliable and slow. An example is the delayed detection of the anthrax attacks in the Fall of 2001, when seven cases of cutaneous anthrax in the New York City area that occurred 2 weeks before the "index" case in Florida were not reported to public health authorities [12]. Since all of these patients were seen by different providers, the overall pattern would not have been evident even if they had each been correctly diagnosed. Effective surveillance systems must have immediate electronic reporting to ensure early detection [13].

20.2.2 Increasing EHR Adoption Provides a Key Opportunity to Move Towards HII

The substantial increase in EHR adoption over the past few years creates a real opportunity for the information they contain to be used to compile more timely and complete longitudinal records for individuals as well as population health information. In 2013, over 50 % of health care providers were using EHRs, according to the Office of the National Coordinator for Health Information Technology (ONC) [14]. While this is very positive, much more progress is needed before we have a fully electronic health information system that can effectively monitor population health in real-time. EHRs alone are not sufficient for this purpose – mechanisms are needed to aggregate the information for each person into a longitudinal record and search those records across the entire population. So far, efforts to develop and deploy such "health information exchanges" (HIEs) have been problematic, with just a few partial successes [15].

It is clear that an HII providing anywhere, anytime comprehensive electronic patient records can simultaneously accomplish the goals of reduced costs, improved care, more effective population health, and more efficient research. Each individual's longitudinal record needs to be accessible for health care encounters, and must also be available for searching to perform population monitoring and customized preventive interventions.

20.3 Health Information Infrastructure Challenges

Establishing an effective HII has proven to be a challenging problem. At least four key obstacles have been identified: (1) *privacy* – the privacy of each individual's medical records must be protected; (2) *incomplete information* – all the records must be electronic in order to facilitate organizing and delivering comprehensive records for each patient; (3) *stakeholder cooperation* – physicians, hospitals, laboratories, pharmacies, imaging centers, etc., must all contribute their patient records; and (4) *financial sustainability* – operational funding must be available on an ongoing basis [16]. A recent study found that 75 % of HII projects in the U.S. have yet to achieve financial sustainability [17].

In considering HII, the critical questions are how such a system would operate and how it can be built. One promising vision that has been proposed is a network of health record banks (HRBs), community repositories of health records with access controlled by patients. Storing health records for each person in one place (but not everyone's health records in the same place) and letting patients control access provides a potentially effective approach for solving the complex, interrelated problems of privacy, stakeholder cooperation, incomplete information, and financial sustainability [16]. In this section, we will discuss the HRB approach in more detail in the context of the first two major HII challenges. The other two challenges will be addressed in the following section on Architecture.

20.3.1 Privacy

Privacy has been defined as the right of individuals to hold information about themselves in secret, free from the knowledge of others [18]. This definition implies that private information has not been disclosed to any third party. *Confidentiality* is the assurance that information about identifiable persons, the release of which would constitute an invasion of privacy for any individual, will not be disclosed without consent (except as allowed by law) [18]. The exception for release of confidential data without consent when allowed by law may at first seem objectionable. However, this exception may be more comfortably interpreted as "community" consent through elected representatives who have determined that this information must be available for the good of all. Confidential data should never be released without consent – but community consent implies that the consent has been codified legally through the legislative process.

It is clear from these definitions that concerns about the release of medical information typically relate to confidentiality rather than privacy, since "privacy" strictly refers to prevention of information release while confidentiality covers the appropriate use of sensitive information after it is released. However, we will adopt the common (although arguably somewhat inaccurate) use of the term privacy to refer to concerns about release of sensitive information.

From the perspective of consumer acceptance, privacy is the most important and overriding requirement of HII. While other aspects of information assurance, such as integrity and availability of information, are also essential to an effective HII, consumers generally focus their concerns on privacy. Clearly, health records comprise a very sensitive – perhaps the most sensitive – type of personal information. Disclosure of medical information can be frankly embarrassing and can even lead to employment (or other) discrimination. Perhaps more importantly, failing to assure the privacy of medical records will make patients much less willing to divulge critical personal details to their providers – and perhaps even avoid seeking medical care at all. Besides the actual contents of the records, the very existence of some records (e.g., a visit to a clinic for sexually transmitted diseases) is sensitive even if no other information is available. Clearly, any HII system must rigorously prevent unauthorized disclosure and use of medical records.

In the U.S., the HIPAA Privacy Rule [19] that governs the release of medical information generally requires patient consent for medical record disclosure and use. However, consent is waived for sharing of records for the purpose of treatment, payment, and healthcare operations. These "TPO" exceptions have, over time, allowed healthcare organizations to utilize medical records extensively without patient consent. An organization that collects and stores medical information has full discretion to decide whether a proposed disclosure is or is not eligible for one of the TPO exceptions. Until recently, there was no requirement for such TPO disclosures to be recorded, thereby effectively eliminating the possibility of audits to determine the existence of improper disclosures. While the 2009 HITECH legislation requires an audit trail of TPO disclosures, such disclosure records are not readily available to patients. As a result, individuals both lack control over the dissemination of their medical records, and are not informed when they are disclosed beyond the provider site (or other location) where they were created.

Overriding individual consent as allowed in the HIPAA privacy rule can be problematic. Most people understand that improving the availability of electronic patient records for appropriate and well-justified purposes simultaneously means they will be more accessible for undesirable uses. Additional efforts to prevent the latter with more stringent protections of the information are therefore needed to avoid (or at least minimize) abuses. Allowing anyone other than patients themselves to approve disclosure of personal medical records inherently erodes trust. By doing this, the message to patients is, in essence, "other people are going to determine who should be able to see your medical records because they understand what's in your interest better than you do." It is inherently difficult for patients to understand why, if a given disclosure is in their interest, their consent should not be obtained. Not seeking patient consent clearly leads to suspicion that the disclosure is in fact not in the interest of the patient, but rather benefits whoever is deciding that records will be shared.

These concerns about medical record privacy are not theoretical. Surveys have shown that 13–17 % of consumers already use "information hiding" behaviors to prevent access to their medical records [20, 21]. Examples of this include using an alias for laboratory testing or seeking treatment in another state. This substantial minority of consumers would certainly refuse to participate in an electronic medical information system unless it provided them with the opportunity to fully control access to their own records. Furthermore, these surveys likely underestimate the proportion of the population with concerns about these privacy issues because of the natural reluctance of respondents to admit to such behaviors. In addition to opting out of a system that did not provide individuals with control over their records, it is likely that these concerned consumers would organize and apply political pressure to prevent the development and operation of such a system. An example of this occurred in response to the original HIPAA legislation that called for a unique medical identifier for all U.S. residents. An extremely small percentage of concerned citizens, citing the threat to privacy, successfully lobbied Congress to defund these unique identifier provisions shortly after their enactment, effectively preventing any implementation activities.

In view of these considerations, a strong case can be made that decisions about access to patient records should be entrusted to the patients themselves (except in rare cases such as mental incompetence) [22]. It is also clear that these access control issues are especially important for enabling HII, because success depends on patients trusting that their records will only be used for their benefit. While there are legitimate concerns that some patients may not be sufficiently informed to make such decisions and could make access choices that may be harmful, delegating this decision-making to anyone other than the patient will likely have a much larger (and more certain) negative impact. As an analogy, we as a society agree that individuals should retain the right to decide how their financial resources are allocated, even though this clearly leads to negative consequences when consumers act unwisely. Indeed, prior to the 2002 HIPAA Privacy Rule establishing the TPO exceptions, patient consent had always been required for access to medical records.

In a system where patients control access to their own medical information, education and assistance related to decisions about sharing that information would clearly be needed. Managing access to personal information is a new concept for most people, so some confusion about this new responsibility is inevitable. Similar to current policies for patient consent to treatment, rules and guidelines need to be established for delegating information access decisions when patients are unwilling or unable to decide for themselves.

While the need for consumer education about decisions relating to release of medical records is clear, medical information privacy policy issues are both important and urgent in the context of the enhanced trust necessary to implement an effective and widely accepted HII. In particular, we will see in the following sections that a key advantage of an HII comprised of health record banks is that privacy is protected through individual control of access to each individual's own records. Each person is therefore able to establish and maintain his/her own custom-tailored privacy policy. As a practical political matter, such a system of individually determined (and easily modifiable) privacy policies is much more likely to engender widespread support than any specific, uniform policy that does not provide for individual choices.

20.3.2 Availability of Electronic Records

To ensure the availability of comprehensive patient information, every medical record from all healthcare providers must be electronic and available for immediate use. With respect to the latter issue, it would be ideal if stakeholder cooperation in supplying these records were voluntary. However, assuring long-term collaboration of competing healthcare stakeholders to make electronic records readily available is extremely difficult. In practice, only a very few communities have been successful in developing an organization with the active participation of the majority of healthcare providers. Even in these rare communities, the arbitrary withdrawal of one or more participants is an ongoing risk, and would be disruptive to the system. The experience in most communities is that healthcare stakeholders, fearing loss of competitive advantage, are quite reluctant to share patient records. Because of this, legally mandated sharing of records is necessary.

Clearly, the electronic exchange of health information requires the information itself to be in electronic form. Although laboratory results and prescription medication information are nearly all electronic already, patient records, particularly in the outpatient domain, are not. While estimates vary, it is clear that a major fraction of office-based physicians have not yet adopted comprehensive EHR systems, even though there have been substantial government incentives to do so for the past several years. In addition, many physicians who do use electronic records have systems with limited capabilities [23].

20.3.2.1 Cost as an Obstacle to EHR Adoption

The biggest cost-related challenge for physician EHR adoption is that most of the benefits of outpatient EHRs accrue not to the physician, but to other stakeholders. One study reported that physicians derive only 11 % of the economic benefit, with the remaining benefits attributed to other stakeholders [24]. It is not surprising that physicians are reluctant to assume 100 % of the cost of systems for which they receive a small fraction of the benefits.

While the substantial EHR subsidies in the 2009 HITECH Act ($44,000–$63,750 over 5 years) have greatly increased EHR usage over the past several years, they only partially cover the costs of physician EHR systems. In particular, conversion costs related to reduced revenue from lost productivity during the transition from paper to electronic records are quite substantial. Furthermore, while the costs of EHRs continue indefinitely for physicians, the HITECH subsidies are temporary. In view of this, it is clear that providing ongoing reimbursement and/or other offsetting benefits for EHRs would better allow physicians to recoup their costs and promote higher levels of EHR adoption. This is important in building a sustainable HII since its effectiveness depends on all the records being electronic.

Hospitals, on the other hand, have a more substantial economic incentive for EHRs, since reducing costs will improve their financial performance under the diagnosis-related groups (DRG) reimbursement system that pays fixed amounts for specific conditions. In addition, it appears that the large HITECH incentives for hospitals have been sufficient to induce widespread EHR adoption. Even so, coordinating patient records during a hospital admission is largely an internal problem that does not benefit from an HII (although having an HII is very helpful prior to and at the time of admission, and can even help prevent unnecessary hospitalizations). But the vast majority of healthcare encounters do not involve hospitals, so HII efforts have the greatest potential for benefit in the outpatient environment.

While universal EHR adoption is necessary for an effective HII, it is not sufficient. In essence, each individual EHR system converts a "silo" of paper-based information into electronic form. EHRs are therefore capable of managing each individual provider's information about each patient, but, with rare exceptions, do not contain *all* the information for each patient. To ensure availability of comprehensive patient information, it is necessary to have a cost-effective and efficient mechanism that compiles and combines the records of each patient that are currently scattered among all their providers. It is these truly comprehensive records that can improve quality and reduce costs, e.g., through elimination of duplicate tests and procedures.

20.4 Health Information Infrastructure Architecture

20.4.1 Institution-Centric Architecture

Most existing HII systems utilize an institution-centric approach to data storage that leaves patient records stored wherever they are created (Fig. 20.1). To efficiently retrieve the records when needed, it is necessary to establish and maintain

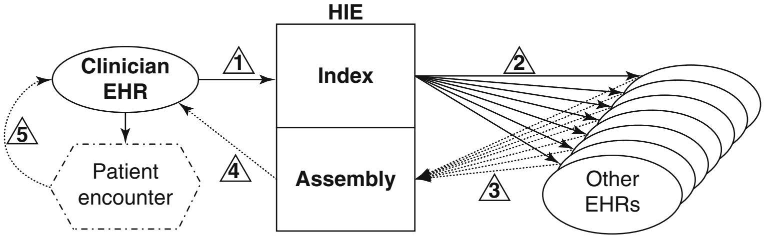

Fig. 20.1 Institution-centric HII architecture. *1*. The clinician EHR requests prior patient records from the health information exchange (HIE); this clinician's EHR is added to the index for future queries for this patient (if not already present). *2*. Queries are sent to EHRs at all sites of prior care recorded in the HIE Index. *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. (Used with permission of the Health Record Banking Alliance [25])

a central index of the locations of information for each patient. If such an index were not available, finding all the information for a given patient would be impractical, requiring queries to every possible source of medical information worldwide. When a patient's record is requested, the index determines which locations are queried to retrieve the needed information. The results of queries to those locations are then combined (in real time) to retrieve and compile the patient's complete record. After the patient encounter is complete, any new data that was generated is entered into the clinician's EHR system. The index is then updated with a pointer to that system (if not already present) so that it will be queried (in addition to all the other prior locations) when that patient's record is subsequently requested.

Healthcare stakeholders like this architecture because it allows them to "control" the records they generate. However, it does not allow efficient searching, is complex and expensive to operate, and does not scale. With this approach, searching the data, e.g., to find all patients with an elevated HbA1c (hemoglobin A1c, an important indicator of blood sugar control in diabetics), requires each patient's records to be assembled from their various locations and checked one at a time. In contrast to routine computer searching techniques that use a pre-computed index (much like using an index of a book to find the location of a word of interest), this is a slow sequential search.[1] This is a huge computing and communications burden that both increases the cost of EHR operation (since the EHR must be able to perform the additional processing associated with queries) as well as reducing security because of the risk of interception of information which is transmitted in full for each query. Standard database systems pre-index the contents of their records to greatly reduce search times. In this architecture, pre-indexing would effectively create a central repository of indices that could be used to reconstruct most of the original data, creating the same security vulnerabilities as a central database itself (which would defeat the purpose of this approach to avoid such a central repository).

To address this problem of slow sequential searching, it has been proposed that queries in an institution-centric architecture could be distributed to each provider system and the results aggregated. However, this approach cannot reliably produce correct output because individual patient records in each system are incomplete. As a result, queries that request multiple patient data items (e.g., patients with diabetes who have taken a certain medication in the past 6 months), will produce anomalous results unless all the relevant data for a given patient happen to be stored in a single provider system (i.e., if one system finds a patient with diabetes, but with no record of the medication of interest [which is in a different system], that patient will not be counted as satisfying the query). In addition, if multiple systems have all the data

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[1] The completion time of such a sequential search increases linearly with the number of records being examined. For example, in a modest-sized community with 500,000 patients, with retrieval and processing time of each patient's records of just 2 s (a low estimate), such a search would take at least 12 days (1 million seconds). Even worse, every search requires that each connected EHR retrieve and transmit all its information.

needed about a specific patient for a given query, that person may be counted twice or more as meeting the specified conditions. Therefore, queries across multiple institution-centric data sources produce unpredictable numbers of undercounts, overcounts, or both.

Besides searching issues, response times for assembling a patient record can also be problematic. To assemble a given patient record, the locations where the patient has available records are determined by the central index. Then, each location where patient records are available is queried to obtain the patient's information. After all the systems have responded, the results are then integrated into a comprehensive record to be sent to the requestor. While the queries can all be done in parallel, the final integration cannot be completed until the last response has been received. As the number of queried systems increases, so does the likelihood of a slow (or missing) response from one of them. Also, more queried systems require more processing time to integrate all the information into a single record. As a result, the response time grows as the number of queried systems increases.

The institution-centric architecture is also operationally complex. To ensure complete patient records, all the systems that contain information about each patient must be available. Assuring this requires a 24 × 7 network operations center (NOC) that constantly monitors the operational status of every medical information system. This NOC must be staffed with senior IT personnel to rapidly troubleshoot and correct any problems that are detected. Even with highly reliable systems (e.g., with failure rates of one per thousand), an institution-centric system with thousands of EHR information sources will frequently have systems that are unresponsive to patient record queries that need immediate expert repair. The cost for such a NOC is very substantial, since least five full-time staff would be needed to assure round-the-clock coverage 7 days a week.

Adding to the cost of the NOC, each EHR in an institution-centric system must have the built-in capacity to respond to 24 × 7 queries in real-time. This means that every EHR would require additional hardware, software, and communications capacity so that it can both serve its local users efficiently and simultaneously respond to outside queries for records. The volume of such outside queries would be substantial, since each patient's records will at a minimum be queried whenever they receive care at any location. This is in contrast to a central repository model (such as health record banking, discussed below), where information from each care episode is transmitted once to the repository and no further queries to the source system are ever needed. A recent simulation study demonstrated clearly that both the transaction volume and probability of incomplete records (because information was not retrieved from a malfunctioning network node) increase dramatically with the average number of sites where each patient's data is stored in an institution-centric architecture [26].

20.4.2 Person-Centric Architecture (Health Record Banking)

Health record banks represent a person-centric approach to community HII that can overcome the challenges faced by current efforts while meeting all the necessary functional requirements [27]. A health record bank (HRB) is defined as "an independent organization that provides a secure electronic repository for storing and maintaining an individual's lifetime health and medical records from multiple sources and assuring that the individual always has complete control over who accesses their information" [28].

20.4.2.1 Overview

The operation of an HRB is much simpler than an institution-centric architecture (Fig. 20.2). Upon enrollment or prior to a care episode (except an emergency), the patient's consent for the provider to access his/her HRB records (either all or part) is captured and stored. The caregiver then accesses (and/or downloads) the records through a secure Internet site. When the encounter is complete, the provider uploads the newly generated information to the HRB, which is added to the account-holder's lifetime health record. The updated record is then immediately available for further use.

Storing health records for each person in one place (but not everyone's health records in the same place) and letting patients control access allows the complex, interrelated problems of privacy, stakeholder cooperation, incomplete information, and financial sustainability to all be successfully addressed. In contrast to the

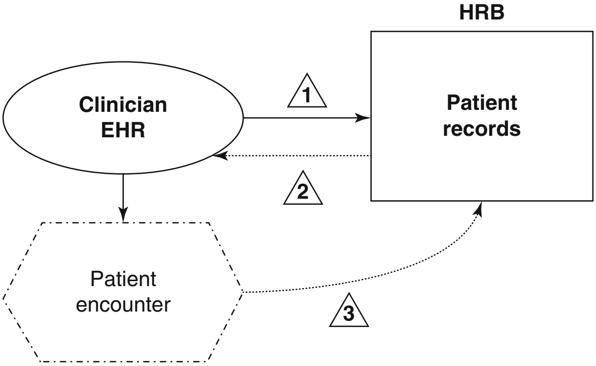

Fig. 20.2 Person-centric HII architecture. *1*. The clinician EHR requests prior patient records from the HRB. *2*. The prior patient records are immediately sent to the clinician EHR. *3*. After the care episode, the new information is stored in the clinician EHR and sent to the HRB; any inconsistencies 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). (Used with permission of the Health Record Banking Alliance [25])

frequently used institution-centric architecture for managing electronic health records, where each patient's records are stored where they are created and only assembled when needed (in real time), the centralized HRB approach has been demonstrated in simulations to be considerably more efficient and less subject to retrieval errors [26]. It can also support efficient searching of health records for research and policy purposes, with patient consent.

20.4.2.2 History

The person-centric health record banking architecture was first described by Szolovits [29]. Several years later, it was called a "health information bank" in the U.K. [30], and was subsequently termed the "bank of health" [31]. The legal aspects of a "health record trust" were described in 2002 [32], and the "health record bank" architecture was highlighted by Dyson in 2005 [33]. In 2006, a policy paper from the Heritage Foundation recommended health record banking [34], other authors provided details of their HRB vision [35, 36], and the non-profit Health Record Banking Alliance (HRBA) was organized [37]. That same year, Washington State recommended HRB implementation after a 16-month health information infrastructure study [38] and the non-profit Dossia consortium of several large employers was started to develop an HRB for their employees [39]. The following year, the Information Technology and Innovation Foundation endorsed the health record banking approach for the U.S. HII [40], and Gold and Ball termed the architecture an "imperative" [41]. Also in 2007, both Google and Microsoft introduced their own patient-controlled medical record repository products designed for general consumer use. In 2009, an HRB pilot was started in Rotterdam, Netherlands,[2] three more pilot HRBs received initial grants from the State of Washington, and the privacy protection benefits of HRBs were described [42]. The HRBA has released white papers describing HRB architecture [25], business models [43], and policy recommendations showing how HRBs can promote and achieve interoperability [44]. Another recent article describes the practical implementation experiences of a community-wide HRB startup in 2010 [45]. The person-centric, patient-controlled architecture of HRBs continues to be regularly referenced in articles discussing the need for comprehensive EHRs [46–50, 15, 51].

20.4.2.3 Security

One security concern about the health record banking approach to HII relates to the misguided belief that information security is weaker in a central database than if the information is physically dispersed. However, it is well known that a properly protected repository is really more secure than the equivalent distributed system [52]. First, the protocol for immediately locating and retrieving each patient's records in

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[2] http://webwereld.nl/nieuws/54340/rotterdam-start-eigen-versie-elektronisch-patiDOUBLEHYPHENntendossier.html. Posted January 14, 2009 (Accessed 26 December 2014).

a distributed system is just as vulnerable as retrieval from a central data repository. Second, when data is aggregated from distributed locations, the risk of interception doubles since data are transmitted twice for each use: once between the storage site and the aggregation point, then again from the aggregation point to the end user. Third, data in a central system are more easily protected because it is "much easier to enforce strict security access controls when there are fewer doors or when the entry points are centralized" [53]. Fourth, double encryption of the data can prevent unauthorized "total access" to the entire database, with one key held by the patient and the other by the HRB. Finally, the use of multiple community-based HRBs limits the quantity of data in any single system, establishing an upper limit on the potential consequences of a breach. Overall, HRB security is objectively superior to an equivalent distributed system.

20.4.2.4 Financial Sustainability

Long-term financial sustainability for HII can be achieved with three general mechanisms either individually or in combination: (1) taxation; (2) redirecting healthcare cost savings; or (3) leveraging new value created by the HII. Advocates of public funding through taxation assert, with some justification, that an effective HII is a public good with universal benefit, analogous to other important infrastructure such as roads. However, new taxes are generally unpopular and therefore politically challenging to enact. Also, there are examples of other critical infrastructure, such as public utilities and the Internet that, although regulated, are supported with user fees rather than taxation. Nevertheless, there are at least two states, Maryland and Vermont, that are using public funds to at least partially support their HII systems.

Redirecting health care savings to pay for HII is the most common sustainability approach. The justification for this is sound, relying on the large evidence base indicating that higher quality and lower cost care can be achieved with the availability of more comprehensive electronic patient records [10, 54]. Examples include several large, generally closed healthcare systems such as Group Health, the Veterans Administration, and Kaiser Permanente, where the widespread adoption and use of electronic medical records has resulted in better care at lower cost. While the evidence that HII can reduce healthcare costs is persuasive, the timing and distribution of the savings cannot reliably be predicted. Also, one healthcare stakeholder's cost savings is another's revenue loss. The organization losing income will of course find this result very undesirable, and as a result will strongly oppose any initiatives that even *appear* to have the possibility of this outcome. In addition, the distribution of savings is not known in advance, making all organizations unable to make specific financial commitments with the confidence that a positive return on their investment will be forthcoming.

The third approach to financial sustainability of HII, utilizing the new value created by the availability of comprehensive electronic information, has generally not been explored. Although there is widespread agreement that HII information will have substantial value for many important and worthy purposes, minimal attention has been devoted to specific methods for capturing this value to create a viable business model. One example of such new value that has been recognized in a few communities is reducing the cost of delivering laboratory results to ordering physicians. A unitary community infrastructure providing electronic lab result delivery to physicians is much more efficient than current duplicative systems. Another example of potential value is the use of medical information for research – both for research queries and to find eligible subjects for clinical trials. Even though the use of the medical information for research can produce revenues that cover a substantial part of the costs of HII, the required supporting mechanisms for both searching data and recording and maintaining patient consent have not typically been implemented in today's HII systems.

Innovative applications that deliver compelling value to consumers and other healthcare stakeholders based on the underlying information are potentially one of the largest and most promising sources of HII revenue [45]. These include timely and accurate reminders and alerts to patients (and their families) for preventive services, medication refills, and other medically related events of immediate interest. Another example is applications that assist consumers to more easily manage their chronic diseases. Such an "application ecosystem" was described as a key element of the business model to support Microsoft's HealthVault™ personal health record system [55]. Utilizing the new value of medical information to sustain HII avoids the allocation, timing, and prediction issues inherent in leveraging anticipated healthcare cost savings, with the added benefit that with this model any such savings accrue to the stakeholder that achieves them.

Finally, the person-centric health record bank approach facilities revenue generation from advertising to consumers (who are more likely to engage with their comprehensive records), including sponsorship of specific patient groups by interested healthcare stakeholders.

20.4.2.5 Interoperability

Interoperability requires the use of standards so that information transferred from one medical information system to another can be understood and interpreted correctly, retaining the same meaning. Ultimately, standards compliance must be mandatory to ensure universal adoption. Such mandates can take the form of regulations, payment incentives, or both. To be effective, compliance must also be monitored continuously.

The HRB approach can incentivize the use of standards to ensure interoperability. If, as has been proposed [45], cloud-based EHRs are provided at no charge to outpatient physicians by an HRB, the HRB will only select those systems that can transmit information back to the HRB in a standard format. For physicians who currently have EHRs, an HRB may provide payments for data deposits from those systems that would be conditioned on the consistent use standards-based transactions. Over time, additional encoding and structuring of medical information can be required with gradually more stringent data deposit requirements (with sufficient lead time to allow systems to be upgraded). Overall, compliance with standards can be consistently assured through the direct relationship to ongoing payments.

20.4.2.6 Challenges

Although the HRB approach can successfully address the key obstacles to a successful HII, as of this writing there are no large-scale operational examples in communities. The most obvious reason has been lack of funding. ONC did not allow any of the $564 million allocated to the states for HIEs over the past several years to be used to build HRBs, even for those few states bold enough to propose this. To some extent, this is because the healthcare stakeholders (and the general public) have been very wary of centralized repositories because of the perceived vulnerability to loss of all the data in a single security breach. As discussed in the Security section above, despite the fact that state-of-the-art computer security requires sensitive information to be segregated in one place so that it can be effectively protected, the fear of the "database in the sky" has permeated HII discussions. A requirement to avoid centralization has been a consistent "precondition" to nearly all such efforts. For HRBs to gain traction, it may be necessary to find an alternative architecture that can store each person's records in one place (with patient control of access) while still allowing efficient searching across records without the need for a central repository or index.

In addition, while HRBs do have a feasible business model, a large critical mass of subscribers are needed to generate sufficient revenue to offset the substantial fixed costs, particularly for the first implementation. The cost of achieving the necessary scale (perhaps $10 million) represents a one-time obstacle that must be overcome to provide an initial successful HRB demonstration project. While these funds could logically be provided by one or more of the many current initiatives promoting innovation in health care, such an investment has yet to occur.

Finally, healthcare stakeholders have been reluctant to cooperate in the creation of HRBs in their communities, fearing loss of competitive advantage when comprehensive information for each patient is readily available. However, the increasing focus on population health, incentivized by the Affordable Care Act, makes HRBs an important potential asset. Population health activities require comprehensive information on each patient, which is not otherwise accessible to Accountable Care Organizations (ACOs) created to promote health and reduce the need for medical care with effective prevention. Hopefully, the recognition that HRBs can solve this problem will accelerate their adoption.

20.5 Policy Issues in Health Information Infrastructure

The trust problems inherent in the current HIPAA policy framework, as modified by HITECH, were described above in the Privacy section. An alternative, and arguably more effective, policy approach would be to require patient consent for any and all use of personal health information. This would reinstate the policy in place prior to the 2002 HIPAA Privacy Rule that created the “treatment, payment, and operations” exceptions to patient consent for medical record disclosure. Such a policy change would be an important first step toward transferring ownership of the medical records to the patient. Today, providers own patients’ medical records, with patients entitled to a copy on request. Reversing this would be very helpful in ensuring privacy since the provider’s copy of the records would then be available only for the provider’s own use. Provider disclosure of records to other parties without patient consent would be prohibited.

However, to avoid disruption of current systems of care, such a major policy change in handling medical information would need to be implemented gradually. One potential first step of such a process could be a large-scale demonstration showing that patient ownership and control of records is practical, can be readily implemented with today’s HIT technology, and can facilitate both better health care for both individuals and the population. After a successful initial project, a plan for gradual transition could be developed and executed in an orderly fashion over several years, allowing sufficient time to implement needed changes in provider health record systems.

20.5.1 Necessary Exceptions to Patient Control of Access to Their Information

Despite patients’ ownership and control of their medical information, there are justifiable cases for overriding individual consent for the good of the community. For example, reporting communicable diseases to public health authorities has historically been done without individual consent since it is necessary to protect the general population. Availability of controlled substance prescription information to providers is another case where consent must be balanced with community needs. It would not make sense to enable fraudulent multiple prescriptions for narcotic painkillers by letting individuals deny consent for providers to access their medication information. However, limitations on individual consent for access to information should be as minimal as necessary to address the specific problems identified. In the case of patients denying providers access to their controlled substance prescription records, for example, any provider treating the patient and accessing their medical records might receive a message indicating that some medication information has been withheld (without actual information being displayed). Providers would thus be alerted to a potential problem, while patients would still have some ability to protect their information. With medical information access controlled by patients, it seems likely that a limited number of additional public policies, such as access control policies for minors, will be needed to ensure that, when it is appropriate, essential community interests supersede individual rights.

Another commonly cited need for an exception to patient control of access to medical information is “break the glass” functionality in an emergency. This would allow emergency providers to access patient records regardless of consent. However, this can easily be addressed by asking patients to agree to such emergency access in advance. If patients indicate that they do not want emergency providers to have access to their records, they would be clearly informed of the potentially lethal consequences of such a decision. Should a patient insist despite this warning, it is difficult to argue that their request should be overridden. Of course, to make such a system of emergency access effective, all providers would need to be aware that abusing the system (i.e., by fraudulently accessing patient records claiming a nonexistent emergency) would immediately and consistently result in serious sanctions.

20.5.2 Current U.S. Government Programs

Under the HITECH Act, the Meaningful Use regulations provide substantial financial subsidies for physicians and hospitals adopting and using EHR systems. This has resulted in a substantial increase in EHR usage. For the Stage 1 Meaningful Use criteria, it has been reported that over 50 % of physician offices [56] and 42 % of hospitals [57] are using qualifying EHR systems. However, even if all eligible physicians and hospitals met all Stages of the Meaningful Use criteria, the availability of comprehensive electronic patient records when and where needed would not be assured. To accomplish this, an effective HII that can aggregate each person's individual records from all sources is also necessary. As recognized in the HITECH legislation, which provided $564 million of HII funding to the states distinct from the Meaningful Use incentives, this aggregation requires additional infrastructure and cannot be accomplished solely by individual providers.

The view, download, and transmit (VDT) requirement included in Meaningful Use Stage 2 (effective October, 2013, for hospitals and January, 2014, for office-based providers) has the potential to be very helpful in facilitating HII. VDT mandates that all providers must give patients the capability to access and electronically transmit their records to any destination they choose using standard coding and formats. To fully qualify, providers must also demonstrate that at least 5 % of their patients are taking advantage of this service. VDT compliance is also required for EHR technology certification, so EHR vendors are adding this capability to their systems. The resultant widespread implementation of VDT will allow patients to routinely direct that their electronic medical records be transmitted to a destination of their choice. This will enable patient-selected third parties (such as health record banks) to compile comprehensive person-centric records over time and make them available to subsequent providers at the direction of each patient.

A related messaging standard, the ONC Direct protocol,[3] is designed to enable transmission of medical record information from one point to another using standards. Although Direct was initially designed to be a "provider to provider"

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[3] http://wiki.directproject.org/file/view/DirectProjectOverview.pdf (Accessed 26 December 2014).

communication capability, it can also effectively transmit patient information as required by VDT. This could, for example, involve sending patient data to a health record bank where it can be integrated with prior information for that patient and stored as a longitudinal record. Therefore, the Direct protocol also has the potential to be very helpful in facilitating HII development.

20.5.3 Opportunities for Innovation and Discovery

The availability of population data from an HII can enable greater health policy flexibility and experimentation. Today, it typically takes years before information is available to assess the impact of a health policy intervention. Naturally, this makes policymakers very reluctant to make changes without compelling justification of the anticipated positive benefits. But if near real-time population data were available for analysis, policy changes would be much less risky because unanticipated negative consequences could be ascertained rapidly. If needed, a new policy that was not working as expected could be reversed before its negative impact was widespread.

Timely availability and appropriate use of population health data can also inform other policy domains at federal, state, and local levels that impact health, such as education, housing, the environment, and criminal justice. An effective HII can provide aggregated personal health data to guide government policy decisions, greatly improving our ability to understand and address critical citizen needs and promote a healthier society.

In addition, population health data would facilitate our discovery and understanding of unanticipated relationships between activities and events, e.g., emergency room visits and air quality. Today, investigating such correlations often requires expensive and time-consuming clinical trials. Readily available data allows these correlations to be found more quickly and easily, and also can facilitate the analysis of complex interactions.

20.5.4 The Information Economy

There is growing value in aggregating many types of personal information, not merely health records. Our progress in extracting this value will be accelerated by replacing our current "whoever has it can use it" approach to the management of highly valuable personal information with a policy of personal ownership and control by declaring each individual's personal information as their property, only to be used by others with permission. Not only is this approach inherently fair and protective of privacy, but persuasive arguments have been made that "permission-based" use of personal information would create huge new markets and economic activity [58]. A recent example of this is the $60 million Genentech agreement with 23andMe for access to the health and genetic information of thousands of patients (with their permission) [59]. Regardless of how policy evolves, it is clear that individual health records have tremendous value for both individuals and the whole community. The policy challenge is to move rapidly to extract those benefits for the good of all, while simultaneously minimizing potential harm.

20.6 Measuring Progress

Metrics that can quantify our progress toward an effective HII have largely been neglected. Several desirable features of such HII progress measures have been described [60]. First, they should be sensitive enough to reflect changes over reasonable time periods, for example, 1 year. A progress measure that remains unchanged over many years despite real advances toward the goals would not be helpful. Second, the measures should be comprehensive so that they incorporate the activities and outcomes that are important to the key stakeholders. A measurement system that ignores a key element that must be present in an effective HII would be suboptimal. Third, the measures should be meaningful to policymakers. If the metrics are overly technical or otherwise difficult to understand, they will not be useful in guiding priorities and resource allocation. Fourth, the measures should be easy to determine (or estimate) so that the evaluation process does not divert substantial resources from the actual work. Finally, when the target values for all the measures are attained, the original goals of a complete and fully functional HII should have been reached.

Based on these criteria, currently used metrics are largely ineffective. For example, measuring whether or not health information is being exchanged at all or how many "exchange messages" occur has little value. The number of messages that need to be exchanged in order to assure the availability of comprehensive information for each patient is unknown (and unpredictable). Therefore, monitoring the message count over time does not indicate whether or not the goal of comprehensive information for all patients is close to being met. Although an increasing number of "exchange messages" would show progress, it does not allow assessment of how much more needs to be accomplished.

Using the above measurement criteria as a guide, Labkoff and Yasnoff identified and validated a combination of four measures for the quantitative evaluation of HII progress in communities: (1) completeness of information, (2) degree of usage, (3) types of usage, and (4) financial sustainability [61]. Using this assessment method, four of the most advanced community HII projects in the U.S. at that time earned scores of 60–78 (on a 0–100 scale), indicating that substantial additional work was required before their community HIIs could be viewed as complete.

However, one critical dimension of progress not covered in the Labkoff and Yasnoff evaluation framework is the extent of semantic encoding of electronic health records. Clearly, the electronic exchange of images or pdfs of clinical documents, where the content is not readily machine-interpretable and can only be read by an end user, will not enable the record integration, analysis, and decision support that an HII must ultimately provide. The end goal is fully standardized and encoded electronic health records so that all the information is computable. A progress measure that would capture the degree to which this standardized encoding has been accomplished would be an important and valuable addition to the evaluation process.

20.7 Conclusion

Health information of individuals is critical to medical care, research, and population health. Clearly, the timely availability of this information can contribute significantly to the overall health of our society. However, in order to successfully implement an effective health information infrastructure (HII), the complex and interrelated problems of privacy, stakeholder cooperation, incomplete information, and financial sustainability must all be addressed. One proposed approach to HII that can overcome these problems and appears to provide a feasible path toward an effective HII is health record banking. This or a similarly effective alternative approach is likely to be the basis of HII implementation over the next few years. Regardless of how it is architected, an HII comprised of both EHRs and mechanisms to aggregate records from them for each person will be a key ongoing data source for monitoring and improving both individual health and the health of our communities in the years ahead.

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