Health Information Infrastructure

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After reading this chapter you should know the answers to these questions:

- What is the vision and purpose of Health Information Infrastructure (HII)?
- What kinds of impacts will HII have, and in what time periods?
- Why is architecture so crucial to HII success?
- What are the political and technical barriers to HII implementation?
- What are the desirable characteristics of HII evaluation measures?

13.1 Introduction

This chapter addresses **health information infrastructure** (**HII**), community level informatics systems designed to make comprehensive electronic patient records available when and where needed for the entire population. There are numerous difficult and highly interdependent challenges that HII systems must overcome, including privacy, stakeholder cooperation, assuring all-digital information, and providing financial sustainability. As a result, while HII has been pursued for years with myriad approaches in many countries, progress has been slow and no proven formula for success has yet been identified.

While the discussion here is focused on the development of the HII in the United States, many other countries are involved in similar activities and in fact have progressed further along this road. Canada, Australia, and a number of European nations have devoted considerable time and resources to their own national HIIs. The United Kingdom, for example, has spent several billion pounds over the last few years to upgrade substantially its health information system capabilities. It should be noted, however, that all of these nations have centralized, government-controlled health care systems. This organizational difference from the multifaceted, mainly private health care system in the U.S. results in a somewhat different set of issues and problems. One can hope that the lessons learned from HII development activities across the globe can be effectively shared to ease the difficulties of everyone who is working toward these important goals.

13.2 Vision and Benefits of HII

The vision of HII is comprehensive electronic patient information when and where needed, allowing providers to have complete and current information upon which to base clinical decisions. In addition, clinical decision support (see Chap. 22) would be integrated with information delivery. In this way, both clinicians and patients could receive reminders of the most recent **clinical guidelines** and research results. This would

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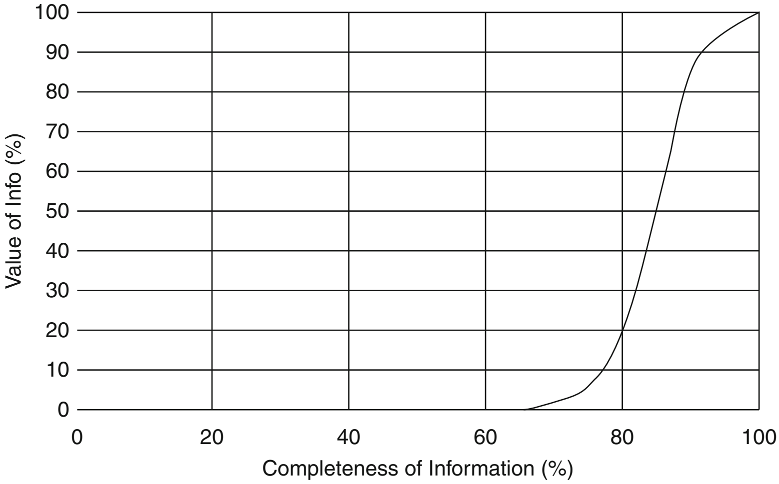

Fig. 13.1 Estimated value vs. completeness of health information. Medical information of any given type for a patient typically needs to be over 85 % complete before it starts being truly valuable to clinicians

avoid the need for clinicians to have superhuman memory capabilities to assure the effective practice of medicine, and enable patients more easily to adhere to complex treatment protocols and to be better informed. Patients could also review and add information to their record and thereby become more active participants in their care. In addition, the availability of comprehensive records for each patient would enable value-added services, such as immediate electronic notifications to patients' family members about emergency care, as well as authorized queries in support of medical research, public health, and public policy decisions.

In considering HII, it is extremely important to appreciate that medical information for a given patient must, in general, be relatively complete before it is truly valuable for clinical use (see Fig. 13.1). For example, if a physician has access to an electronic information system that can retrieve half of each patient's list of medications, it is unlikely such a system will be actively used. Knowing that the information is incomplete, the physician will still need to rely on other traditional sources of information to fill in the missing data (including questioning the patient). So there is little added benefit for investing the time to obtain the partial information from the new system. Similarly, applying clinical decision support to incomplete patient data may produce erroneous, misleading, or even potentially dangerous results. Therefore, HII systems must reliably provide reasonably complete information to be valuable to clinicians for patient care, and to make their use worthwhile.

The potential benefits of HII are both numerous and substantial. Perhaps most important are error reduction and improved quality of care. Many studies have shown that the complexity of present-day medical care results in very frequent errors of both omission and commission (Institute of Medicine 1999). The source of this problem was clearly articulated by Masys, who observed that current medical practice 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." (Masys 2002). Electronic health information systems can contribute significantly to alleviating this problem by reminding practitioners about recommended actions at the point of care. This can include both notifications of actions that may have been missed and warnings about planned treatments or procedures that may be harmful or unnecessary. Literally dozens of research studies have shown that such reminders improve safety and reduce costs (Bates 2000; Kass 2001). In one such study, medication errors were reduced by 55 % (Bates et al. 1998). Another study by the RAND Corporation showed that only 55 % of U.S. adults were receiving recommended care (McGlynn et al. 2003). The same techniques used to reduce medical errors with electronic health information systems also contribute substantially to ensuring that recommended care is provided. This is becoming increasingly important as the population ages and the prevalence of chronic disease increases.

Guidelines and reminders also can improve the effectiveness of dissemination of new research results. At present, widespread application of a new research in the clinical setting takes an average of 17 years (Balas and Boren 2000). Patient-specific reminders delivered at the point of care, highlighting important new research results, could substantially accelerate this adoption rate.

Another important contribution of HII to the research domain is improving the efficiency of clinical trials. At present, most clinical trials require the creation of a unique information infrastructure to insure protocol compliance and to collect essential research data. With an effective HII, every practitioner would have access to a fully functional **electronic health record** (**EHR**), so clinical trials could routinely be implemented through the dissemination of guidelines that specify the research protocol. Data collection would occur automatically in the course of administering the protocol, reducing time and costs. In addition, there would be substantial value in analyzing **de-identified aggregate data** from routine patient care to assess the outcomes of various treatments, and monitor the health of the population.

Another critical function for HII is early detection of patterns of disease, particularly early detection of outbreaks from newly-virulent microorganisms or possible bioterrorism. Our current system of disease **surveillance**, which depends on alert clinicians diagnosing and reporting unusual conditions, is both slow and potentially unreliable. These problems are illustrated by delayed detection of the anthrax attacks in the Fall of 2001, when seven cases of cutaneous anthrax in the New York City area 2 weeks before the so-called “index” case in Florida went unreported (Lipton and Johnson 2001). Since all the patients were seen by different clinicians, the pattern could not have been evident to any of them even if the correct diagnosis had immediately been made in every case. Wagner et al. described nine categories of requirements for surveillance systems for potential bioterrorism outbreaks—several categories must have immediate electronic reporting to ensure early detection (Wagner et al. 2003).

HII would allow immediate electronic reporting of both relevant clinical events and laboratory results to public health (see Chap. 16). Not only would this be an invaluable aid in early detection of bioterrorism, it would also serve to improve the detection of the much more common naturally occurring disease outbreaks. In fact, early results from a number of electronic reporting demonstration projects show that disease outbreaks can routinely be detected sooner than was ever possible using the current system (Overhage et al. 2001). While early detection has been shown to be a key factor in reducing morbidity and mortality from bioterrorism (Kaufmann et al. 1997), it will also be extremely helpful in reducing the negative consequences from other disease outbreaks.

Finally, HII can substantially reduce health care costs. The inefficiencies and duplication in our present paper-based health care system are enormous. One study showed that the anticipated nationwide savings from implementing advanced **computerized physician order entry** (**CPOE**) systems in the outpatient environment would be $44 billion/year (Johnston et al. 2003), while a related study (Walker et al. 2004) estimated $78 billion more in savings from **health information exchange** (**HIE**) (for a total of $122 billion/year). Substantial additional savings are possible in the inpatient setting—numerous hospitals have reported large net savings from implementation of EHRs. Another example, electronic prescribing, would not only reduce medication errors from transcription, but also drastically decrease the administrative costs of transferring prescription information from provider offices to pharmacies. Another analysis concluded that the total efficiency and patient safety savings from HII would be in range of $142–371 billion each year (Hillestad et al. 2005), and a survey of the recent literature found predominantly positive benefits from HII (Buntin et al. 2011). It is important to note that much of the savings depends not just on the widespread implementation of EHRs, but the effective interchange of this information to insure that the complete medical record for every patient is immediately available in every care setting.

Inasmuch as the current cost trend of health care is unsustainable, particularly in the face of our aging population, this issue is both important and urgent. Without comprehensive electronic information, any health care reform is largely guesswork in our current "black box" health care environment where the results of interventions often take years to understand. We do not currently have mechanisms for timely monitoring of health care outcomes to inform needed course corrections in any proposed reform. In essence, health care must be "informed" before it can be "reformed."

13.3 History

In the U.S., the first major report to address HII was issued by the Institute of Medicine of the National Academy of Sciences in 1991 (IOM 1991). This report, "The Computer-Based Patient Record," was the first in a series of national expert panel reports recommending transformation of the health care system from reliance on paper to electronic information management (see Chap. 12). In response to the IOM report, the Computer-based Patient Record Institute (CPRI), a private not-for-profit corporation, was formed for the purpose of facilitating the transition to computer-based records. A number of **community health information networks** (**CHINs**) were established around the country in an effort to coalesce the multiple community stakeholders in common efforts towards electronic information exchange. The Institute of Medicine updated its original report in 1997 (IOM 1997), again emphasizing the urgency to apply information technology to the information intensive field of health care.

However, most of the CHINs were not successful. Perhaps the primary reason for this was that the standards and technology were not yet ready for cost-effective community-based electronic HIE. Another problem was the focus on availability of aggregated health information for secondary uses (e.g., policy development), rather than individual information for the direct provision of patient care. Also, there was neither a sense of extreme urgency nor were there substantial funds available to pursue these endeavors. However, at least one community (Indianapolis, Indiana) continued to move forward throughout this period and has now emerged as an a national example of the application of information technology to health care both in individual health care settings and throughout the community (McDonald et al. 2005).

Widespread attention was focused on this issue with the IOM report "To Err is Human" (IOM 1999). This landmark study documented the accumulated evidence of the high error rate in the medical care system, including an estimated 44,000–98,000 preventable deaths each year in hospitals alone. It has proven to be a milestone in terms of public awareness of the negative consequences of paper-based information management in health care. Along with the follow-up report, "Crossing the Quality Chasm" (IOM 2001), the systematic inability of the health care system to operate at a high degree of reliability has been thoroughly elucidated. These reports clearly place the blame on the system, not on the dedicated health care professionals who work in an environment without effective tools to promote quality and to minimize errors.

Several additional national expert panel reports have emphasized the IOM findings. In 2001, the President's Information Technology Advisory Committee (PITAC) issued a report entitled "Transforming Health Care Through Information Technology" (PITAC 2001). That same year, the Computer Science and Telecommunications Board of the National Research Council (NRC) released "Networking Health: Prescriptions for the Internet" (NRC 2001), which emphasized the potential for using the Internet to improve electronic exchange of health care information. Finally, the National Committee on Vital and Health Statistics (NCVHS) outlined a vision for building a National HII in its report, "Information for Health" (NCVHS 2001). NCVHS, a statutory advisory body to the U.S.

Department of Health and Human Services (DHHS), indicated that Federal government leadership was needed to facilitate further development of HII. In response, DHHS began an HII initiative, organizing a large national conference in 2003 to develop a consensus agenda to guide progress (DHHS 2003; Yasnoff et al. 2004).

In April, 2004, a Presidential Executive Order created the Office of the National Coordinator for Health Information Technology (ONC) in DHHS (see also Chap. 27). The initial efforts of ONC focused on promoting standards and certification to support adoption of EHRs by physicians and hospitals. It also promoted implementation of an "institution centric" model for HIE by **Regional Health Information Organizations** (**RHIOs**), wherein electronic records for a given patient stored at sites of past care episodes are located, assembled, and delivered in real time when needed for patient care. Four demonstration projects implementing this model were funded, but did not lead to sustainable systems.

In 2008, ONC was codified in law by the Health Information Technology for Economic and Clinical Health (HITECH) portion of the ARRA statute (Chap. 27). In addition, $20+ billion was appropriated including $2 billion for ONC and the remainder for payment of EHR incentives through Medicare and Medicaid to providers who achieve "Meaningful Use" of these systems. The ONC used its resources to establish **regional extension centers** (**RECs**) to subsidize assistance to providers adopting and using EHRs ($677 million), fund states to establish HIEs ($564 million), and initiate several research programs.

In December, 2010, the President's Council of Advisors on Science and Technology (PCAST) issued a report expressing concern about ONC strategy, specifically indicating that its HIE efforts through the states "*will not solve the fundamental need for data to be universally accessed, integrated, and understood while also being protected*" (PCAST 2010). Findings of a recent survey of HIEs "*call into question whether RHIOs in their current form can be self-sustaining and effective*"(Adler-Milstein et al. 2011). It is clear that more than two decades after the 1991 IOM report urging universal adoption of EHRs, the U.S. still lacks a clear and feasible roadmap leading to the widespread availability of comprehensive electronic patient information when and where needed. Despite much progress, no one in the U.S. as yet receives their medical care with the assured, immediate availability of all their records across multiple providers and provider organizations.

13.4 Requirements for HII

As with any informatics system development project, it is critical at the outset to understand the desired end result. In the case of a large, extremely complex system such as HII, this is especially important because there are many stakeholders with conflicting incentives and agendas, as well as challenging policy and operational issues. The ultimate goal is the "availability of comprehensive electronic patient records when and where needed." In transforming this goal into a design specification, it is critical to understand the issues and constraints that must be addressed. Then any proposed system design must demonstrate (on paper) how the objectives will be achieved within those limitations.

13.4.1 Privacy and Trust

The most important and overriding requirement of HII is privacy. Clearly, health records are very sensitive – perhaps the most sensitive personal information that exists. In addition to our natural desire to keep our medical information private, improper disclosure can lead to employment discrimination. Furthermore, failure to assure the privacy of records will naturally result in patient unwillingness to disclose important personal details to their providers – or even to avoid seeking care at all. In addition to the contents of the records, the very existence of certain records (e.g., a visit to psychiatric hospital) is sensitive even if no details are available. Therefore, extraordinary care must be taken to ensure that information is protected from unauthorized disclosure and use.

In general, U.S. Federal law (the HIPAA Privacy Rule as introduced in Chap. 10) requires patient consent for disclosure and use of medical records. However, consent is not required for record release for treatment, payment, and health care operations. These "TPO" exceptions have, as a practical matter, allowed health care organizations to utilize medical records extensively while bypassing patient consent. The organization that holds medical information has sole discretion to make the decision whether a proposed disclosure is or is not a TPO exception. Until recently, TPO disclosures did not even need to be recorded, effectively preventing discovery of improper disclosures. Even under the recent HITECH legislation that requires records of TPO disclosures, such records are not automatically available to the subjects of the disclosures. The net effect is that individuals not only lack control over the dissemination of their medical records, but are not even informed when they are disclosed beyond where they were created.

It seems appropriate to question whether this disclosure regime is adequate for electronic health records. The general public understands that making electronic patient records available for good and laudable purposes simultaneously makes them more available for evil and nefarious purposes, thereby necessitating higher levels of protection to avoid abuses. Assigning decision-making for disclosure of personal medical records to anyone other than the patient or the patient's representative inherently erodes trust. In essence, the patient is being told, "we are going to decide for you where your medical records should go because we know what's in your interest better than you do." Patients may wonder why, if a given disclosure is in their interest, their consent would not be sought. Furthermore, failing to seek such consent inevitably leads to suspicion that the disclosure is in fact not in the patient's interest, but rather in the interest of the organization deciding that the records should be released.

The concern about privacy of medical records is not at all theoretical or insignificant. In two recent consumer surveys, 13–17 % of consumers indicated that they already employ "information hiding" behaviors with respect to their medical records (CHCF 2005; Harris Interactive 2007). This includes activities such as obtaining laboratory tests under an assumed name or seeking out-of-state treatment to conceal an illness from their primary care provider. Even assuming that everyone engaged in such behaviors was willing to admit to them in such a survey, this represents a substantial proportion of consumers who would, at a minimum, refuse to participate in an electronic medical information system that did not provide them with control over their own records. Of even greater concern, such a large percentage of consumers would likely organize and use their political power to halt the deployment and operation of such a system. Indeed, it was a much smaller percentage of concerned citizens that, citing the threat to privacy, convinced Congress to repeal the provisions in the original HIPAA legislation calling for a unique medical identifier for all U.S. residents (see Chap. 10).

In view of this, there are those who argue that all decisions about release of patient records need to be entrusted to the patient (with rare exceptions, such as mental incompetence). They also suggest that attention to these concerns may be especially important for enabling HII, because patients must trust that their records are not being misused in such a system. Some argue that patients are not sufficiently informed to make such decisions and may make mistakes that are harmful to them, whereas others believe that the negative consequences of delegating this decision-making to others than the patient could be much greater. Advocates of patient control of medical information argue, by analogy, that society has accepted that individuals retain the right to make decisions about how their own money is spent, even though this can lead to adverse consequences when those decisions prove to be unwise. In considering these issues, it should be noted that prior to the 2002 HIPAA Privacy Rule that established the TPO exceptions, both law and practice had always required patient consent for all access to medical records. While acknowledging the need for consumer education about decisions relating to release of medical records, patient-control advocates believe that the same freedom and personal responsibility that applies to an individual's financial decisions may need to be applied to the medical records domain. These medical information privacy policy issues may be even more urgent in the context of the enhanced trust necessary when seeking to implement an effective and accepted HII.

13.4.2 Stakeholder Cooperation

To ensure the availability of comprehensive patient records, all health care stakeholders that generate such records must consistently make them available. While it would be ideal if such cooperation were voluntary, assuring long-term collaboration of competing health care stakeholders is problematic. Indeed, only a handful of communities have succeeded in developing and maintaining an organization that includes the active participation of the majority of health care providers. Even in these communities, the system could be disrupted at any time by the arbitrary withdrawal of one or more participants. The unfortunate reality is that health care stakeholders are often quite reluctant to share patient records, fearing loss of competitive advantage.

Therefore, some would argue that mandating health care stakeholder participation in a system for sharing electronic patient records is highly desirable, since it would result in consistently more comprehensive individual records. Since imposing a new requirement on health care stakeholders would be a daunting political challenge, such an approach would be most feasible as part of an existing mandate. Proponents of this approach have noted that one such mandate that could be utilized is the HIPAA Privacy Rule itself, which requires all providers to respond to patient requests for their own records (U.S. 45 CFR 164.524(a)). Furthermore, if patients request their records in electronic form, and they are available in electronic form, this regulation also requires that they be delivered in electronic form. Although not well known, this latter provision is included in the original HIPAA Privacy Rule (U.S. 45 CFR 164.524(c)(2)), and has been reinforced by HITECH. It is also being promoted by the more recent "blue button" initiative that seeks to allow patients to retrieve their own records electronically (Chopra et al. 2010).

Advocates argue that patient control, in addition to being an effective approach to privacy, could also serve to ensure ongoing, consistent health care stakeholder participation. Of course, in order for this approach to be practical, the rights of patients to electronic copies of their records under HIPAA would need to be enforced. Such enforcement has to date been inconsistent, and, until recently, exclusively dependent on the Office of Civil Rights at DHHS (since patients do not have a private right of action). Under HITECH, state attorneys general may also bring legal action, which may be helpful in improving compliance.

13.4.3 Ensuring Information in Electronic Form

It is self-evident that the electronic exchange of health information cannot occur if the information itself is not in electronic form. While medication information and laboratory results are already predominantly electronic, patient records, particularly for office-based physicians, are not. While estimates vary, it is clear that the majority of office-based physicians still do not utilize EHR systems, even though there is a major effort to incentivize the adoption of such records (see Chaps. 12 and 27). Furthermore most of those who do have electronic records utilize systems with limited capabilities (DesRoches et al. 2008).

The major obstacle for physician adoption of EHRs is not merely cost, as is often cited, but the very unfavorable ongoing cost/benefit ratio. Most of the benefits of EHRs in physician offices accrue not to the physician, but to other stakeholders. In one study, 89 % of the economic benefit was attributed to other stakeholders (Hersh 2004). It is unreasonable to expect physicians to shoulder 100 % of the cost of systems while accruing only 11 % of the benefits.

While the substantial physician subsidies in HITECH ($44,000–$63,750) are helpful (Chap. 27), they do not cover the majority of costs for physician EHR systems. This is particularly evident when including the substantial conversion costs related to reduced revenue from lost productivity during the transition from paper to electronic records. In addition, the HITECH subsidies are one time only, while the costs of EHRs continue indefinitely for physicians. To assure EHR adoption by the vast majority of practices, many observers believe it will be necessary to provide permanent reimbursement and/or other offsetting benefits to allow physicians to recoup their costs. At the very least, any proposed approach to building a sustainable HII will be more effective if it includes mechanisms that result in a favorable cost/benefit ratio for physician EHRs.

As for hospitals, they also have not uniformly adopted EHRs. However, hospitals have a more substantial economic incentive to do so, since reducing their costs improves financial performance under the **diagnosis-related groups** (**DRG**) reimbursement system that pays a fixed amount for a specific condition. While it remains to be seen if the HITECH incentives for hospitals are sufficient to induce widespread adoption, it appears that their effectiveness will be substantially greater than for office-based physicians. In addition, once patients are admitted to the hospital, coordinating their records is largely an internal problem that cannot be greatly aided by external HII. Furthermore, the large majority of health care encounters do not involve hospitals, and therefore HII should focus primarily on the outpatient environment.

It is important to note that EHRs alone, even if adopted by all health care providers, are a necessary but not sufficient condition for achieving HII. Indeed, each EHR simply converts an existing paper "silo" of information to electronic form. These provider-based systems manage the *provider* information on the patient in question, but do not have *all* the information for each patient. To achieve the goal of availability of comprehensive patient information, there must also be an efficient and cost-effective mechanism to aggregate the scattered records of each patient from all their various providers. Major gains in quality and efficiency of care will be attainable only through HII that ensures the availability of every patient's comprehensive record when and where needed.

13.4.4 Financial Sustainability

There are three fundamental approaches that can be used individually or in combination to provide long-term financial sustainability for HII: (1) public subsidy; (2) leveraging anticipated future health care cost savings; or (3) leveraging new value created. The first approach has been advocated by those who assert, with some justification, that HII represents a public good that benefits everyone. They compare HII to other publicly available infrastructure, such as roads, and suggest that taxation is an appropriate funding mechanism. Of course, new taxes are consistently unpopular and politically undesirable, and other key infrastructures such as public utilities and the Internet, although regulated, are funded through user fees rather than taxation. Note, however, that at least two states (Maryland and Vermont) are using this mechanism to help fund their HII.

The most common approach suggested for long-term HII sustainability is leveraging anticipated health care cost savings. This is based on the substantial and growing body of evidence that the availability of more comprehensive electronic patient records to providers results in higher quality and lower cost care (AHRQ 2006; Buntin et al. 2011). Some of the best examples include large, mostly closed health care systems such as Kaiser, Group Health and the Veterans Administration, where the conversion of records into electronic form over time has been consistently associated with both cost savings and better care. While the case for HII reducing health care costs is compelling, the distribution and timing of those savings is difficult to predict. In addition, cost savings to the health care system means revenue losses to one or more stakeholders – clearly an undesirable result from their perspective. Finally, the allocation of savings for a given population of patients is unknown, with the result that organizations are reluctant to make specific financial commitments that could be larger than their own expected benefits.

The final but least frequently mentioned path to financial sustainability of HII is utilizing the new value created by the availability of comprehensive electronic information. While it is widely recognized that this information will be extremely valuable for a wide variety of purposes, this option has remained largely unexplored. One example of such new value is the potential reduction in cost for delivering laboratory results to ordering physicians. The expenses borne by individual laboratories for their own infrastructure providing this essential service can be greatly reduced by a single uniform community infrastructure providing electronic delivery to physicians through one mechanism. Another example is availability of medical information for research – both to find eligible subjects for clinical trials and to utilize the data itself for research queries. While this latter application has the potential to defray a substantial portion of the costs of HII, it requires efficient mechanisms for both searching data and recording and maintaining patient consent that have not generally been incorporated into HII systems.

Perhaps the most lucrative HII revenue source lies in the development of innovative applications that rely on the underlying information to deliver compelling value to consumers and other health care stakeholders. For example, HII allows the delivery of timely and accurate reminders and alerts to patients for recommended preventive services, needed medication refills, and other medically related events of immediate interest to patients and their families. It also would allow deployment of applications that assist consumers automatically with management of their chronic diseases. Microsoft recognized and identified such an “application ecosystem” as the ultimate business model that could support HII when it introduced its HealthVault™ personal health record system (Microsoft 2012). Utilizing new value to finance HII avoids the prediction and allocation problems inherent in attempts to leverage expected health care cost savings, with the added incentive that any such savings would fully accrue to whoever achieves them.

13.4.5 Community Focus

Most observers believe that successful HII must be focused on the community. An essential element in HII is trust, which is inherently local. Furthermore, health care itself is predominantly local, since the vast majority of medical care for residents of a given community is provided in that community. Indeed, people traveling away from home who are injured or become ill inevitably will return home at their earliest opportunity if their condition permits (and does not resolve quickly). Since medical care is predominantly local, creating a system that delivers comprehensive electronic patient information in a community solves the overwhelming majority of information needs in that community. While movement of health information over long distances has some value and ultimately must be addressed to assure completeness of records, its contribution to a total solution is marginal.

The lack of any examples of working HII in communities larger than about ten million people provides additional evidence of the need for local focus. Keeping the scope of such projects relatively small also increases their likelihood of success by reducing complexity, thereby avoiding the huge increases in failure rates of extremely large-scale IT projects. For example, the need for local focus was a key part in planning for HII in the U.K., which was divided into five regions of approximately 12 million people in an attempt to facilitate addressing HII development through multiple systems, each working at a feasible scale (Granger 2004).

In thinking about HII, analogies are often made to the international financial system that efficiently transfers and makes funds available to individuals anywhere in the world. However, it is often forgotten that these financial institutions, that also are heavily dependent on trust, began as “building and loan funds” in small communities designed to share financial resources among close neighbors. It took many decades of building trust before large-scale national and international financial institutions emerged.

13.4.6 Governance and Organizational Issues

Trust is arguably the most important element in considering the appropriate governance for HII. Even in a system where patients exert full control over their own records, the organization that operates the HII must earn the full faith and confidence of consumers for the security, integrity, and protection of the records, as well as ensuring that records are appropriately available for purposes that consumers specify. Furthermore, the organization ideally must be devoid of any biases or hidden agendas that would favor one category of health care stakeholders over another, or favor specific stakeholders within a given category.

None of the existing health care stakeholders seem well suited to meet the trust requirement. Many argue that government cannot operate an HII because it is inherently not trusted with sensitive personal records, and furthermore needs to assume the role of providing regulatory oversight for whatever organization does take the HII responsibility. Similarly, it seems problematic for employers to be responsible for the HII since one of the primary concerns of consumers is to avoid disclosing sensitive medical information to their employers. Health plans and insurers are typically not trusted by consumers because their incentives are not aligned–they have a financial incentive to deny care, which is a natural concern to consumers. Hospitals are in competition with each other and therefore are not in a good position to cooperate in a long-term HII effort. Physicians are the most trusted health care stakeholders, from a consumer perspective, but are not organized in a way to facilitate the creation of HII. Furthermore, they are also in competition with each other and, most importantly, do not generally have the informatics capabilities necessary for such a complex endeavor.

Therefore, many believe that an independent (perhaps entirely new) organization is needed to operate HII in communities. This organization would have no direct connections to existing health care stakeholders and therefore would be unbiased. Its sole function would be to protect and make available comprehensive electronic patient records on behalf of consumers. Such an independent organization would also ideally facilitate cooperation among all existing stakeholders, who would know that the HII activity was completely neutral and designed primarily to serve consumers.

13.5 Architecture for HII

13.5.1 Institution-Centric Architecture

With rare exceptions, most existing HII systems have chosen an institution-centric approach to data storage, leaving patient records wherever they are created (Fig. 13.2). Although records are not stored centrally, there is a need to maintain at least a central index of where information can be found for a particular patient; without such an index, finding information about each patient would require queries to every possible source of medical information worldwide – clearly an impractical approach. When a given patient's record is requested, the index is used to generate queries to the locations where information is stored. The responses to those queries are then aggregated (in real time) to produce the patient's complete record. After the patient encounter, the new data is entered into the clinician's EHR system and another pointer (to that system) is added to the index so it will be queried (in addition to all the other prior locations) next time that patient's record is requested.

While this architecture is appealing to health care stakeholders because they continue to "control" the records they generate, one can argue that it fails to meet several key requirements, does not scale effectively, and is complex and expensive to operate. The most critical requirement that is not addressed by this architecture is searching the data, e.g., to find all patients with a cholesterol level above 300. To do such a search, the records of every patient must be assembled from their various locations and examined one at a time. This is known as a sequential search, and has a very long completion time that increases linearly

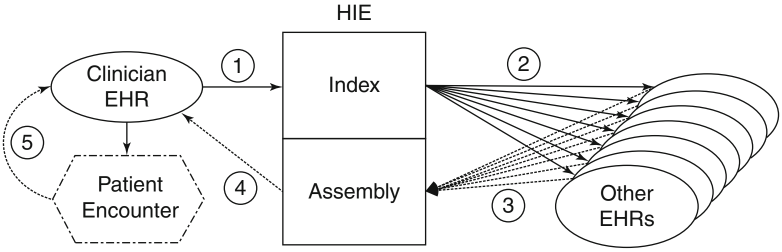

Fig. 13.2 Institution-centric HII architecture. *1*. The clinician EHR requests prior patient records from the HIE; this clinician's EHR is added to the index for future queries for this patient (if not already present). *2*. Queries are sent to EHRs at all sites of prior care recorded in the HIE index. *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 (© Health Record Banking Alliance, 2013. Used with permission)

with the size of the population. For example, in a modest-sized HIE with 500,000 patients, assuming retrieval and processing of each patient's records requires just 2 s (a very low estimate), each such search would take at least 12 days (1 million seconds). Furthermore, every such search would require that each provider record system connected to the HIE retrieve and transmit all its information – a very substantial computing and communications burden (that also increases the risk of interception of information). In standard database systems, impractical sequential search times are reduced by pre-indexing the contents of the records. However, such pre-indexing would in essence create a central repository of indices that could be used to reconstruct most of the original data, and therefore is inconsistent with this architectural approach.

It may be argued that the searches could themselves be distributed to the provider systems, and then the results aggregated into a coherent result. However, this approach also fails for this architecture because individual patient records are incomplete in each system. Therefore, searches that require multiple items of patient data (e.g., patients with chest pain who have taken a certain medication in the past year), will produce anomalous results unless all the instances of the relevant data for a given patient are in a single provider system (i.e., if one system finds a patient with chest pain, but without any indication of the medication of interest [which is in another provider's system], that patient will not be reported as satisfying the conditions). It is possible to limit searches to a single criterion and then combine the results from each such search to generate a correct result. However, this would mean that such searches would require multiples of the completion time for a single criterion (e.g., 12 days × 2 = 24 days for the two criteria example), making the retrieval times and processing burdens even more untenable.

In addition to the scaling issues for this architecture related to searching, there is also a problem with response time for assembling a patient record. When a given patient record is requested, the locations where the patient has available records are found using the central index. Then, a **query-response cycle** is required for each location where patient records are available. Following completion of the query-response cycles, all the information obtained must be integrated into a comprehensive record and made available to the requestor. While the query-response cycles can all be done in parallel, the final integration of results must wait for the slowest response. As the number of connected systems increases, so does the probability of a slow (or absent) response from one of them when queried for patient records. In addition, more systems mean more processing time to integrate multiple sources of information into one coherent record. Thus, the response time will become slower as the number of connected systems increases.

The institution-centric architecture also introduces high levels of operational complexity.

Fig. 13.3 Example of a Network Operations Center (NOC) (Reproduced with permission from Evans Consoles Corporation)

Since the completeness of retrieval of a given patient's records is dependent on the availability of all the systems that contain information about that patient, ongoing real-time monitoring of all connected information sources is essential. This translates into a requirement for a 24 × 7 **network operations center** (**NOC**), that constantly monitors the operational status of every medical information system and is staffed with senior IT personnel who can immediately troubleshoot and correct any problems detected (Fig. 13.3). Even with modest system failure rates (e.g., 1/1000), a community with thousands of EHRs will typically have a handful of systems that are unresponsive to queries for patient records and require immediate expert attention to restore to full operation. The cost of this around-the-clock monitoring is very substantial, since a staff of at least five full-time network engineers is required to assure that at least one person is always available for every shift 7 days a week.

In addition to the cost of the NOC, every EHR system in an institution-centric model must always be able to respond to queries in real-time. In addition to the cost of assuring 24 × 7 operation of all these systems, which will be extremely problematic for physician offices, every system will need additional hardware, software, and telecommunications capabilities to simultaneously support such queries while also serving its local users. Clearly, the transaction volumes generated will be substantial, since each patient's records will be queried whenever they receive care at any location. Contrast this to a central repository model where the information from a care episode is transmitted once to the repository and no further queries to the source system are ever needed. This analysis has recently been confirmed by a simulation study of the institution-centric architecture demonstrating that both the transaction volume and probability of incomplete records (from missing data due to a malfunctioning network node) increase exponentially with the average number of sites where each patient's data is located (Lapsia et al. 2012).

13.5.2 Patient-Centric Architecture (Health Record Banking)

Health record banking is a patient-centric approach to developing community HII that both addresses the key requirements and can overcome the challenges that have stymied current efforts (Yasnoff 2006). 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 assures that the individual always

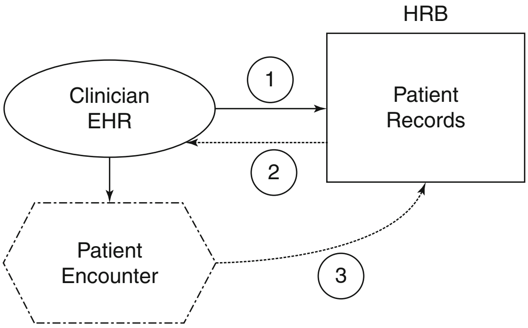

Fig. 13.4 Patient-centric HII architecture. *1*. The clinician EHR requests prior patient records from the HRB. *2*. The prior patient records are immediately sent to the clinician EHR. *3*. After the care episode, the new information is stored in the clinician EHR and sent to the HRB; any inconsistencies 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). (Note: this process is repeated whenever care is provided, resulting in the accumulation of each patients's records from all sources in the HRB) (© Health Record Banking Alliance, 2013. Used with permission)

has complete control over who accesses their information" (HRBA 2008).

Using a community HRB to provide patient information for medical care is straightforward (Fig. 13.4). Prior to seeking care (or at the time of care in an emergency), the patient gives permission for the caregiver to access his/her HRB account records (either all or part) through a secure Internet portal. The provider then accesses (and optionally, downloads) the records through a similar secure web site. When the care episode is completed, the caregiver then transmits any new information generated to the HRB to be added to the account-holder's lifetime health record. The updated record is then immediately available for subsequent care.

The health record banking concept has been evolving for nearly two decades since it was initially proposed (Szolovits et al. 1994). The term "health information bank" was introduced in 1997 in the U.K. (Dodd 1997), and was subsequently described as the "bank of health"(Ramsaroop and Ball 2000). A legal analysis of the implications of a "health record trust" was published in 2002 (Kostyack 2002), an Italian system known as the "health current account" was described in 2004 (Saccavini and Greco 2004), and the "health record bank" concept was described by Dyson in 2005 (Dyson 2005). In 2006, a Heritage Foundation policy paper endorsed health record banking (Haislmaier 2006), additional papers described HRBs in more detail (Ball and Gold 2006; Shabo 2006), the non-profit Health Record Banking Alliance was formed (HRBA 2006), the State of Washington endorsed the concept after a 16-month study (State of Washington 2006), and the non-profit Dossia consortium was formed by several large employers to implement and operate an HRB for their employees (Dossia 2006). In 2007, the Information Technology and Innovation Foundation recommended that the health record banking approach be used to build the U.S. HII (Castro 2007), while Gold and Ball described the "health record banking imperative" (Gold and Ball 2007). That same year, both Microsoft and Google introduced patient-controlled medical record repositories. In 2009, three pilot HRBs were funded by the State of Washington, another one was started in Rotterdam, Netherlands,[1]and the role of HRBs in protecting privacy was described (Kendall 2009). The HRB concept, although not always named as such, is now appearing with greater frequency in articles discussing the need for comprehensive EHRs (Steinbrook 2008; Mandl and Kohane 2008; Kidd 2008; Miller et al. 2009; Krist and Woolf 2011).

13.5.2.1 Patient Control Ensures Privacy and Stakeholder Cooperation

In an HRB, everything is done with *consumer consent*, with account-holders controlling their copy of all their records and deciding who gets to see any or all of it. This protects privacy (since each consumer sets their own customized privacy policy), promotes trust, and ensures stakeholder cooperation since all holders of medical information must provide it when requested by the patient (Kendall 2009). Of course, the operations of an HRB must be open and transparent with

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[1] http://webwereld.nl/nieuws/54340/rotterdam-start-eigen-versie-elektronisch-pati--ntendossier.html. Posted January 14, 2009. (accessed 21Apr 2013).

independent auditing of privacy practices. World-class state-of-the-art computer security is needed to protect the HRB, which will be a natural target for hackers. However, this is no different from any other system design for HII, even if the information is not stored centrally, since by definition any such system must be capable of immediately assembling a complete patient record on request.

Natural concerns arise from the ability of the patient to suppress any or all of their HRB account information, which could lead to misdiagnosis and dangerous treatment. This capability could be abused by patients who, for example, may seek multiple prescriptions for controlled substances for the purpose of diversion for illegal sale. With respect to the possibility of medical errors resulting from incomplete information, the patient would be clearly and unmistakably warned about this when choosing not to disclose any specific information (e.g., "Failure to disclose any of your medical information may lead to serious medical problems, including your death"). The expectation is that few people will choose to do this, particularly after such a warning. However, as noted earlier, 13–17 % of patients already engage in this practice, leading many observers to conclude that the general public may not be comfortable with a system that provides easy access to their records unless they are in control of such access. This issue ultimately becomes one of public policy and may also be a subject of discussion between the doctor and the patient (i.e., the doctor will want to be assured by the patient that all information is being provided). Clearly, physicians should not be liable for the consequences of the patient's choice to withhold information.

With respect to patients who use their power to withhold information as a way to facilitate improper or illegal activity, there is clearly an overriding public policy concern. For example, in the case of controlled substances, it may be necessary to report to the physician (or, if legislatively mandated, to regulatory authorities) whenever a patient suppresses any information about controlled substance prescriptions. The information itself would still be under the patient's control, but the physician would be alerted with a notice such as "some controlled substance prescription information has been withheld at the patient's request." There may be other situations where such warnings are needed.

13.5.2.2 Assuring the Information Is in Electronic Form and Complies with Standards

HRBs can provide ongoing incentives for EHR adoption by clinicians. To ensure electronic information, all providers must have EHRs. As indicated earlier, since most of the economic benefits of office-based EHRs do not accrue to providers, high levels of outpatient EHR adoption will most likely require some kind of ongoing compensation or value for their costs. For physicians who already have EHR systems, a per-encounter or per-month payment system can be used. Those physicians who do not currently have EHRs could receive no-cost Internet-accessible EHR systems (at HRB expense) with the understanding that information from patient encounters will be automatically transferred to the HRB. "Meaningful Use" of those EHRs is assured and can be easily audited on an ongoing basis since the information from each patient encounter must be deposited in the HRB. It is even possible to link reimbursement for medical services to HRB deposits – i.e., providers would not be paid unless the medical record information generated from those services is transmitted to an HRB. This makes sense economically, as the value of medical services is greatly limited if the information about patients is not readily available for their ongoing care.

HRBs also serve to ensure compliance with data standards, both initially and on an ongoing basis. Clearly, any EHR provided through the HRB can, by definition, transmit information back to the HRB in a standard format (since the HRB only provides systems that can do so). For physicians who already have EHRs, HRB reimbursements for those systems naturally require standard transactions to be used to send encounter data to the HRB. Over time, higher levels of encoding of medical information can be promoted through the gradual introduction of more stringent standards requirements (with plenty of lead time to allow for system upgrades).

Compliance with such changes in standards can also be assured through the direct relationship to reimbursement.

13.5.2.3 Business Model

Health record banking has advantages on both the cost and revenue sides of the business model; the cost is lower and the revenue opportunities greater. Because of the lower operating costs and additional functionality for searching records, one can envision a variety of business models for HRBs that do not depend on public subsidies or attempt to capture any health care savings, but are solely funded through new value created for consumers and other stakeholders (HRBA 2012).

Due to the simplicity of HRB operations, the cost is substantially less than an equivalent institution-centric architecture. For an HRB, providing access at the point of care only involves a single retrieval from the bank's repository of records. In an institution-centric model, the records for a given patient are located at an arbitrary number of dispersed sites, and must be assembled in real-time and integrated into a comprehensive record before they can be used for patient care. Not only is this process of assembly complex, time-consuming, and prone to error, it necessitates, as noted above, the creation of a fully staffed 24×7 NOC to monitor the availability of all information sources as well as troubleshoot and correct those that are malfunctioning.

The estimated cost for the NOC in an institution-centric model is substantial. For example, given a population of 1,000,000, at least 1,000 systems would need monitoring (1 for every 1,000 patients). Assuming a reasonable failure rate for fully functional query connectivity to each system of once/year (representing a **mean time between failures** [**MTBF**] of over 8,700 h), there would be an average of 2.73 failures/day or 0.91 failures per 8-h shift that would need troubleshooting attention. A minimum staff for the NOC would be 1 person 24×7; given 21 shifts/week plus leeway for vacations and sick leave, this would require at least 5 full-time equivalent staff costing about $200,000 each including equipment, overhead and fringe benefits. Assuming an additional $500,000/year for hardware and software to operate the institution-centric system (over and above the data repository needed for an HRB) yields an annual cost of $1.5 million or $1.50/person/year. This would add nearly 20 % for the institution-centric model to the estimated $8/person/year needed to operate an HRB (Kaelber et al. 2008).

Beyond this, the additional costs imposed in the institution-centric model for each connected EHR for additional hardware, software, telecommunications capability, and additional operational expenses to maintain 24×7 system availability must also be included. Even if such costs were only a very modest $1,000/year/system (less than $100/month), this would result in an additional $1,000,000 or $1/person/year. Adding this to the $1.50/person/year for the NOC gives a total estimated cost of $2.50/person/year, resulting in over 30 % higher costs for the institution-centric model than a basic HRB. Added to this would be the costs and complexity of establishing and maintaining data sharing agreements among all the entities, which would be substantial.

On the revenue side, the inability of the institution-centric model to efficiently search the data impedes generation of potentially significant revenue from consumer applications and research. For example, generating medication refill reminders to consumers alone could potentially yield $20/year of revenue per consumer, paid by pharmaceutical firms as a completely ethical and appropriate mechanism to improve both compliance and their own bottom line. Even if only 20 % of consumers used this service, potential average revenue from this application alone would be $4/person/year, half the estimated HRB cost.

Another key source of revenue could be targeted advertising to consumers (based on the information in their accounts), which could generate an estimated $6/person/year or more. Consumers would also be allowed to opt-out of such advertising by paying the $6/year. To protect privacy, advertisers would not be allowed to identify anyone viewing their ads unless the consumer voluntarily provided contact information.

Revenue from searching the data (with consumer permission) could also be substantial. Finding eligible subjects for clinical trials is quite

Table 13.1 Comparison of the institution-centric and patient-centric approaches to Health Information Infrastructure

Issue	Institution-centric	Patient-centric (HRB)
Cooperation needed	Extensive; community-wide	Unifying; HIPAA mandates records on patient request
Organizational complexity	High; ongoing collaboration of multiple competing stakeholders necessary	Low; HRB is neutral and independent of all stakeholders
Privacy	Patient consent difficult to implement; many complex data sharing agreements needed	Simple; patients in control of all access to their own records; consent easy to implement
Startup funding	Substantial (due to high complexity)	Minimal
Business model	Complex; no clear approach has emerged	Flexible; many options possible funded by patients/payers/purchasers
Clinician EHR incentives	Not included	Easy to include
Clinician EHR processing burden	Extensive; incoming query each time current patients seen anywhere	Minimal; information deposited once in HRB; no incoming queries
Interoperability (data standards)	Compliance voluntary	Compliance can be assured with financial incentives
IT system design	Complex; requires queries to multiple entities, real-time reconciliation of inconsistencies, and NOC	Simple; no secondary queries or real-time reconciliation needed; NOC unnecessary
Completeness of patient records	Requires data source queries each time a patient's records are requested; all must respond for completeness	Comprehensive data available at all times for each patient

expensive, and could be greatly facilitated by sending electronic invitations directly to qualified patients identified through an HRB (to protect privacy, the identities of the recipients of the invitations could be hidden from the researchers). Also, anonymized reports from searches of HRB data would be very valuable to medical researchers, public health officials, and policymakers. Reasonable fees for such reports would therefore be another important revenue source. While it is difficult to estimate the magnitude of this revenue, it seems likely that it would be at least a few dollars per patient each year.

Finally, the low cost of HRBs allows them to subsidize outpatient EHRs. To cover fully the expense of office-based EHRs costs about $10/person/year. This is based on a cost of $5,000/year/physician for an internet-accessible EHR (a high estimate) allocated to 500 people (300 million U.S. population divided by 600,000 physicians needing EHRs). Given the strong revenue potential for HRBs, this additional $10/person/year expense could be included in operating costs over and above the expected $8/person/year anticipated as baseline expenditures. There are several key advantages if the HRB assumes these costs: (1) it promotes much higher levels of EHR adoption, thereby ensuring that more patient information is electronic; (2) it allows the HRB to ensure that EHRs submit data using standards (by subsidizing only compliant EHRs); (3) it provides a mechanism for ensuring updates to standards as they are needed; and (4) it creates a mutually beneficial relationship with clinicians that facilitates their cooperation as a marketing channel for HRB (by offering no-cost accounts to their patients). While the additional $10/person/year for EHRs is a substantial cost burden, revenue opportunities from value-added applications, consumer advertising, and research could more than cover the resultant total operating costs of $18/person/year without the need to quantify or capture any potential health care savings.

Table 13.1 summarizes the characteristics of the institution-centric approach to HII compared to the patient-centric (health record bank) model. The patient-centric model is simpler and more straightforward, and deals directly with the issue of privacy by putting patients in control of their own information. Interoperability is much more easily accomplished in the patient-centric model since standards compliance can be reinforced with financial incentives, and reconciliation of inconsistencies between records need not be real-time. The patient centric approach is financially sustainable with a variety of business models, and can provide powerful incentives to clinicians to acquire EHRs. Finally, the patient-centric model avoids the substantial processing burden on clinician EHRs from queries each time any patient whose record is stored is seen anywhere.

13.6 HII Evaluation

The last element in the strategy for promoting a complex and lengthy project such as the HII is evaluation to both gauge progress and define a complete system. Evaluation measures should have several key features. First, they should be sufficiently sensitive so that their values change at a reasonable rate (a measure that only changes value after 5 years will not be particularly helpful). Second, the measures must be comprehensive enough to reflect activities that affect most of the stakeholders and activities needing change. This ensures that efforts in every area will be reflected in improved measures. Third, the measures must be meaningful to policymakers. Fourth, periodic determinations of the current values of the measures should be easy so that the measurement process does not detract from the actual work. Finally, the totality of the measures must reflect the desired end state so that when the goals for all the measures are attained, the project is complete.

A number of different types or dimensions of measures for HII progress are possible. Aggregate measures assess HII progress over the entire nation. Examples include the percentage of the population covered by an HII and the percentage of health care personnel who utilize EHRs. Another type of measure is based on the setting of care. Progress in implementation of EHR systems in the inpatient, outpatient, long-term care, home, and community environments could clearly be part of an HII measurement program. Yet another dimension is health care functions performed using information systems support, including, for example, registration systems, decision support, and CPOE. Finally, it is also important to assess progress with respect to the semantic encoding of EHRs. Clearly, there is a progression from the electronic exchange of images of documents, where the content is only readable by the end user viewing the image, to fully encoded EHRs where all the information is indexed and accessible in machine-readable form using standards.

Sadly, the evidence is now overwhelming that U.S. HIEs in their current form are, with rare exceptions, not succeeding. Labkoff and Yasnoff described four criteria 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 (Labkoff and Yasnoff 2007). Using these criteria, four of the most advanced community HII projects in the U.S. achieved scores of 60–78 % (on a 0–100 scale), indicating substantial additional work was required before the HII could be viewed as complete.

The 2010 PCAST report stated, "*HIEs have drawbacks that make them ill-suited as the basis for a national health information architecture*" (PCAST 2010). Among those drawbacks, PCAST cited administrative burdens (data sharing agreements to ensure stakeholder cooperation), financial sustainability, interoperability, and an architecture that cannot be scaled effectively. The most recent (Adler-Milstein et al. 2011) of a series of surveys of HIEs (Adler-Milstein et al. 2008, 2009) found only 13 HIEs in the U.S. (covering 3 % of hospitals and 0.9 % of physician practices) capable of meeting Stage 1 Meaningful Use criteria, and even those metrics by no means ensure the availability of comprehensive electronic patient information when and where needed. Of those, only six were reported to be financially viable. More importantly, *none* of the HIEs surveyed had the capabilities of a comprehensive system as specified by an expert panel.

Overall, the current approaches to building HII consistently fail to meet one or more of the requirements described above: privacy, stakeholder cooperation, ensuring fully electronic information, financial sustainability, and independent governance. While these problems are highly interdependent, it is useful to consider them in the context of the decisions that communities have made about HII architecture, privacy, and business model that, while appearing attractive to stakeholders in the short term, have so far been largely unsuccessful. Exploration and large-scale testing of alternative approaches that directly address the requirements, such as health record banking, seem both necessary and increasingly urgent.

13.7 Conclusion

While progress has been made and efforts are continuing, successful development and operation of comprehensive HII systems remains a largely unsolved problem. The extensive focus on building HII systems has greatly improved our understanding of the requirements, barriers, and challenges, as well as potential solutions. Despite the daunting obstacles, the benefits of HII are sufficiently urgent and compelling to ensure major ongoing work in this domain. Through these activities, the HII path to comprehensive electronic patient records when and where needed is becoming clearer, and substantial advances are likely in the next few years.

Suggested Readings

Aanestad, M., & Jensen, T.B. (2011). Building nationwide information infrastructures in healthcare through modular implementation strategies. *Journal of Strategic Information Systems, 20*(2), 161–176. An interesting study comparing two large-scale HII implementations, one of which failed, suggesting that both a gradual transition of the installed base and a modular approach are needed for success.

Adler-Milstein, J., Bates, D.W., & Jha, A.K. (2011). A survey of health information exchange organizations in the United States: Implications for meaningful use. *Annals of Internal Medicine, 154*, 666–671. The recent comprehensive survey of 179 HIEs that found that none of them had comprehensive capabilities and concluded that the current development path was unlikely to succeed.

Castro D. (2007) *Improving health care*: *Why a dose of IT may be just what the doctor ordered*. Information Technology and Innovation Foundation. Available at http://www.itif.org/publications/improving-health-care-why-dose-it-may-be-just-what-doctor-ordered. Accessed 17 Dec 2012. This is the first independent report that endorsed patient-centric architecture (HRBs) as an effective approach to HII. It describes clearly the problems and challenges of HIEs.

Krist, A.H., & Woolf, S.H. (2011). A vision for patient-centered health information systems. *JAMA: The Journal of the American Medical Association, 305*(3), 300–301. A vision of how fully functional patient-centric electronic medical record systems could be the basis for an effective HII.

Miller, R.H., & Miller, B.S. (2007). The Santa Barbara County Care Data Exchange: What happened? *Health Affairs, 26*(5), 568w–580w. This paper describes the history of one of the earliest HIEs, including details about the factors leading to its failure.

National Committee on Vital and Health Statistics. (2001). *Information for health*: *A strategy for building the National Health Information Infrastructure*. *Report and recommendations from the National Committee on Vital and Health Statistics*. Available at http://www.ncvhs.hhs.gov/nhiilayo.pdf. Accessed 17 Dec 2012. This seminal work was the first to call for a national HII, coining the term. It comprehensively describes the need for HII, the problems it would solve, and the necessity for government investment to incentivize its development.

Steinbrook, R. (2008). Personally controlled online health data—The next big thing in medical care? *The New England Journal of Medicine, 358*(16), 1653–1656. A physician's perspective on the need for patients to control their own electronic health data.

Yasnoff, W.A., Humphreys, B.L., Overhage, J.M., Detmer, D.E., Brennan, P.F., Morris, R.W., Middleton, B., Bates, D.W., & Fanning, J.P. (2004). A consensus action agenda for achieving the national health information infrastructure. *Journal of the American Medical Informatics Association, 11*(4), 332–338. This paper describes the results of the first national consensus conference on HII held in Washington, DC, in 2003. This was the meeting that led to the creation of ONC in 2004.

Questions for Discussion

1. Make the case for and against investing $billions in the HII. How successful have the HITECH Meaningful Use incentives been in promoting HII development? What could be done to make them more effective?
2. What organizational options would you consider if you were beginning the development of HII? What are the pros and cons of each? How would you proceed with making a decision about which one to use?
3. Estimate the required bandwidth and transaction rate for central (HRB) vs. institution-centric HII architecture.
4. Consider the policy implications of universal availability of comprehensive electronic patient records. What are the risks and how could they be mitigated?
5. Given the architectural and other advantages of HRBs, why have most communities adopted institution-centric architectures up to now? What are some steps that might be helpful in encouraging communities to evaluate alternative architectures such as HRBs?
6. Show specifically the potential locations where patient consent functionality could be added to the institution-centric and patient-centric HII architectures in Figs. 13.2 and 13.4 and describe the granularity of consent that would be possible at each proposed location. After eliminating any redundant functionality, compare and contrast the consent implementation issues for the two alternative architectures, describing the advantages and disadvantages of each. Which architecture more efficiently addresses the issue of patient consent? Why?