Building the National Health Information Infrastructure

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Linking community-based health information sources into a national network would improve care and save money. A collection of public andprivate organizations have begun sketching the plans.

Some of the most serious challenges facing healthcare today—medical errors, inconsistent quality, and rising costs—can be addressed through effective application of readily available information technology that links providers and health information throughout a community and throughout the country. Such networks enable decision support anywhere at any time, improving public and individual health and reducing cost.

A national network of health information may be years in the future, but the technologies needed to enable such a network exist today, and many elements are already operational in communities around the country. The future network even has a name: the national healthcare information infrastructure, or NHII.

A variety of private and public entities are working to build the NHII, envisioned as a system of decentralized, local data sources. Guided by input from a wide range of healthcare industry representatives, the Department of Health and Human Services (HHS) is working to accelerate that progress.

Why Healthcare Needs an NHII

The US healthcare system is facing significant challenges from medical errors, inconsistent quality, and rising costs. The Institute of Medicine (IOM) estimates that medical errors account for between 44,000 and 98,000 preventable deaths in US hospitals each year.[1] The dissemination of anthrax in 2001, followed by the outbreak of SARS and monkey pox in 2003, highlighted the significant new challenges to our public health system.[2,3]

The current paper-based healthcare system is unable to consistently deliver recommended care, particularly for chronic diseases.[4] Increasing investment in medical research in the public and private sectors is advancing our ability to diagnose and treat health conditions; however, it takes an average of 17 years for new discoveries to be widely used in patient care.[5] Moreover, the ability to apply the relevant findings of more than 11 million bibliographic citations in MEDLINE in clinical settings is overwhelmingly challenging.[6] Finally, the cost of healthcare is continuing to increase much faster than the overall rate of inflation.

Substantial improvements in these patient safety, quality of care, and efficiency challenges are dependent on the ubiquitous availability of complete healthcare information and decision support at any point of care through a national health information infrastructure.[7] A series of IOM reports starting in 1991 have called for establishing an NHII.[8-14] Additional national expert panel reports also support such a project.[15-17] Most recently, a 2003 IOM report asserts that establishing an NHII should be the "highest priority for all healthcare stakeholders."[18]

The consistent support for an NHII expressed in these reports is based on abundant evidence that effective use of information technology can both improve care and reduce costs. For example, computerized provider order entry alone has been shown to reduce the number of "nonintercepted" medication errors by more than 80 percent.[19] Disease management systems have been shown to improve the health of patients while reducing costs. Moreover, preventive service reminders have been shown to significantly improve the delivery of preventive healthcare.[20] The estimated potential gain of efficiency through the use of information technology in healthcare is at least $87 billion a year.[21]

The NHII Model

The NHII is a comprehensive knowledge-based network of interoperable systems capable of delivering information for sound decisions about health when and where needed. It is not a central database of medical records. Instead, it is a distributed system that collects information from diverse sources as needed for patient care. NHII therefore encompasses both electronic health record (EHR) systems for all providers and the capacity to electronically communicate the stored information within them to assemble a complete record whenever a patient presents for care.

As envisioned by the National Committee on Vital and Health Statistics (NCVHS), the NHII includes not just applications and technologies but practices, relationships, laws, and standards. It supports four major domains—personal health, clinical care, public health, and research and policy. As such, it will provide an improved link between healthcare and public health, facilitating disease surveillance and response. For the provider, it will eliminate the need for redundant tests and X rays because prior results will be readily available. It will facilitate the use of decision support, allowing clinicians to apply the latest treatment recommendations and research advances without the need for superhuman memory. It will automate billing and quality reports from the record of care, minimizing additional work. Consumers will have improved access and control of their own records.

The NHII is comprised of many elements. At the core are standards for messaging and content to allow information to flow easily from diverse sources and be integrated without loss of meaning. Clinician information systems—the EHR—provide structure for health information derived from practice settings such as hospitals, outpatient clinics, and long-term care facilities. Consumer health information systems support the personal health record, electronic communication between patients and providers, educational content, and support groups. Ancillary health systems support pharmacy, laboratory, physical and other therapy, and public health. Communication or networking systems support consultation, integration of health information across sites, and movement of information to the point of care. Decision support systems enable reminders and recommendations to be generated for users throughout the system. Educational content supports both healthcare providers and consumers. Security systems and business rules provide confidentiality protection through authentication, encryption, and audit trails.

Challenges Spell Need for Leadership

With the need for an NHII clearly identified, it's logical to ask why the network isn't already in place. The answer lies in the complexity of the healthcare sector, composed of large numbers of widely distributed, relatively independent elements.

There are approximately 450,000 ambulatory healthcare service firms (e.g., physician offices, dentists, chiropractors), 5,800 hospitals, 16,700 nursing homes, and 7,000 home health agencies involved in US healthcare delivery.[22-24] It is estimated that there were more than one billion US healthcare ambulatory care visits in 2000 (83 percent of which were to physician offices).[25] The vast majority of health facilities rely on paper-based documentation. The numerous pharmacies, laboratories, researchers, and public health agencies also have key information needs that must be supported by the NHII. In addition to ensuring access to healthcare information for these providers and organizations, the NHII must support the approximately 281 million people that reside in the United States, 12 percent of whom are over the age of 65.[26]

In addition to the necessary magnitude of the NHII, stakeholders represent many different interests and are often not aligned by similar incentives. With the increasing costs of healthcare delivery and the tightening reimbursement rates, many smaller organizations do not have the capital or expertise to effectively implement the needed health information technology. Moreover, benefits often have not accrued to those expected to pay for the systems needed to support the NHII. In light of these financial challenges, the organizational and change management issues from health information technology systems are especially difficult.

Despite these challenges, nearly every component of the NHII is already operating somewhere. Current examples of organizations that share health information at the point of care demonstrate the feasibility of creating the NHII. Many of these are one-of-a-kind systems with minimal interoperability, however. There is also substantial duplication of work and ineffective sharing of lessons learned. In view of this, the NCVHS's recommendation that federal leadership is needed to accelerate progress comes as no surprise.[27]

Building the NHII

HHS has provided leadership in moving the NHII forward since September 2002. Guided by input from a wide range of healthcare industry representatives, HHS has adopted a voluntary approach in its efforts to encourage and promote the NHII.

Consistent with this approach, in 2003 HHS convened a meeting of key healthcare system stakeholders to develop an agenda for NHII development.

Recommendations were in four general categories: management, enablers, implementation strategy, and targeted domains. With respect to management, the attendees favored public-private coordination to guide NHII activities, ensure the availability of needed descriptive information and education, implement shared information resources, and develop and track meaningful metrics to assess progress. Key enablers identified included financial incentives, health information standards, and reducing the impact of perceived legal obstacles on community NHII investments. For an implementation strategy, the participants recommended the development of community and regional health information infrastructures that would interconnect to form the NHII.

In the consumer health domain, the development and implementation of personal health record systems was recommended. Finally, the attendees urged substantial expansion of research on the impact of health information systems on patient safety, quality, and cost.

NHII is not a government project—it will be developed, built, and operated in the private sector. HHS's role is to promote and encourage these private sector activities. Consistent with the recommendations of NCVHS, the multiple IOM and other national expert panel reports, and the consensus action agenda, a six-point strategic approach is being pursued to accelerate NHII progress: inform, collaborate, convene, standardize, demonstrate, and evaluate.

HHS is informing all stakeholders by disseminating the NHII vision through a Web site (http://aspe.hhs.gov/sp/nhii), providing presentations to stakeholder groups, cataloging NHII activities, and actively sharing lessons learned through communities of practice, presentations, and online.

To ensure that the direction of NHII activities continues to be fully informed by the views of the various groups comprising the private healthcare sector, HHS is collaborating through a series of targeted stakeholder meetings, continued input from the NCVHS, and participation in the development of local health information infrastructures. HHS is also convening annual national NHII meetings for all the stakeholders to review and refine their action agenda and report on progress. The next such meeting, NHII 04, will be held in Washington, DC, in July.

Like the initial meeting in 2003, NHII 04 will be highly interactive, providing opportunities for breakout group discussion and input on key topics from multiple stakeholder perspectives. As a new feature, final reports from the breakout groups will be given at formal hearings of the NCVHS NHII work group. This ensures that the results of the conference will be considered immediately by this statutory advisory committee and reported to HHS.

HHS is identifying and promoting the standards necessary to move the NHII forward. Through the Consolidated Health Informatics initiative (led by HHS), the federal government has already selected standards for government-wide adoption and implementation.[28] Additional standards are under consideration. Moreover, as announced by the secretary of Health and Human Services in 2003, HHS has licensed the SNOMED comprehensive standard clinical vocabulary and made it available at no charge for use within the US.

In cooperation with the Veterans Administration (VA), HHS has also supported the development of standard functions of the EHR by HL7. HHS is planning a follow-up project with HL7 to define an EHR interoperability standard that will allow easy exchange of complete or partial electronic health records. Also, a significant portion of the FY04 HHS budget allocation of $10 million for the support of standards development and adoption is being used for the collaborative development of the medication vocabulary standard RxNORM by the National Library of Medicine, VA, and the Food and Drug Administration.

A Foundation of Community-based Networks

The NHII is envisioned as a network of local health information infrastructures (LHIIs), each facilitating exchange of health information in a community. These LHIIs would be connected to each other to form the NHII. Utilizing standards within each LHII will minimize the difficulties of this interconnection. The use of interface standards for communicating between LHIIs and national organizations will avoid the problems of multiple incompatible information exchange interfaces throughout the nation.

There are significant advantages to the LHII approach. The first is the understanding that healthcare delivery is generally a local event providing local benefits. The trust necessary between organizations agreeing to share health information is easier to build in the local context. Moreover, local needs can be addressed, increasing the likelihood of long-term success and sustainability. Implementation lessons learned can be rapidly shared with other communities. With parallel implementation, progress can proceed more rapidly.

Since few patients receive all their care from a single provider, availability of complete medical records requires collection and integration of healthcare information from multiple organizations in the community. Since current data indicate that about two-thirds of the economic benefit from NHII will come from such exchange of health information in communities, funding of local, state, and regional demonstration projects is a central strategy of the HHS NHII effort.[29]

The Agency for Healthcare Research and Quality FY04 budget includes $50 million for health information technology research to assess costs and benefits and explore the patient safety and quality issues related to planning and development of LHIIs. Added to those funds in the FY05 HHS budget request is an additional $50 million targeted specifically to LHII implementation. Ongoing evaluation of these early efforts will provide valuable lessons that will guide further development and implementation. In addition, specific assessments of NHII costs and benefits are ongoing, as are evaluations of various policy options for aligning financial incentives.

Many things must be accomplished to move the NHII forward. Additional cost-benefit data are needed. Facilities are encouraged to share their data, which will greatly assist others in understanding the business case for health information technology. Facilities and HIM professionals are also encouraged to join local LHII initiatives or consider starting one by convening community partners to discuss health information sharing. It is also important to keep informed about the NHII initiative and to express views about it, including at the various stakeholder meetings convened at the national level.

Notes

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Article citation:
Rippen, Helga E., and William A. Yasnoff. "Building the National Health Information Infrastructure." *Journal of AHIMA* 75, no.5 (May 2004): 20-26.