Language of Health Data Exchange

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Rapidly advancing data exchange initiatives have left a trail of acronyms in their wake. Is a SNO a RHIO, and where did LHIIs go?

As thinking on the nature of regional and nationwide data exchange evolves, terms devised from necessity have been left behind just as quickly. Their origins can often be found embedded in federally funded projects and regulatory and legislative policy discussionsAfter a busy 2005, the information exchange dictionary lay relatively dormant. It will not stay that way for long, however. Following is a quick review of key vocabulary in national and regional data exchange.

From Infrastructure to Network, National to Nationwide

The vision for a nationwide network for health data exchange began more than a decade ago with the Institute of Medicine's report "The Computer-Based Patient Record." In that study, the institute recommended a major coordinated national effort, with federal funding and strong private-sector advisory support, to accelerate the adoption of computerized medical records. In the following years, consensus began to emerge that the nation's medical system must replace its outdated and frequently error-plagued paper-based approach to information management.

Because moving patient data from paper to computer dramatically increases its potential mobility, discussion soon turned to ways that data could be organized and shared to improve care and decrease cost. An early champion was the National Committee on Vital and Health Statistics (NCVHS), which advises the Department of Health and Human Services (HHS) on national health information policy.

In 1997 NCVHS began to explore the concept of a *national health information infrastructure* (NHII), the framework that would support the appropriate and secure exchange of health information. To NCVHS, the NHII was more than technology behind data exchange. "More importantly," the committee wrote, it included, "values, practices, relationships, laws, standards, systems, and applications that support all facets of individual health, health care, and public health."[1]

"Infrastructure" gave the name a somewhat remote, technical ring, but it did emphasize that under discussion was a framework for exchanging data, not a centralized system to house it. (The finer point of whether it was "a national health information infrastructure" or "the National Health Information Infrastructure" depended in part on whether the writer was comfortable using a proper name for something that did not exist.)

A policy agenda for computerized health information developed rapidly, both in the public and private sectors. What became called "healthcare IT," was soon shortened to health IT and, because familiarity breeds abbreviation, simply *HIT*.

The current surge in activity seemed to start with the president's January 2004 State of the Union Address, which contained a mention of the benefits of computerized health records. It was followed in spring by an executive order creating the Office of the National Coordinator for Health Information Technology within HHS. One of the coordinator's duties would be to oversee development of an NHII.

Another was to report within 90 days on a strategic plan to guide the development and implementation of interoperable health IT. In July 2004 the newly appointed national coordinator for health IT--David Brailer, MD, PhD--and HHS secretary Tommy Thompson did so, releasing "The Decade of Health Information Technology," which became better known, through a twist of its subtitle, as the "Strategic Framework."

Soon after this, NHII disappeared. When late that year Brailer's office requested public input on a health IT infrastructure, it was referring to the *national health information network* (NHIN).

The new name, more intuitive to audiences beyond IT, stuck. It received a tweak the following year when the office promoted a largely successful switch from *national* to *nationwide*, reflecting continuing concerns that the concept might be perceived as a single national database rather than the integration of locally managed networks. Brailer's office itself underwent an acronym change of sorts around the same time, when its official abbreviation was changed from ONCHIT to ONC, following its formalization within HHS.

Funders and Shakers

More challenging than keeping track of data exchange terms is keeping track of the public agencies and private organizations that fund research and demonstration projects and help shape HIE development.

There is a great deal of health IT activity within the federal government, some of it focused on internal needs, such as initiatives in the Department of Defense and the Department of Veterans Affairs. Much of the activity concerning the private sector comes from within the Department of Health and Human Services. Two agencies there play leading roles. The **Agency for Healthcare Research and Quality** provides funding and information for health IT projects, including grants to state and regional HIE initiatives. The agency also hosts the National Resource Center for Health Information Technology. The **Office of the National Coordinator for Health Information Technology** plays an active role promoting industry discussion, research, and demonstrations. Early this year, the office announced work to support the development of statewide RHIOs by identifying minimum functional capabilities and operational best practices. (AHIMA's Foundation of Research and Education will support this work under a federal contract. Look for more information in the following issue.) Both agencies provide information on other federal HIE efforts, including funding opportunities.

Two federal programs in particular will keep high profiles in the immediate future (and will no doubt generate new terminology). The **American Health Information Community** has a charge to drive the private market to demonstrate consumer benefits in several aspects of health IT. **Private-sector contractors** to the Office of the National Coordinator will present work on electronic health record certification, privacy and security laws, NHIN prototypes, and data standards harmonization.

The private sector has been actively supporting consensus building and research efforts. **Connecting for Health**, a public-private collaborative launched and funded by the Markle Foundation, with additional support from the Robert Wood Johnson Foundation, works for consensus on its Roadmap for Electronic Connectivity. The Robert Wood Johnson Foundation is also funding projects in public health and HIE through a program called **InformationLinks**. Several large employers and health plans are conducting so-called market experiments that involve incentives to practicing clinicians, hospitals, and other providers who improve quality through health IT. **Bridges to Excellence** and the **Leapfrog Group** are two of the better known.

Numerous health and IT **professional organizations** provide research, information, and programming related to HIE. These include physician associations, health informatics and information management organizations, IT organizations, and data standards organizations. All are online; many link to other resources, both private and public. For more on these programs, visit the FORE Library: HIM Body of Knowledge, online at www.ahima.org and HHS's Health IT Web site at http://hhs.gov/healthinformationtechnology.

Flashback: CHINs and CHMISs

Attempts to communicate patient information across multiple entities are not new, of course. Prior efforts that have come and gone were known by various names, such as regional data networks, community health management information systems, integrated delivery networks, and community health information networks (CHINs).

The reasons for forming or participating in a CHIN varied--establishing the loyalty of practicing physicians in a community hospital's struggle to survive; sharing real-time patient care data in a successful communitywide effort to avoid expensive duplication of services; and driving the transition from a multihospital integrated delivery system to a full-risk accountable health plan. CHINs provided a structure for sharing financial and clinical information among a defined group of entities.

Several key decisions affected how individual CHINs functioned. These included the data that would be included, the technical infrastructure, who owned the data, what organization or group of organizations would lead the CHIN's development, the type of information to be shared, and how to safeguard patient confidentiality. A number of data-sharing initiatives focused on point-to-point messaging and others on regional data storage. Many were attempts to connect not just providers, but also payers, commercial diagnostic centers, and pharmacies.

In fact, there were even earlier efforts to facilitate community and regional data sharing. The John A. Hartford Foundation provided seed funding to support planning and development grants in seven communities in Iowa, Washington, Minnesota, New York, Vermont, Ohio, and Memphis (MidSouth Healthcare Alliance). These efforts were known as community health management information systems (CHMISs). Another set of organizations were involved in CHIN efforts (Wisconsin Health Information Network; MedCom in Dallas, TX; Ameritech-Aurora Health in Wisconsin; and the Metropolitan Healthcare Council in Chicago). In addition, from August 1997 to March 2002, the Foundation for Health Care facilitated the collaboration of IT organizations in a program called the Multi-state Initiative to Help Build a Health Information Infrastructure. Organizations in Minnesota, Massachusetts, Washington, Utah, and North Carolina participated.[2-8]

What Do You Call a Regional Network?

As discussion of a nationwide network took shape, a related discussion began on the need to organize local and regional providers. In part this is because most discussions of a nationwide network envision it being developed through the networking of many smaller initiatives. Local organizations were needed to support information exchange, oversee and govern that exchange, and enforce and support technical systems standards. Many local, state, and regional health information networks began to form.

The first description to gain wide currency was *local health information infrastructure* (LHII). With its obvious parallel to NHII, it was one of the first terms widely used to describe the architectural needs to support the exchange of information among providers and provider organizations. Initial work on LHIIs included at least one model to define characteristics, variables, and categories at different stages of development and a strategy for creating them.[9]

The term seems to have faded when the Strategic Framework was published. There, *regional health information organization* (RHIO) was used to describe a group that supports electronic exchange of personal health information. The report described RHIOs as "collaborative entities that facilitate the development, implementation and application of secure [health information exchange] across care settings." Given how few entities had actually tried this, the definition understandably focused on broad function more than organization or membership. Many regional networks formed since do call themselves RHIOs, though some may do so out of the simple need to call themselves something.

In the broadest sense, *health information exchange* (HIE) describes the concept of interoperable, secure health data exchange. It evolved over time and encompasses diverse definitions and approaches. The Agency for Health Research and Quality, for instance, thoroughly lays out the benefits, challenges, and models of health data exchange using only the term HIE. Some speakers and writers make a distinction between HIE (the ability to share information) and an HIE initiative (an organization that enables information sharing). And it's common for HIE and RHIO to be used interchangeably.

ONC's request for information on the NHIN produced at least one other term for regional networks. *Subnetwork organization* (SNO) was coined in a collaborative response led by the Markle Foundation. SNOs support data exchange subordinate to the larger nationwide network--they are the essential building blocks of data exchange.

The collaborative response describes the subnetwork as an affiliation of users who share health information and adhere to a common IT framework. Like RHIOs, subnetworks can be regionally or geographically based, and some cross state or other jurisdictional boundaries. Others, such as national research communities, major federal programs, and large commercial enterprises, are organized around different criteria. A SNO encompasses the notion of a RHIO and expands it to include other types of organizational structures.

The HIE dictionary may require little update currently, but new terms as well as changes to existing terms are sure to keep arriving. The NHIN prototypes currently in development under contract to ONC are one likely source of new terms. The growing interest in consumer awareness campaigns may be another. As talk about health data exchange widens from the technical underpinnings that would enable it to the consumer benefits that would result from it, the language has edged toward the plainspoken. That trend may well continue. One sign that widespread health data exchange has taken hold will be the day when its terms are common and commonplace.

Notes

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