

HIE Takes Shape in the States

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Local factors shape state and regional health information exchange, but as differing models develop, common defining principles are emerging.

The exchange of health information across traditional institutional boundaries is inevitable. Nearly every stakeholder group—hospitals, clinical laboratories, physicians, employers, health plans, quality improvement organizations, and public health agencies—is expressing a desire to participate in data exchange in the belief that broader availability of clinically relevant information and a wider array of interoperable IT can both improve care and increase choice among patients and healthcare professionals.

Although inevitable, health information exchange (HIE) won't come easily. Creating data networks is difficult because of a tradition of competition, a lack of trust, large and expensive information systems that do not communicate with one another, competing priorities, relatively little penetration of clinical systems in ambulatory care settings, and insufficient financial incentives. Equally daunting are the unresolved issues surrounding data ownership, information security, privacy, confidentiality, and liability.

Over the past two years a significant amount of activity has taken place at both the federal and state levels aimed at facilitating collaboration and solving these issues.¹ Most recently, Michael Leavitt, secretary of the Department of Health and Human Services, established and will chair a 17-member federal advisory commission on health information technology called the American Health Information Community.² The department also issued requests for proposals addressing pressing challenges that must be addressed to create a national health information network.³

No Single Approach

Federal initiatives, however, will not be sufficient to realize public aspirations. Consistent with Leavitt's maxim of "national standards, neighborhood solutions," state and local government and community leaders are beginning to collaborate and develop consensus among diverse stakeholders on the vision, goals, and plans required to foster better care through timely and appropriate regional information exchange.

Perspectives on how to achieve effective and timely exchange of clinical data vary widely. Some stakeholders believe exchange implies the creation of a large centralized database vulnerable to intrusion and privacy violation; others believe incremental approaches building upon set relationships are sufficient; still others believe such activities should initially focus on health plans and large care delivery organizations.

Clearly, there is no standard solution that is widely accepted. Indeed, early experience suggests that successful efforts often differ in their initial approaches, their convening groups, and their core organizational approach. Where the latter is concerned, some efforts build on administrative transactions infrastructures, others respond to legislation, and still others create entities independent of legislation or existing collaborations.

Growing in tandem with these initiatives is the need to understand how various approaches will affect patient care. Classifying emerging exchange models also helps identify new challenges and opportunities for HIM professionals and healthcare providers, because whether a data-sharing initiative is local, regional, or statewide, common issues arise that require the skill and leadership of these professionals.

Starting Points and Initial Approaches

State, regional, and community-based organizations often have an acute issue—a “burning platform” that fosters the development of a guiding coalition to address healthcare challenges through IT and data sharing. Examples of such acute issues include employer concerns over high cost and low quality healthcare; provider concerns over Medicaid reimbursement; care of the uninsured; public distress over high insurance premiums and high administrative costs; inadequate or unnecessary care; and inappropriate use of emergency departments and other costly settings and technologies.

Conveners. Conveners begin with a set of identified problems or capabilities and grow awareness and organization as their efforts evolve. Such networks can also be thought of as awareness or education organizations. Examples of conveners include:

- Massachusetts Health Data Consortium, a neutral agency that collects, analyzes, and disseminates healthcare information and supports health policy development, technology planning and implementation, and improved decision making in the allocation and financing of healthcare
- North Carolina Healthcare Information and Communications Alliance, a nonprofit organization that champions the adoption of IT to improve healthcare, operating in many venues as a promoter, catalyst, and innovator in demonstration projects, educational sessions, collaborative efforts, and IT initiatives

Administrative Transactions. States or regions having a strong framework for administrative transactions have by virtue of their function created a means by which diverse stakeholders can share resources to lower individual and overall operational costs. Such efforts provide models for similar initiatives in the clinical arena, either built upon the administrative transaction entity or operated in parallel of administrative transactions. Examples of organizations beginning with administrative transactions are:

- New England Healthcare Electronic Data Interchange Network, a Massachusetts-based group that designed and implemented secure electronic commerce for reducing administrative costs
- Utah Health Information Network, a coalition including the Utah state government that created a secure, electronic network to exchange administrative health data and electronic commerce

Legislative. Where a long-standing convener or widely adopted administrative transaction organization is not available, legislation can provide incentives to bring together diverse groups for planning and implementation. Many of these initiatives involve university medical centers as the foci for initial planning. States with legislative-driven organizations include:

- Kentucky, where the governor signed legislation to create a statewide electronic health information network and establish an academic research partnership to investigate ways that IT can improve healthcare
- Oregon, where the state legislative assembly created the Oregon Health Policy Commission to develop and oversee state health policy and planning

New Entity Formation. In some instances, either state government or state healthcare leaders have created new organizations to plan and develop regional data exchanges. Examples include:

- California Regional Health Information Organization, a collaborative, statewide effort that brings together stakeholders to develop governance, operational processes, technology, and financing models for HIE
- Indiana Health Information Exchange, one of the earliest and most successful initiatives and a strong collaborator with others both on business models and technologies, focuses on clinical connectivity
- Volunteer eHealth Initiative, a three-county initiative in southwest Tennessee, focuses on clinical connectivity infrastructure
- West Virginia eHealth Initiative, a statewide working group studying implementation of electronic health record technology

Incubation Model. In other states, established groups have expanded their roles to “incubate” the governance, information sharing, and funding models. These public-private collaborations work to build momentum and focus efforts until alternative plans are made. Examples include:

- CareSpark, serving 16 central Appalachian counties, proposes to develop a secure network that allows physician offices, hospitals, public health departments, pharmacies, laboratories, and imaging centers to communicate electronically. The effort focuses on the clinical infrastructure and the “last mile” of office and consumer connectivity.

- Delaware Health Information Network, created by an act of the general assembly, provides the organizational infrastructure to advance the creation of statewide health information and electronic data interchange network.
- Department of Health and Hospitals and Louisiana Health Care Review are in the early stages of convening stakeholders from across the state to shape a vision and plan for health IT and exchange.

Five Emerging Models

Examples of State and Regional HIE Initiatives

Initiative	Description
Conveners	
Massachusetts Health Data Consortium www.mahealthdata.org	The consortium is a neutral agency that collects, analyzes, and disseminates healthcare information and supports health policy development, technology planning and implementation, and improved decision making in the allocation and financing of healthcare.
North Carolina Healthcare Information and Communications Alliance, Inc.	NCHICA is a nonprofit organization that champions the adoption of IT to improve healthcare. Its members include leading organizations in healthcare, research, and IT. NCHICA operates in many venues as a promoter, catalyst, and innovator. It leads demonstration projects, hosts educational sessions, fosters collaborative efforts, and supports initiatives that promote HIT.
Administrative Transactions	
New England Healthcare Electronic Data Interchange Network www.nehen.net	NEHEN designed and implemented secure electronic commerce for reducing administrative costs. The network electronically processes transactions dealing with eligibility, claims status, specialty care referrals, and referral authorizations and inquiries.
Utah Health Information Network www.uhin.com	UHIN is an electronic commerce coalition, which includes the state government, that has created a secure, electronic network to exchange administrative health data and electronic commerce statewide.
Legislative	
Kentucky www.lrc.ky.gov/record/05rs/SB2.htm	Kentucky governor Ernie Fletcher, MD, signed legislation to create a statewide electronic health information network and establish an academic research partnership between the University of Kentucky and the University of Louisville to investigate IT uses to improve healthcare.
Oregon egov.oregon.gov/DAS/OHPPR	The Oregon legislative assembly passed House Bill 3653, creating the Oregon Health Policy Commission to develop and oversee health policy and planning for the state.
New Entity Formation	
California Regional Health Information Organization www.calrhio.org	CalRHIO is a statewide initiative begun by Health Technology Center with support from California Health Care Foundation. It is a collaborative effort to support the use of IT and the creation of secure HIE. CalRHIO serves as an umbrella organization that brings together healthcare stakeholders to develop governance, operational processes, technology, and financing models.

Indiana Health Information Exchange www.ihie.com	IHIE is the result of a multiyear effort in regional data sharing initiated by the Regenstrief Institute and several regional hospitals and clinics. It is one of the earliest and most successful initiatives and a strong collaborator with others both on business models and technologies. It focuses on clinical connectivity.
Tennessee www.volunteer-ehealth.org	A three-county initiative in southwest Tennessee with strong leadership by the governor is one of the five state and regional demonstration projects funded by the Agency for Healthcare Research and Quality. The effort focuses on clinical connectivity infrastructure.
West Virginia www.wvehi.org	A statewide working group is studying implementation of electronic health record (EHR) technology. The effort is at the planning phase.
Incubation Model	
CareSpark (central Appalachian) www.carespark.com	The central Appalachian region served by CareSpark includes 16 counties in southwest Virginia and northeast Tennessee, as well as areas of adjacent counties in western North Carolina and southeastern Kentucky. The initiative proposes to develop a secure network that allows physician offices, hospitals, public health departments, pharmacies, laboratories, and imaging centers to communicate electronically in order to improve patient care. It focuses on the clinical infrastructure and the “last mile” of office and consumer connectivity.
Delaware Health Information Network www.dhin.org www.state.de.us/dhcc	DHIN, a public-private collaborative, was created by an act of the general assembly and signed into law in 1997 to advance the creation of statewide health information and electronic data interchange network for public and private use. DHIN functions from the direction of the Delaware Health Care Commission.
Louisiana www.dhh.state.la.us , www.lhcr.org	The Department of Health and Hospitals and the Louisiana Health Care Review are bringing together healthcare stakeholders from across the state to shape a vision and plan for health IT and exchange. The effort is at the planning stage.
Massachusetts eHealth Collaborative www.maehc.org	The collaborative will establish and operate broad connectivity within three communities in Massachusetts. These communities will help to achieve universal adoption of EHRs across the state.
Minnesota e-Health Initiative www.health.state.mn.us/e-health	The Minnesota Department of Health and Minnesota e-Health Initiative steering committee will make recommendations to the Minnesota legislature on issues related to EHRs.
New Mexico Medical Review Association www.nmmra.org	NMMRA and various healthcare stakeholders are developing an approach for a regional health information organization.
New York www.uhfnyc.org	The United Hospital Fund, in conjunction with eHealth Initiative, brings together key organizations to stimulate information sharing and shape a strategic vision for health IT.

Emerging Principles

A number of initiatives are under way to develop a systematic review of state and regional efforts. Notable groups include eHealth Initiative’s Connecting Communities for Better Health program (in cooperation with the Health Resources and Services Administration), the Agency for Healthcare Research and Quality’s National Resource Center, and eHealth

Initiative's State Health Information Technology Policy Program. An early assessment of this work suggests the emergence of several principles in the foundation of data exchange networks.

Approach for Organizing Work. IT adoption and HIE will require local and regional collaboration—statewide, one-size-fits-all approach will not work. Leadership must be largely local, but it must foster a regional, a state, and a national dialogue where required.

Role of the State. State government must play a visible leadership role by raising awareness of the need for IT to address healthcare challenges and by creating legislation to remove unnecessary barriers to patient-focused data exchange. As employers and Medicaid administrators, state governments are often the largest purchasers of healthcare within their states. Accordingly, their approach to health IT will create a de facto standard approach. By virtue of their size and influence, it is essential that states understand their influence and develop infrastructures that support all citizens and all healthcare markets. Because of this influence, states must assist in the adoption of standards and through various mechanisms create means of financing health IT and healthcare transformation.

Organization and Governance Attributes. To the extent possible, state and regional initiatives must be convened by a trusted, neutral party representing a broad view of public healthcare interests. Although attempting to involve every stakeholder initially is not practical, an approach to ensure widespread future involvement—particularly of consumers and employers—is essential. The initial group must arrive at shared vision and goals that include explicit value statements for each stakeholder. This must be followed by a practical plan that ensures a high degree of coordination and collaboration.

Financing and Sustainability. Under current reimbursement mechanisms, the sources of community value in regional exchanges are limited. Some examples include secure provider communications; measurable improvements in management of chronic disease; lower medical care expenditures; lower pharmaceutical expenditures; better reporting of public health and quality data; and coordination of pay-for-performance programs. Not all of these options will be attractive to all regions, either because of disagreement over their management or the presence of one or more organizations that claim to already provide a specific service without employing a regional exchange. There is strong movement to phase out rewards for acquisition and use and phase in rewards for performance.⁴

Technologies. Many major technical issues remain unresolved. These include the final architecture for a national health information network; standards for allergies and other key clinical issues; common and practical means of ensuring privacy and security; and mechanisms to ensure accurate identification and linking of information from a specific patient into a common clinical record. In many instances, the technical issues raise new policy and legal issues. Many groups are addressing these issues both through deliberation and through the construction of prototype systems.⁵ Examples include the Agency for Healthcare Research and Quality, the Department of Health and Human Services, and the Connecting for Health Initiative led by the Markle Foundation with additional support of the Robert Wood Johnson Foundation.

Growing federal, state, and regional interest in HIE is the result of a clearer understanding of the extent to which our nation suffers the consequences of a highly fragmented healthcare delivery system. By beginning now to develop interoperable systems that enable greater exchange in a secure way, new ways of empowering consumers and healthcare professionals will emerge, for an infrastructure is just that—a means of enabling new opportunity and a greater good, which hopefully will yield future benefits far in excess of initial costs. Just as the developers of electric generators or interstate highways could not anticipate the ways in which electrical devices and automobiles would transform US culture, the developers of a national health information infrastructure can see enough good ahead to commit but cannot foresee every long-term opportunity or potential that this infrastructure will enable.

These initiatives, played out at the local and regional level, will only succeed if HIM professionals bring to bear their expertise in the secure management of patient information. Without such expertise, these efforts will fail. With concerted effort, they will succeed and may initiate a new era in healthcare delivery. The ultimate beneficiary of such an era will be the patients who manage and navigate the healthcare systems. And lest we forget, these patients include us.

Notes

1. Department of Health and Human Services (HHS). "HHS Releases Report on Nationwide Health Information Exchange." News release. June 3, 2005. Available online at www.hhs.gov/news/press/2005pres/20050603.html.

2. HHS, Office of the National Coordinator for Health Information Technology. "American Health Information Community (AHIC)." Available online at www.hhs.gov/healthit/ahic.html.
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4. eHealth Initiative, Working Group for Financing and Incentives. "Parallel Pathways for Quality Healthcare: A Framework for Aligning Incentives with Quality and Health Information Technology." May 2005. Available online at www.ehealthinitiative.org.
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