State Connection: State-level Efforts in Health Information Exchange

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by Lynn Dierker, RN

Operating between community efforts and a nationwide health data network, statewide public-private partnerships are showing unique potential to advance interoperability and promote effective governance.

The early proliferation of health data-sharing networks produced numerous configurations of local and even regional data-sharing partnerships. Variable in their technology models, these business affiliations developed predominantly among providers and healthcare organizations serving distinct locales and patient populations now labeled as "medical trading areas."[1]

Subsequent high-profile failures of some of these health information exchange (HIE) efforts have raised questions about the viability of broader regional health information organizations (RHIOs) as a basis for an interconnecting nationwide health information network.

Persistent challenges in mobilizing the large-scale resources necessary to support timely and widespread HIE adoption are dampening optimism about what can be accomplished to interconnect the country beyond corporate HIE interests.[2] Amid heightened scrutiny of privacy and security protections, concern is growing about how to ensure consumers have control of their health information.

Despite this evolving and unsettled landscape, interest in HIE remains strong. Three-quarter of states are pursuing HIE strategies of some kind, varying in their level of development. Growing interest in HIE as a healthcare reform priority has resulted in the introduction of more than 200 bills focused on health IT in 41 states since January 1, 2007.[3]

Entities with a Statewide Reach

These efforts include state-level initiatives that operate between the national and local levels, seeking to catalyze statewide HIE development. While the word "states" commonly refers to state governments, the term "state level" here refers to efforts organized with a statewide reach, ranging in structure and development but sharing two key dimensions: a statewide scope for advancing interoperability and a multistakeholder, public-private partnership as a governance structure.

The roles and functions of these initiatives, as well as the implications for their place in widespread HIE development and sustainability, are the focus of the State Level Health Information Exchange Consensus Project. The project began in 2006 under a contract from the Office of the National Coordinator for Health Information Technology and is conducted by AHIMA's Foundation of Research and Education.

Over the course of two years, the project has studied and fostered consensus regarding the evolving functions and distinct potential of organized state-level efforts to lead and coordinate HIE development. Guided by a steering committee of 11 state-level HIE leaders, the project has offered research and recommendations on crafting a nationwide health information system based upon the realities of implementing HIE across diverse state cultures and healthcare environments. In March of this year, the project published two reports summarizing findings and recommendations based on its 2007 research.[4]

Emerging Roles in Governance

HIE-related functions at the state level are coalescing into two key organizational models that provide either governance or governance combined with state-level technical operations, according to the research. Developmental pathways also are

becoming evident.

Some statewide strategies for advancing interoperability include the provision of centralized state-level technical HIE services (e.g., a federated clinical data exchange); however, state-level organizational roles in technical operations are a variable component of these approaches.

The key driver for organizational state-level HIE efforts is ensuring effective governance—convening and coordinating functions required for effective collaborative data-sharing practices.

While state governments carry out their consumer protection roles through statutory and regulatory rule making and oversight activities, state-level HIE "governance" involves distinct characteristics. As this role is emerging, the state-level HIE governance organization sits between state government and the healthcare sector, including any configuration of HIE networks or local and regional RHIOs, agencies, and relevant medical trading areas. Its mission is to facilitate compliance with prevailing laws and regulations and sound data management practices across diverse interests and organizations.

The state-level HIE entity serves as a neutral and skilled resource for convening diverse statewide stakeholders and leading and coordinating consensus-based efforts to develop and implement a statewide road map for interoperability. This road map represents the strategies, timelines, and goals for achieving connectivity across the particular characteristics of a statewide landscape.

The Good of the Public Good

There is growing consensus about the vital "public good" contributed by state-level HIE governance entities. Promoting consistent application of HIE policies, practices, and interoperability standards avoids inefficient electronic data silos and ensures essential consumer confidentiality and security protections.

Fostering consensus-based approaches for data sharing requires redefining relationships among sources and users of health information. To achieve the social capital gained from interoperable health systems, degrees of collaboration must replace competition. This entails the ability to facilitate data sharing across sectors and diverse interests, mobilize resources, and remain entrepreneurial to guide progress.

To be effective, a state-level governance entity must not be constrained by political variables or governmental budgetary constraints, according to participants in the project. Even in states where government currently plays a key sponsorship role for early HIE efforts, it is most viable for a state-level HIE governance organization to be an independent public-private partnership structure that engages, but sits outside of, state government.

As state governments and statewide stakeholders seek to incorporate HIE in health policy goals and healthcare reform strategies, they are beginning to confront the realities of how oversight of data access, use, and control will be effectively carried out. The confidentiality of health records, consumer empowerment, and accountability for managing secure and effective HIE practices are growing public concerns.

Recognizing the limits of government in this practical regard, and seeing the value of an HIE governance entity with the expertise to coordinate and oversee the development of consistent data management practices, there is an increasing effort to support and participate in state-level HIE entities. Among the current activity are calls to codify state-level HIE functions in statute as well as develop explicit systems that define and measure the accountabilities of HIE entities that play key roles in ensuring effective data management practices.

Fostering a State-level Role in the Nationwide Network

Among the recommendations made by the State Level Health Information Exchange Consensus Project are the following related to national-level action for "building the nationwide network of networks":

- Establish a structured collaborative process to develop and vet options for an accountability structure that incorporates the roles and contributions of HIE entities at various levels, including state-level HIE governance entities.

- Identify a set of options for structuring and maintaining accountability and oversight for key HIE functions and organizational roles, including regulatory and accreditation models.
- Develop standards and associated qualification criteria and methods for accrediting HIE entities related to key HIE functions and state-level HIE organizational roles (governance and technical operations).
- Structure appropriate time frames and approaches for implementing standards and accountability mechanisms, including certification, accreditation, and statutory/regulatory oversight, that accommodate the nascent stages of HIE development and create appropriate incentives.
- Strengthen and enhance mechanisms to promote strategic synergy between state and federal HIE agendas and initiatives.
- Build upon the project's success in convening state-level HIE leaders to continue and expand the communication and coordination among states and between states and federal agencies. Continue to support expanded dialogue and consensus building among states and provide a defined voice for state issues in the emerging federal HIE agenda.
- Structure mechanisms to involve state-level HIEs and the project more effectively as part of ongoing NHIN development.
- Structure explicit mechanisms to bring together federal agencies and offices to communicate and coordinate HIE agendas and foster alignment of support for HIE development, including state-level HIE, Medicaid, Medicare, Health Resources and Services Administration, and the Agency for Healthcare Research and Quality.
- Work actively with representatives of governors and elected officials to define and foster communication, coordination, and alignment across emerging strategies that incorporate and support the roles of state-level HIE entities.
- Support efforts to clarify and vet options for a lexicon of defined HIE terms, roles, and functions.

Source: Foundation of Research and Education, American Health Information Management Association. "State Level Health Information Exchange: Roles in Ensuring Governance and Advancing Interoperability. Final Report, Part I." March 2008. Available online at www.staterhio.org.

A Need for Accountability and Sustainability

Part of a viable accountability structure for HIE activity at the state level is the crucial link of state-level efforts to nationwide HIE governance. Efforts to define a permanent national-level HIE governance structure in the successor to the American Health Information Community must also consider the need for explicit alignment of standards and accountabilities across state and federal levels.

In addition to efforts such as the standards harmonization work of the Healthcare Information Technology Standards Panel and the IT certification work of the Certification Commission for Healthcare Information Technology, participants in the research project identified the need to develop accreditation criteria and processes for HIE organizations. The work to develop a formal accountability system must acknowledge the need for research and careful work to accommodate the incremental stages of development across HIE environments.

State-level HIE entities are demonstrating steady and important progress, but these efforts remain fragile and are subject to the widespread concerns about the value proposition for HIE sustainability. In their start-up phases, state-level HIE organizations have pursued pragmatic, incremental local and statewide strategies to engage data-sharing partners to build and expand HIE. Along with federal grants and contracts, state funding has played an important part in advancing early HIE development. However, the current research points to critical relationships between longer range sustainability and nationwide HIE efforts.

For HIE to advance, there is an urgent need to define its value proposition and related sustainability models across a multilevel HIE infrastructure that will foster and sustain desired levels of interoperability. Ensuring the continued roles for emerging state-level HIE efforts in providing governance is key, regardless of technical models and strategies.

Alone, governance-related functions are not an expensive component of the HIE price tag. However, strategies to fund both initial capacity as well as the full scope of widespread HIE require consideration for how governance will be subsidized and

sustained in conjunction with variable types and levels of HIE interests and investments in connectivity.

Public payers, both state and federal, are key influencers on how participants will engage and support statewide HIE. State Medicaid programs can structure powerful incentives for provider adoption and provide important contributions to building statewide HIE capacity. Project participants emphasize that federal strategies for reimbursement and efforts to make Medicare and Medicaid data available are key to building and sustaining HIE capacity at the state level.

Advancing HIE efforts relies on consensus and collaboration among diverse interests and stakeholders; achieving this at any level is a significant endeavor. State-level HIE entities are emerging in roles that offer distinct value in this work both locally and nationally.

Through ongoing research, analysis, dissemination, and consensus-building efforts, the State Level HIE Consensus Project will continue to serve as a resource to statewide constituents, state-level HIE entities, and the federal strategic agenda. All project resources, including the final reports on 2007 research, are available at www.staterhio.org.

Notes

1. eHealth Initiative. "Health Information Exchange: From Start Up to Sustainability." May 2007. Available online at http://ehr.medigent.com/assets/collaborate/2007/07/10/Health_Information_Exchange-Start_Up_to_Sustainability_Full_Report_07.09.2007001.pdf.
2. Glaser, John. "The Advent of RHIO 2.0" *Journal of Health Information Management* 21, no. 3 (2007): 7–9.
3. eHealth Initiative. "eHealth Initiative BluePrint: Building Consensus for Common Action." October 2007. Available online at www.ehealthinitiative.org/blueprint.
4. Foundation of Research and Education, American Health Information Management Association. "State Level Health Information Exchange: Roles in Ensuring Governance and Advancing Interoperability, Final Report, Part 1" and "State Level Health Information Exchange: Coordinating Policies that Impact the Access, Use, and Control of Health Information, Final Report, Part 2." March 2008. Available online at www.staterhio.org.

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