HIE at the State Level: a Role for States in Regional Data-Sharing Networks?

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by Ruth Carol

Leaders from HIEs forming at the state level talk about their organizations' unique potential and unique challenges.

Just as healthcare is local, the solutions for sharing patient data are often local, also. However, there is growing interest in the role of networking initiatives at the state level, where a statewide reach and a public-private approach may offer unique abilities to foster collaboration and promote development of individual regional efforts. At a more advanced stage, a state-level health information exchange (HIE) effort could help mitigate statewide barriers to data exchange and act as a bridge to other states and federal efforts.

There aren't many state-level HIE initiatives, and most are in the early stage of development. In many cases, the real work that involves bringing together stakeholders and developing a business plan to sustain it is just getting started. And by all accounts it is time consuming, slow going, and requires a huge learning curve.

"There are many barriers," says Antoine Agassi, director and chair of the State of Tennessee eHealth Council. The HIE initiatives are trying to work through privacy, legislative, proprietary, and competitive issues, to name a few. "You just have to be persistent. You have to chip away at it and stay the course."

Laura Adams, president and CEO of the Rhode Island Quality Institute (RIQI) in Providence, concurs. "It's important for the group to remember when they begin an HIE initiative, they will be in it for the long haul. It takes an inordinate amount of time…time spent bringing the stakeholders together and building relationships."

Agassi, Adams, and leaders from seven other state-level HIEs served as steering committee members on a research project funded by the Office of the National Coordinator for Health Information Technology (see sidebar [below]). The office contracted AHIMA's Foundation of Research and Education (FORE) to take an early look at state-level HIE efforts and identify successful governance, legal, financial, and operational characteristics and to gather guidance for other state initiatives just getting started.

Identifying Champions, Stakeholders

All HIEs need champions. HIEs operating at the state level need champions who understand and value the opportunities of a state-level effort.

Getting started in 2002, RIQI sought chief executive officers and other organization leaders. Having high-level leaders pays off, Adams says, because this type of endeavor requires individuals who are capable of executing plans. In addition, people support what they create.

A balance needs to be maintained between having individuals serve on the board of directors for a purely representational purpose versus those who will make things happen, adds another steering committee member, Lynn Dierker, RN, director for community initiatives at the Colorado Health Institute. The institute acts as the coordinating body for the Colorado Regional Health Information Organization (CORHIO), formed in 2004.

Champions at the top of state government can make a big difference. A former healthcare executive, Tennessee's governor is very supportive of the eHealth Council, established in April 2006, says Agassi. The 16 members he appointed represent the

local HIE initiatives, top three payers, top four employers, academic institutions, provider groups, pharmacy benefit managers, and consumers.

Local Needs Determine State-level Roles

A state-level HIE's first and fundamental contribution may be its ability to get major stakeholders in the same room. Adding a governor's support can give regional efforts a substantial push.

Roles largely depend on the unique needs and opportunities throughout the state. Whether regional efforts are already under way is likely the biggest factor determining the role. Further, roles can change over time and from place to place within the state.

"Depending on the landscape at the county level, we play multiple roles to get a grass-roots initiative going that everyone can support," Agassi elaborates. "In some counties, we are the convener, and in some, the participant."

Working through not-for-profit associations, AHIMA state associations, chapters of the Healthcare Information and Management Systems Society, medical associations, and health departments, eHealth Council is creating interest and involvement in the communities. To date, it is overseeing four initiatives across the state that reach all 95 counties.

Eventually, the council will endorse standards developed by community leaders, says Agassi. It is already on the record as endorsing the national standards for ambulatory electronic health records issued by the Certification Commission for Healthcare Information Technology. The state will provide the infrastructure for HIE services and partner with an organization to provide the actual services.

Many of the state-level HIEs are seen as the primary entity for setting HIE policy and standards; being the conduit for HIE services; providing technical assistance and support to local entities that provide these services; and helping catalyze health information improvements in state governmental agencies.

A state-level HIE initiative may have authority to lend in creating necessary efficiencies for local HIEs statewide, such as removing or mitigating state barriers to HIE through policy changes. It can serve as a bridge to other states and federal efforts.

Determining the Role of the State

State government is itself a major healthcare stakeholder, acting in different capacities as a payer, employer, provider, regulator, and public health authority. Thus the roles state governments play in state-level HIE initiatives can vary widely from state to state.

In the case of Tennessee, the state-funded and -established council advises the governor on HIE issues. But in other states, determining the most effective role for state government in the HIE initiative has been more complex.

In Rhode Island, state leaders were initially on the board as voting members. As the initiative matured, the state began awarding contracts for the development of certain components of the HIE, creating a potential conflict of interest. Consequently, the state became a nonvoting board member. "The leadership of the HIE initiative has the responsibility to balance the influence and needs of both public and private interests," says Adams.

In Colorado, the prevailing sentiment is that CORHIO does not want to be government dependent but that it does need the state at the table, says Dierker. The recommendation is to start a not-for-profit entity with the state on the board as a nonvoting member.

In Utah, the state government has been supportive in a quiet way, says Jan Root, assistant executive director and steering committee member of the Utah Health Information Network (UHIN). In the 1990s, through legislative and regulatory efforts, the initiative was chosen as the entity responsible for convening the community to create uniform administrative standards, which became incorporated into state rules, she explains.

In Search of Solvency

Financial sustainability-at the state-level or otherwise-is likely to be an HIE's greatest challenge. A single best answer has yet to emerge, and given the variability in local markets and their changes over time, one may never.

Follow-up research to FORE's original study noted that although few HIEs are financially sustainable, some of the individual services they provide are. The study also reports that to date, local initiatives appear to be more successful than those at the state level. The reason may be the relative newness of state-level efforts. It may also be that creating a state-level project or service is inherently more difficult because of the broader array of stakeholders.

Regardless, all HIEs are faced with first obtaining funding for start-up and then expanding their services in a financially sustainable way. UHIN raised start-up funds by allowing interested companies to purchase a general membership, which gave them a seat on the board. For administrative data exchange, membership fees cover operational costs and more.

To determine pricing, UHIN figures out the cost to run a specific service, and the members jointly determine its value, explains Root. When setting up electronic claims, for example, members determined that the payers would benefit 70 percent and the providers would benefit 30 percent. Payers chose a click fee, and providers an annual membership fee to cover their proportional share of operating costs.

Root has learned through this whole process that "if you want to start an HIE you have to run it like a business, even if it's not-for-profit. You can talk about quality," she says, "but you can't make the argument that payers should pay for it because 15 years down the road diabetics will be more cost-effectively managed. Quality of care is important, but in terms of information exchange it's not going to sell it." The key, she says, is knowing the market well and being able to identify the principal players who can determine which propositions make compelling business sense.

In Rhode Island, initial funding came from stakeholder donations, e-prescribing services provider SureScripts, and small grants. Over time, some board members have provided major funding. Still, RIQI maintains a level playing field, says Adams, because large contributors, small contributors, and individual consumers have the same number of votes: one.

Currently, RIQI is in the process of narrowing its options for a financial sustainability model. The leading concept being discussed is based on the notion of community good and spreading the cost out over as much of the population as possible, Adams says. "Although the health plans have agreed in principle, we are determining how to best proceed with implementing the model," she says. "It is a tough process to work through."

Colorado received a good portion of its initial funding as one of six states chosen to participate in the State and Regional Demonstration Project funded by the Agency for Healthcare and Research Quality. CORHIO is currently exploring a subscription fee model. "We don't know how it will play out yet," Dierker says. Developing a financial model is challenging because issues of efficiency and quality, which have a longer-range pay out, have to be considered, she notes. "But it's important to determine the financial sustainability model because it helps justify the kinds of investment that stakeholders need to make to get to a certain critical mass."

Aligning Stakeholder Interests

Despite verbal support for sharing healthcare data electronically, bringing together competitors to collaborate on a network model is one of the biggest challenges.

Some counties in Tennessee are more successful at reducing nonaligned stakeholder interests than others, says Agassi. "In some markets, we can't get competing healthcare entities to rise above the competition and think about transparency and collaboration to manage the spiraling costs of healthcare."

Although UHIN members have agreed not to compete on HIE, they still employ competitive strategies around it, Root says. For example, at the request of the provider community, UHIN became involved in the development of a tool that would allow providers to put credentialing information into a central database, eliminating the need to submit this information to several different payers in a variety of forms. It took three years to pull the community together to standardize the process and contract with a company to create the database. In the meantime, one organization represented on the board developed its own tool and does not want to participate in the database.

"That's the kind of thing we have to manage all the time," Root says. "A payer or any large healthcare entity goes off to do its own thing, often with the best of intentions. But then the provider/payer community says we should do it together. It's a difficult tightrope to walk because the payer has already invested a lot of money and time."

For as many challenges faced by the state-level HIE initiatives, there are valuable lessons learned. First and foremost, there is no one-size-fits-all HIE initiative. "Each state has to tailor its approach to its own circumstances," says Dierker. She recommends conducting background work to design an approach that best fits the state. "And take the learning curve seriously," she advises. It's easy to get caught up in talk about what is possible, rather than focus on what is realistic in each state's particular situation.

Similarly, Adams recommends taking the time to understand the HIE community. "Keep an eye on how it is evolving and changing. Watch the community to understand the balance of power and the shifts," she says. "Most importantly, pay close attention to building relationships, because they will enable you to get through whatever barriers you come across."

While many challenges still lie ahead, as Agassi sees it, the HIE initiatives and regional health information organizations have already had success. "When you are able to get competing entities collaborating on a portable health record at the point of care on a state level, that's already a success," he says.

An Early Look at State-level Efforts

Interested in the role that a statewide, public-private initiative could play in promoting regional HIE efforts and in acting as liaison for federal initiatives, the Department of Health and Human Services sought research on state-level HIE initiatives. Through the Office of the National Coordinator for Health Information Technology, the department contracted with AHIMA's Foundation of Research and Education (FORE) in 2006 to gather information on existing state-level initiatives.

The project researched current policies and practices at nine state-level initiatives in the areas of governance, structure, financial models, HIE policies, operations, and short- and long-term priorities. FORE then brought together leaders from those initiatives with other industry leaders to develop consensus on guidance for forming a state-level effort.

Participating in the research were state initiatives in California, Colorado, Florida, Indiana, Maine, Massachusetts, Rhode Island, Tennessee, and Utah. Technical advisors, project staff, and staff from the Office of the National Coordinator also were involved in committee activities.

The research is summarized in a report of key findings and recommendations, and the consensus meeting resulted in a workbook providing guidance on some of the issues, options, and strategies in developing a state-level HIE initiative.

Adams says the workbook provides a good framework and helped RIQI's board members understand all of the components involved in developing a state-level HIE initiative. Additionally, it has served as a benchmarking tool to assess RIQI's progress.

Agassi agrees that the workbook is a good reference. He has turned to it to address specific issues and see if the eHealth Council could adapt some of the solutions used by other states.

For Dierker, the research serves as both a guide book and a networking directory. "I recommend that people digest what's in the report and use the individuals in it as a peer network," she says.

The research was extended with four additional tasks exploring the relationship of state-level HIE to federal and other major health IT activities; HIE services that are financially sustainable; the role of state Medicaid programs and their involvement with HIE; and the potential relationship of HIE and quality and transparency initiatives.

The workbook and all reports are available online at www.staterhio.org.

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