Harmonization Destination: HISPC at Work on Privacy and Security Solutions for Data Exchange

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by Chris Dimick

Last year federally funded research documented the privacy and security barriers to health information exchange. Now HISPC moves into its next phase, seeking common practices that enable confidential, secure, and timely cooperation.

Individualism is a cherished American institution. So is mobility. However, the two are at odds when it comes to exchanging personal health information. With each US state seemingly having its own privacy and security regulations, an individual's health information can get stopped at the state line even as the person crosses over.

Some federal privacy laws connect the states, but not to the point that any practical interoperable, nationwide health information exchange could take place. Privacy and security studies show that even where there are state and federal standards regarding health data exchange, providers are so confused by the laws that they err on the side of caution and greatly limit data exchange.

The Health Information Security and Privacy Collaboration (HISPC) is trying to change all that. The nationwide privacy and security work group hopes its current work will help harmonize state practices and enable confidential, secure, and timely health information exchange (HIE).

Now the Hard Part: Consensus

HISPC represents the widest-reaching privacy and security work group assembled in the US. In 2007 its state-based work groups reported on state-level privacy and security roadblocks to nationwide health information exchange. Now in 2008, as a third phase of work begins, the state work groups have joined one or more of seven national work groups to create shared privacy and security policies, practices, and even standardized forms.

Phase 3 is about bringing some harmony to the chaotic state of privacy and security practices across the country, says Linda Dimitropoulos, director of the health services program in the survey research division of RTI International, the organization overseeing the HISPC project. "The goal is to have the states come together and harmonize some of these areas that are so critical to nationwide interoperability."

The plan is for the seven large groups to form consensus solutions, then each state group take those practices back home to implement, Dimitropoulos says. For example, one of the collaboratives will work to develop a commonly accepted approach to obtaining patient consent for disclosure, something Dimitropoulos calls a "critical outcome" given the barriers to data exchange that are caused by confusion and variance over this issue.

The total number of participants in phase 3 has grown from 34 to 46, representing 43 states, two territories, and the District of Columbia. Phase 3 is funded solely by the Office of the National Coordinator for Health Information Technology, which moves the focus from individual state work to national solutions.

Phase 3 ends in December 2008. The seven collaboratives will turn in their work to RTI, which will compile a report detailing the work and its implications. "The goal is to have the states harmonize on the various practices that they develop through this collaborative phase so that they are not perpetuating the variations individually," Dimitropoulos says.

HISPC will work to harmonize different state laws. "Many of the states have discussed whether the federal privacy regulations are stringent enough," Dimitropoulos says. "And if states feel they need stricter privacy laws, then the hope is that the states can harmonize on something, instead of creating silos." As phase 1 work documented, individualism has already erected barriers between the states.

Phase 3 National Collaboratives

For the phase 3 work, more than 40 groups based in states and territories joined one or more of seven national work groups focused on key topics identified in the first phase of the project:

- Consumer education and engagement
- Harmonizing privacy law
- Interorganizational agreements
- Patient consent (data elements): obtaining and managing patient consent and disclosure requirements
- Patient consent (policies): intrastate and interstate consent policy
- Provider education
- Standards adoption

Some HIPSC History

The HISPC work began in 2006, when the Agency for Healthcare Research and Quality and the Office of the National Coordinator for Health Information Technology contracted with RTI to create 34 state-based work groups composed of healthcare professionals, payers, and other HIE stakeholders. Those participants formed the first phase of the HISPC work.

The group's goal was to identify privacy and security practices at the organization, state, and federal levels that either fostered or prevented the interoperable exchange of health information. The groups were to then suggest solutions for overcoming barriers and facilitating nationwide, interoperable HIE.

The state-level groups drew up reports of their work and submitted them to RTI for consolidation. The individual and summary reports were released in July 2007, documenting many shared barriers and concerns regarding privacy and security and HIE.

HISPC then moved into a short second phase, where state groups began projects based on their recommendations from phase 1. The individual state groups were grouped into seven collaboratives, where they joined both existing and new member state groups in working on major issues selected from the phase 1 reports.

In phase 2, the multistate collaboratives met and drew up proposals detailing the work to be completed in phase 3. Each state also outlined its individual phase 3 projects. Phase 2 was completed on December 31, 2007.

A look at the work of three state groups illustrates the types of issues HISPC tackled during phase 2, as well as the transition to phase 3.

Illinois

In phase 2 the HISPC-Illinois group drew up three types of consent forms that can be used statewide. The first is a notice of privacy practices form, which notifies typical patients that their records may be shared within the HIE. The second is a consent form for patients possessing specially protected information, like substance abuse information. The third form would allow patients to authorize the exchange of their specially protected health information for research.

These forms have been passed out to several Illinois state health associations, such as the Illinois Hospital Association and the Illinois State Medical Society, which plan to distribute them to healthcare providers statewide.

In addition to the consent forms, HISPC-Illinois developed 12 policy recommendations that could be used in creating a state HIE network. The recommendations cover many issues, including the provision that "people should have the right to request restrictions on the release of their personal health information," according to Jeff Johnson, HISPC-Illinois project director.

Currently there is no state HIE in Illinois, so the HISPC group hopes that its work saves a future startup some development effort. The recommendations identify and address stakeholder issues in advance, which hopefully "can move the process along a little quicker," Johnson says.

Ohio

The Ohio HISPC team also worked on developing a state model consent form it could use to obtain patient permission for the electronic exchange of health information. The model consent form sought to correct the various provider interpretations regarding HIPAA and data exchange, according to Bill Mitchin, Ohio-HISPC project director. It is a problem that many states identified in phase 1 work.

"We decided we would come up with a standardized form that would be available to all providers that would address all of the legal components, based on Ohio law," Mitchin says, "so that there would no longer be a question of whether or not this information could be exchanged legally."

The group ended up with two consent forms, similar to the Illinois approach: one form for the standard patient, the other for those with specially protected information in their records.

The team also worked in phase 2 to develop technical standards that would ensure access to patient information was reliable, secure, and universal across the state. This was done by focusing on defining the "four As" of security—access, authority, authorization, and audit—that they could apply to any entity wanting to exchange or modify information in the HIE.

To ensure that the HISPC-Ohio work reaches healthcare providers throughout the state, Ohio's governor created the Ohio Health Information Partnership Advisory Board. The board will advise the governor and legislature on key issues related to HIE and will replace the Ohio HISPC steering committee this year. The organization will disseminate HISPC's recommendations to healthcare organizations around the state through education and training initiatives, Mitchin says, "so that everyone is aware of how this consent form can be used [and] how these standards will be applied in the various stakeholder settings."

Washington

The Washington state HISPC group began phase 2 at the same time the state's Health Information Infrastructure Advisory Board (HIIAB) took root. The coincidence was good for the state, officials say. HIIAB was created by the state government with the end goal to develop a statewide health record bank, but it was modified to also oversee phases 2 and 3 of the Washington HISPC work.

HIIAB hopes to develop the health record bank by using the recommendations and policies generated by Washington's HISPC group as well as the nationwide collaboratives that will be developed in phase 3, says Peggy Evans, Washington HISPC project director.

In phase 2 HISPC-Washington created recommendations for consumer engagement in HIE and incentives for the adoption of health record banking, according to Evans. In addition, the group focused on developing authentication standards. All materials developed in phase 2 were funneled to HIIAB for use in creating the Washington health record bank.

Working through the Fundamentals

When the phase 2 collaboratives were first organized, consent was a single group of about 16 states. But due to differences in each state's evolution toward the development of an HIE, the group was split into two groups that would discuss different issues. These are the data elements collaborative and the intrastate and interstate consent policy collaborative.

The data elements collaborative discusses the data that must be exchanged between two states in order to show that consent requirements for the exchange were obtained. The intrastate and interstate consent policy collaborative is focusing on developing policies for how that exchange will take place, both between states and inside states. The collaborative is discussing ideas such as a uniform consent requirement that would be adopted by all states.

The group is also discussing the right for states to develop their own consent policies, along with the development of conflict laws that could be used to settle interstate disputes about whose consent law applies during certain exchanges. If a "snow-bird" goes south from Illinois to Florida in the winter, Johnson asks by way of example, how will those states address their difference in consent requirements? The Illinois and Ohio state groups have both joined the intrastate and interstate consent policy collaborative.

At the end of phase 3, the collaborative's goal is to have developed a standardized approach for exchanging data. To do this, each state in the collaborative will need to develop its own consent form, keeping in mind the consent requirements of other states. The collaborative also hopes to develop the legal processes that would enable states to use the forms internally, as well as during interstate exchange, Mitchin says.

The Ohio HISPC team is cochairing the intrastate and interstate consent policy collaborative. The team also is part of the standards adoption collaborative, which will develop business processes, such as those around the four As, that will ensure trusted HIE. The group is developing privacy and security policies and technical solutions that will help states implement HIE.

The Washington HISPC group joined the standards adoption collaborative, hoping to develop authentication standards—one of the four As—that would allow HIE administrators the opportunity to screen and validate exchange requests. Different HIE business models will be examined to find the best practices for authenticating and auditing HIE, Evans says. "From there [the collaborative] wants to create a best practices guide and then push that out to the different states so they can test it."

Washington also joined the consumer education and engagement collaborative, which is developing methods for educating consumers on privacy and security issues. It is working on resources like a "readable" patient guide to HIPAA and a frequently asked questions list defining, for example, terminology for HIE, Evans says. The collaborative is interested in developing a central repository of education tools and resources that different states in different levels of HIE implementation could go to for help in reaching out to consumers.

This collaborative is one of the most important to the project, in Evans' opinion. "Bottom line is that you can develop the coolest, most amazing technology for a health information exchange network and yet it is not going to be successful unless you have consumers who want to use the information," she says. "And one of the major concerns of people in deciding whether they want to sign up for health information exchange is, 'Well, what happens with my data if it falls into the wrong hands.'"

That's why Evans finds the intersection of privacy, security, and consumer engagement so essential. "It is important to focus on privacy and security issues because ultimately the consumers are going to need answers to their questions," she says.

The Future of HISPC

When all is said and done, HISPC could be just another government-funded report stacked against a wall. It all comes down to whether individual organizations, states, and regions really implement the HISPC privacy and security solutions into their daily practice and future plans.

"The hope is that, clearly, it doesn't end up in reports that sit somewhere in an office," Dimitropoulos says. "The hope is that by the end of phase 3 the states participating will together make recommendations for what should be done on a nationwide scale."

State HISPC groups can funnel their information into a state e-health alliance, make recommendations to their respective governors about HIE implementation, or get the information to state legislators in a position to enact rules that put the changes in place.

There is also the potential for an additional year to be added to HISPC, Dimitropoulos says, a phase 4, though any such extension has not yet been discussed.

The project's size reflects its importance, she says. "It is appropriate that this project is one of the biggest, because it is a big issue and you want to make sure that the decisions are made at the local level," Dimitropoulos says. The broad goal is widespread adoption of the HISPC privacy and security practice standards beyond just the collaborative, she says. No more 50 states, 50 privacy and security practices. Instead, 50 states with one agreed-upon set of policies and practices that fit all states' needs.

Nationwide HIE is not possible without solid privacy and security practices, Mitchin says. "The cornerstone of the entire initiative is the whole concept of security and privacy," he says. "Exchange for the sake of exchange is not the goal. Secure and private exchange for the improvement of health quality and better outcomes, that is really the goal."

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