RHIOs and Health Information Ownership: a Need for Strong Safeguards and Clear Ownership, Say Experts

Save to myBoK

by Mark Hagland

In the past several years, the concept of the regional health information organization (RHIO) has taken root, as dozens of information-sharing initiatives have been founded across the US. While no more than a handful of RHIOs are actively sharing clinical and other data, dozens could be online within the next year or so. Healthcare industry leaders, as well as the Bush administration and Congressional leaders, see the development of RHIOs as a crucial step in the creation of a nationwide health information network.

However, with RHIOs have come concerns from industry experts and consumer and patient advocates over the privacy and security of identifiable personal health information. They stress the need for strong policies and safeguards to protect that data and for consumers to be given clear ownership of their information. Missteps made now at the individual RHIO level or at the local, regional, state, or federal policy levels, could produce nightmares later on, they warn.

"You have to design [RHIOs] so that patients can opt in or out," believes Erica Drazen, ScD, a vice president in the Emerging Practices Institute at First Consulting Group in Boston, MA. "And the ability to opt in selectively will maximize patient participation. But," she adds, "I don't think people imagined how problematic this would be. What you'd really like is for patients to be able to opt in or out very specifically. They should be able to opt in or out both by role (certain types of providers) and by type of information involved. The first RHIOs weren't developed that way; patients could only opt in or out altogether. Now it's being done at the visit level, because that's actually the only unit that anybody could figure out how to do. And all this is actually a very big problem."

On a broader level, says Jeffrey C. Bauer, PhD, a health futurist, medical economist, and partner in the Management Consulting Practice at ACS Healthcare Solutions in Dearborn, MI, a way will have to be found to satisfy privacy and security concerns while encouraging the opportunities for scientific knowledge and clinical care improvement that can come out of data-sharing.

"With the advent of genetic information, more and more people will want to benefit from broad, anonymous sharing of genetic information," says the Chicago-based Bauer. "If we could get good antidiscrimination laws in place, then I think some people would feel more comfortable having their data shared on things like mental health and substance abuse, so that, for example, the molecular basis of bipolar [disorder] might be uncovered."

With consumers reading and hearing about more advances in science and medical care every day, Bauer believes, "we're heading quickly toward a time when societal attitudes will change, as we learn, for example, that there is a gene that explains the potential for alcoholism." With the proper safeguards in place, Bauer says that a wealth of research-based knowledge and improvements in patient care are possible through the development of RHIOs and a national health information network, as have been predicted.

Striking a Balance, in Principle and in Practice

How can the developers of RHIOs strike a balance between the need to vigorously share clinical information, both for research and analysis purposes, and the need to protect individual patients' rights to privacy and security? Some consultants working with RHIO developers are tackling that issue every day. One such consultant, Linda Frank, RHIA, president of New Age Systems, Inc., in Evansville, IN, says, "That question speaks to my HIM training, which says that it's really the patient who owns the information. And if we keep that in mind, that can help guide us."

For example, Frank says, "We've done some work with Blue Cross and with a hospital in Alabama, where the patient signs a release when they register as an inpatient. And if they decline to allow the appropriate sharing of information, it will be flagged.

And that's worked out.

"The key here is, how do you educate the patient appropriately when you explain what you're trying to do? It's important for patients to understand the benefits and risks so they can make good choices about whether they want to participate or not. If you're doing this at the point of registration, this is yet another task to have to train your registration people on, so it's not an easy thing. But if the emphasis is on improved quality of care and giving clinicians the information they need to best care for you, then with appropriate education, it will work out." For example, Frank says, patients readily understand the example of the benefit of data-sharing among patient care organizations to the patient who enters an emergency room in a diabetic coma.

Those working in organizations participating in data exchange say that things are actually working out well so far, with minimal problems and an appropriate level of concern among the stakeholder organizations with regard to patient information ownership issues.

"I think it's developing well, at least in Massachusetts," says Debra Mikels, corporate manager, confidentiality, for Partners HealthCare System, based in Boston. "We support the federated approach, in which the information resides with the entity that developed it. We're working out some of the issues around opting in and opting out," she says, as Partners continues to work with statewide and New England-wide data initiatives. Consumer education is crucial in that regard, Mikels says. "Patients need to know what this is about. We need to achieve a balance of access to information for improving care and protecting patients' rights."

So far, Mikels says, most patients respond well when they are informed how and why their clinical information will be shared. In fact, she says, many patients are very eager to see the kinds of connectivity that RHIOs offer.

Still, a smaller number of patients do express wariness about any sharing of their personal health information. "We need to respect patients and their desires, but also need to educate them as to the possibility that they or someone could be harmed down the road because of nonsharing of data," notes Mikels. "And we need to make sure we're safeguarding information and then need to assure patients of that."

The good news, Mikels says, is that the organizations participating in RHIO development "are definitely thinking about the patients. I think it's hard to please all the people, though, and that's going to be challenging."

Right now, she reports, "We're testing different varieties of opt-in/-out options, even within the state. So I think we're going to learn from the different tests being developed, based on the various types of RHIOs that are evolving and the various types of opt-in/opt-out mechanisms. I think the important thing is to let patients know what we're doing with their information, so that if they read the notice, they'll know."

All of this is complicated, of course, by the fact that every RHIO appears to have a different structure (not to mention business and operating model). "It's complicated, because there is no one structure for RHIOs, and the privacy implications differ depending on the structure of each RHIO," notes Joy Pritts, JD, assistant research professor at Georgetown University in Washington, DC.

What's more, Pritts adds, "Almost every study done has shown that patients believe that they own their own information. And in fact, under state law, they at best share ownership with their providers. And it gets very murky if you're dealing with RHIOs and information-sharing."

The danger if patients become dissatisfied is that some patients could go "underground" in seeking treatment for sensitive health problems (such as mental healthcare, sexually transmitted diseases, and abortions). The good news, Pritts says, is that innovative patient data-sharing systems in other countries have allowed for a more granular level of opt-in and opt-out options, so that, "For instance, if I had an abortion when I was 18, and I want that to be masked, the only people who would have access to that information would be the OB/gyn who was involved in that health encounter, even as I agreed to have all my other health data shared."

Pritts and other experts agree that it will be crucial to move toward the kinds of protocols that will anticipate where technologies can take us in the future. HIM professionals are in an excellent position to advocate for effective, nuanced safeguards for patient privacy and security. And with effective advocacy for such protections, everyone agrees RHIOs can improve care while avoiding ownership pitfalls.

Mark Hagland *(mhagland@aol.com) is a healthcare journalist based in Chicago.*

Article citation:
Hagland, Mark. "RHIOs and Health Information Ownership: a Need for Strong Safeguards and Clear Ownership, Say Experts." *Journal of AHIMA* 77, no.10 (November-December 2006): 62-63,68.

Driving the Power of Knowledge