Health IT for the People: An Increasing Movement—but No Road Map—for Patient-centered Health IT

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By Chris Dimick

There is increasing recognition that health IT should work for patients, too, providing them with information they need in ways that are convenient to them. But although the journey is beginning, no one has a map.

The health IT landscape is still uncharted territory for most US providers, but federal initiatives have sent the industry on a trip of historic proportions. The HITECH Act-part of the ARRA stimulus bill that devoted $2 billion to health IT adoption-is encouraging the industry to hit the health IT highway. The final destination is a place where technology enables providers to improve care, lower costs, and provide patients with personal information they can use to manage their health.

The last point is significant in its own right, because health IT has traditionally been designed for providers and their organizations. Still lacking is a road map to guide healthcare policy makers, product developers, and providers from “here”-siloed data and minimal patient involvement-to “there”-accessible data and maximum patient involvement.

This lack of a plan could hinder the development of health IT standards and products that directly help patients affect and manage their healthcare, according to Cindy Throop, an independent healthcare IT consultant specializing in patient-centered healthcare. The less health IT engages patients, the less it will improve the quality of care and reduce costs, she believes.

But the federal government has begun to point the way, according to Joshua Seidman, PhD, acting director of the meaningful use division, office of provider adoption support, at the Office of the National Coordinator for Health Information Technology (ONC). The HITECH Act does incorporate patient-centered ideas, and it sets goals for advancing health IT that can support patients’ information needs.

What Is Patient-centered IT?

Today patient-centered health IT is more of an idea than a product.

While health IT tools are used to achieve healthcare that is patient-centered, the goal is to give patients and their families the ability to access meaningful, useful information. Patient-centered health IT should help patients communicate with their providers better and get them information how, when, and where they want it.

The technology that supports patient-centeredness could be a personal health record (PHR) or an EHR with a patient portal that gives patients access to their records in the manner they need. Patient-centered health IT converts clinical and administrative data into understandable and useable information for the full range of the population-which can vary greatly from person to person, Seidman says.

Patient-centered health IT would give patients access to their medical information, but more importantly, it would give them access in a way they can use it to improve their care.

For example, an EHR that is patient-centered would allow patients with diabetes to compare their health information with the de-identified information of other patients to see how different treatments might affect their care.

Or it could be a personal health record in which a diabetic tracks his or her daily blood sugar levels. The technology would provide links to information patients could use to help manage their diabetes, and it would alert physicians if levels dip or spike.

However, technology will not be a miracle worker. Some patient advocates argue that IT development is too narrowly focused on physicians and reimbursement. Patients should be put at the center of health IT development, creating systems that allow patients to better access, interact, and use their health information for improved care, Throop says.

Who Draws the Map?

Various healthcare industry organizations have all worked on different patient-centered health IT tools, but no one organization has come forward with a plan, Throop says. That is because organizations have their own specific interests and approach the problem from their own vantage points. What is needed is for organizations to approach the problem with a broad view.

"The government is looking out to the private sector, looking for the expertise, and meanwhile the private sector is looking towards the government," Throop says. "Everyone is looking at each other, asking, 'Where is the road map? Where are we going? How are we going to get there?'"

The federal government has the power to insist providers implement certain patient-centered tools, while the private sector possesses the expertise for ensuring such implementations can be done with maximum benefit, she says. Many feel the federal government-specifically, ONC-is in the unique position to take this step.

"There is no business model for developing a road map for patient-centered IT," Throop says. "I'm not sure where the misunderstanding has come in, but people have been expecting the government to establish that road map. People have been waiting for the 'meaningful use' regulations to come out, assuming that would be a road map to where we are going."

Part of the HITECH Act within ARRA, the meaningful use program establishes incentive payments for providers who meet care goals through the use of approved health IT. The goals and their measures were in large part drafted by the Health Information Technology Policy Committee, also established by ARRA to advise HHS. The industry debated the program proposal through the first months of the year, with the government now hurrying to release a final rule in advance of the program launch in October.

The meaningful use definition is not robust enough to serve as the missing road map, says patient-centered health IT advocate Steve Daviss, MD, DFAPA. Daviss is chair of the department of psychiatry at Baltimore Washington Medical Center and co-chair of the Behavioral Health Work Group for the Certification Commission for Health Information Technology.

"While the HITECH money is supposed to motivate physicians and hospitals to get wired and adopt certified EHRs, people are starting to question whether this will be adequate, or [whether it] will simply turn the silos of paper records into silos of electronic ones," he says.

Drawing the road map requires a clearly defined destination. No organization, including ONC, has clearly defined just what type of patient-centered health IT is needed to improve patients' lives.

"Meaningful use is nudging us in the right direction, but I don't think ONC knows ultimately where we are going," Throop says. She thinks the government has "just enough of an idea" to head the industry in the right direction.

ONC Leading through "Meaningful Use"

The meaningful use definition is not the last step for a patient-centered healthcare system. But it is a great first step, says Seidman, the meaningful use developer at ONC. While it is not ONC's goal to develop a road map specifically for patient-centered health IT, it is implementing patient-centered ideas into its heath IT requirements-especially the meaningful use definition.

"The meaningful use workgroup really is trying to create a set of recommendations for the policy committee that will create a road map for the whole healthcare industry around meaningful use," Seidman says. "And that road map will certainly address patient-centered HIT as well as many other things.

"The Health IT Policy Committee is making it clear that it wants patient-centered health IT to be an important part of that road map."

Taking It in Stages

The meaningful use requirements include many patient-centered elements in the first stage of the proposed program, Seidman notes, with more to come in stages 2 and 3.

One example is the inclusion of "patient-family engagement" as one of five health outcome priorities for meaningful use. Each of the five broad outcomes is comprised of required objectives, and each objective has a measure. The patient-family engagement outcome is focused on instituting health IT that provides patients with useable health information and engages them in the care process through health IT. For example, the domain requires professionals and hospitals to provide patients with electronic copies of their information within 48 hours.

All five priority domains have pieces that relate to how consumers use health IT, Seidman says. The "improving quality" domain, for example, includes a requirement that patients receive reminders for preventive medicine appointments and follow-up care.

"This is in our proposed rule, but it gives you a sense of the kinds of things that we hope will be part of the meaningful use of electronic health records," Seidman says.

He notes that the policy committee reviewed private-sector work when drafting the meaningful use requirements, such as that produced by the Consumer Partnership for e-Health, a patient-centered health IT advocacy group.

Accelerating Progress in Stages 2 and 3

While stage 1 criteria feature several patient-centered heath IT requirements, the policy committee had to be somewhat reserved in how much change it required of providers. If regulations were too hard to implement, providers would not join the voluntary program.

Using EHRs meaningfully requires change in how care is delivered, Seidman says. "And that certainly means that it takes some time."

Starting in 2015, all providers must have EHR systems that comply with the meaningful use objectives or face a reduction in Medicare and Medicaid payments. If the carrot has not worked, the thinking is, the stick will. The meaningful use program is seen as a rare opportunity to institute wide-reaching change.

When developing stages 2 and 3 of the meaningful use definition in the coming months, the Health IT Policy Committee plans to meet directly with patient-centered advocates to discuss how they feel healthcare should be changed.

"There are plans for creating an even more methodical approach to thinking through how patient-centered HIT should be addressed with respect to future meaningful use," Seidman says.

In April the policy committee's meaningful use workgroup planned to hold a hearing on the patient-family engagement domain to discuss how its requirements should advance in stages 2 and 3. The meeting was set to discuss various patient-centered health IT topics, with members hoping to hear from patients and patient advocates on their ideas for ensuring health IT endorsed by HHS is geared toward patients.

The committee will ask, "What are consumers' needs with respect to [health IT]? What are the kinds of tools that can be used? How do we measure meaningful use from their perspective?" Seidman says. "Certainly that hearing will be instrumental in starting to lay groundwork for where [patient-centered] work goes."

After the meeting, the workgroup will draft recommendations on how the patient-family engagement domain of meaningful use should advance in stages 2 and 3.

The plan is for the stage 2 definition to take effect in 2013, and stage 3 to take effect in 2015, when the meaningful use criteria will be required by facilities looking to avoid payment reductions from CMS.

Hiring Seidman to work on the meaningful use definition was itself an indication that ONC aims to develop patient-centered health IT. Seidman has been passionate on the topic for years. He founded the Center for Information Therapy, which promoted the direct use of information by patients to improve healthcare quality.

Health 2.0 Meeting Offers a Platform

An upcoming conference has the potential to increase ONC's focus on patient-centered health IT issues. The Health 2.0 organization is hosting the "Health 2.0 Goes to Washington Conference" on June 7 in Washington, DC.

Since 2007 Health 2.0 has held conferences to discuss emerging patient-centered healthcare technology. While its focus has been primarily on IT used outside the provider facility, such as PHRs and medical search engines, discussions have begun at conferences regarding integrating user-generated information and tools into the wider healthcare provider system.

Several HHS and ONC staffers will be presenting and attending the conference, including ONC's chief, David Blumenthal, as well as other major federal and private health IT players based in Washington. The conference is a chance for HHS and ONC to be introduced to the Health 2.0 movement, Seidman says, and discuss the potential impact various patient-centered IT tools could have on the HITECH Act and healthcare at large.

"The conference is further recognition of ONC's desire to think creatively and innovatively about how new technologies can be used to facilitate patient-centered HIT," Seidman says. Discussion is expected on meaningful use and other HHS priorities.

The meeting "recognizes an important part of understanding both the patient-centered IT agenda but also, more broadly, the need for other innovative technologies and how they can be integrated into future definitions of meaningful use," Seidman says.

Doubts Remain on the Direction

However, not everyone is confident ONC is doing enough to put the patient at the center of its HITECH Act efforts. Patient-centeredness is not written explicitly into the legislation. That granularity of how health IT should be implemented and used is decided by ONC and various HHS subgroups.

HHS staff must decide whether to interpret HITECH literally or go beyond what is written and strive for forward-thinking innovation, Throop says. It is a fine line to walk, as HHS must institute regulations that advance healthcare but are still manageable by today's healthcare providers.

It does not help that patients lack a strong patient-centered advocacy group to promote their position with HHS, Daviss says.

"We are all patients-all of us-but who is sitting at the conference tables in Washington representing our interests?" Daviss asks. "The doctors have lobbyists. So do the nurses, hospitals, drug companies, and insurance companies. But who is the lobbyist for patients? We are barely on the map. That needs to change."

While the meaningful use requirement that hospitals must provide patients with electronic copies of encounter summaries is a good example of positive change, Daviss says this provision does not go far enough.

"A patient should be able to make a single request for their information that would automatically push all new information to the patient or to the patient's designated PHR, family member, or other entity, like an RSS feed of their data," he says. "ONC should be more forward thinking in mapping out how patients, providers, and other entities could interact with each other in the context of an EHR or UHR [universal health record]."

While there are some criticisms, advocates for patient-centered health IT are pleased that ONC has begun to develop regulations with the patient in mind. The federal organization's recent steps, like the Health 2.0 conference and its committee work with consumer advocates, is a great sign it is considering patient-centeredness at this critical time, Throop says.

Hearing from Patients

Part of the responsibility for implementing patient-centeredness into new health IT developments rests with patients, Daviss says. Daviss is the spokesperson for a new patient-centered organization called Speak Flower, which brings together patients, doctors, health IT professionals, and policy wonks.

Speak Flower views patient-centered IT as the “killer app” in reforming healthcare, and it promotes the creation of a common EHR language so health information can be shared between patients and all their providers. A central element of the Speak Flower group is creating a universal health record that can be accessed by patients and shared with designated providers.

The group has started work on a road map to patient-centered care. Patients will be prime movers in getting that map implemented by pressuring their providers to use EHR systems that speak to each other-or “speak Flower,” the intentionally nontechy term the group gives to interoperable EHR systems.

“If it was something simple that patients could ask for by name, without all the technical jargon and acronyms, then all they’d need to know is that their information could be easily shared among their healthcare team members,” Daviss says. Details on the project can be viewed at www.speakflower.org.

The healthcare industry has started down the health IT road. How the trip will lead to a destination where both providers and patients effectively use health information is currently unclear.

“We need to know where we are going to get there efficiently,” Throop says. “I would hope we are all interested in getting there sooner than later, and without wasting a lot of money, as well.

“We absolutely need a plan. The healthcare system is at least 20 to 30 years behind every other industry, it seems,” Throop says. “We need to catch up...”

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