ELECTRONIC HEALTH RECORDS: IN THEATERS EVERYWHERE BY 2014

By Lauren Gerstmann, MPH

When I was a kid, you could tell I had assorted ailments by my thick medical chart. Every time I visited the doctor, he would ruffle through a tattered, overstuffed file with pages falling out. Of course the best doctors didn't rely too much on charts. They held their patients' medical histories in their heads. This worked well when people developed lifelong relationships with one primary doctor.

But the model is very different now. Doctors see more patients each day, and the patients often move from doctor to doctor as their insurance coverage dictates. Patients also see more and more specialists to individually treat our hearts, our backs, our immune systems—each distinct part of our bodies. We have no way of developing the kind of intimate relationship that I had as a child with my family doctor, but doctors still need a reliable way to access our medical histories, our prescriptions and our previous treatments.

Going Digital

Today, the patient chart is critical, and ideally it would be accessible to every doctor who treats an individual patient. As a result, there is a halting, uneasy movement to make our medical records electronic, standardized and available. But available to whom and to what standard?

Right now, many medical practices and hospitals have their own electronic health records systems. The electronic chart is accessible to all of the doctors within the practice or hospital, for instance, but not beyond. This helps within the given organization, but it is not a huge leap beyond the old system of paper charts.

Despite years of effort to improve this, there are many reasons electronic health records have not evolved further, the most significant of which is patient privacy. Doctors and hospitals will release protected health information (PHI) only with the explicit consent of the patient. But, in recent years, the federal government has been advocating for a national healthcare information infrastructure. ➢

Linked, Interoperable and Protected

On July 21, 2004, at the direction of President Bush, the Department of Health and Human Services (HHS) released a 10-year plan to build a national electronic health information infrastructure in the United States.[1] HHS Secretary Mike Leavitt announced the goal to create an infrastructure that will "link all health records through an interoperable system that protects privacy as it connects patients, providers and payers, resulting in fewer medical mistakes, less hassle, lower costs and better health."[2]

At the president's order, HHS designated a national coordinator[3] for Health Information Technology (HIT) within the Office of the HHS Secretary. The coordinator's job is to facilitate access of most Americans to an integrated electronic health information system by 2014.

What form would a national healthcare information infrastructure take—how would it be different from a database?

"A database is a place where you store information, and it can be gathered from lots of different places," Dr. Robert Kolodner, the HIT national coordinator, said. "And yet, it is by itself not an infrastructure. It is just one piece of an infrastructure. You can also have a structure that does not store data centrally, but accesses it when it is needed.

"If you think about the Internet, there are lots of web pages out there, but it isn't as though they are pulled into a single machine or database. But you can get to all of those things when you need to."

Robert Kolodner, MD, HIT national coordinator

But several pieces need to be in place before such an infrastructure becomes feasible.

"We need to have standards, so that the data can be understood when we retrieve it," Dr. Kolodner explained. "And we need to have policies and rules for how that information is used, and when that information is used, and who it is used by, and we need to have a network or a way of connecting over a network. [W]e are not creating something new, we are essentially creating a secure channel—a secure way of communicating information over the Internet."

The logistics of creating such an infrastructure are hard to fathom. But, according to Dr. Kolodner, many of the pieces are already in place. "[T]here is a lot of information that is already electronic. All of your medications are available electronically," he explained. "If you went to a pharmacy… all of them have computers and I think something like 70 percent can receive ePrescribing or something at a distance if your doctor places an order. But, all of your medicines, essentially, are entered into a computer database at the pharmacy. And much of your laboratory [data] is already automated."[4]

Dr. Kolodner emphasized that we are not going to be able to coordinate all the different databases currently used by individual healthcare providers. Instead, the plan is to standardize the data. He used the example of telephone service. "If you think about your…phone system, you [could] be on a land line or a cell phone or you could be [making a call from a] computer. You don't have to have the same brand, but as long as they use the standard going back and forth, we can all talk to one another.

"And, so by standardizing on the information and not the software, we can move that information around, and it is up to the software (some are more capable than others) to take that information and do something that would be beneficial to your health and well-being."

Despite the fact that there is a lot of data already available, Dr. Kolodner believes the emphasis will be on building a new record, not on uploading existing data. This type of forward thinking, he explained, would involve standardizing new data entry to make it more easily utilized by the infrastructure.

"What we are really doing is building and going forward," Dr. Kolodner said. "And what we want to do is really standardize that data. So if I want to know that a penicillin allergy is really to penicillin or a spelling artifact (error)…

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[1] www.hhs.gov/news/press/2004pres/20040721.html.

[2] www.hhs.gov/healthit/onc/mission.

[3] For more information on the Office of the National Coordinator, please see www.hhs.gov/healthit/onc/mission.

[4] For more on ECLINCs (a detailed specification for the formatting and coding of lab results messages from laboratory information systems to ambulatory electronic health records) see the California HealthCare Foundation's website at www.chcf.org/topics/chronicdisease/index.cfm?itemID=114774. For more on ePrescribing (software that allows healthcare practitioners to send electronic prescriptions to pharmacies) see www.rxnt.com.
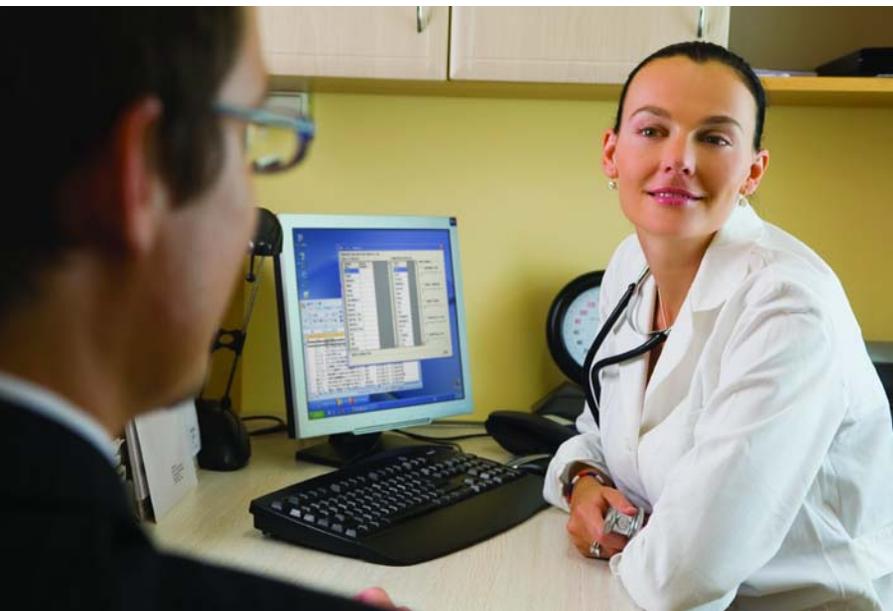
Improved Care, Decreased Costs and — Again — Protected

Why is there such a widespread interest in a health information infrastructure?

"Potentially, a health infrastructure could improve safety and quality of care delivery while reducing costs," Dr. Kolodner said. "Many of us consult with multiple health practitioners…and if one of them knows about an allergy, and the others don't know about it, and they write a prescription for that other medication, that could cause a problem for you.

"My mother is 95 years old. She is seeing four or five doctors, and, one of them wrote a medication that aggravated a condition that another doctor was treating. And, if I had not worked with her, we would not have figured out why she deteriorated."

According to Dr. Kolodner, electronic records can improve the quality of healthcare delivery. "Because no matter how much doctors want to do the right thing, we can't remember all the things we want to do for all the patients. And so, having a computer that reminds us, 'Hey, this person is at risk for pneumonia, they should get an influenza vaccine — they have not had one yet,' then I'll get closer to having 100 percent of people who should get that shot, get it."

Electronic health records can also decrease costs to consumers and insurance companies. "Turns out that 20 percent of the lab tests that are ordered in this country are ordered because an existing result cannot be accessed by that doctor. So we are paying more for healthcare," Dr. Kolodner explained.

Dr. Kolodner pointed out that the database can be configured so that our healthcare providers have access to just the necessary information they need to keep us safe, but not enough to impinge on our privacy rights. He also mentioned that a health data infrastructure might allow people greater access to view and edit their own health information than is currently possible.

"[We need] to make sure that the infrastructure we put in place is one that respects the individual's privacy and honors their preferences," Dr. Kolodner said. "And it is ➢

[we need to] use codes and standards. We have standards that have been out there a while, but unfortunately everyone has different standards. So we started a process in 2006 with the Healthcare Information Standards Technology panel, a way of harmonizing the standards. It does not create them, but it harmonizes them so that we can decide for a given purpose, what is the right set of standards to use? And then we take those standards and write additional specifications."

Medicare is also invested in making health data electronic and has taken steps that may mean there is more data available to the national infrastructure once it goes live. Until recently, the software that doctors and hospitals would need in order to keep comprehensive health records electronically was so expensive that many balked at the cost. Now, however, there is software available in the public domain: the VistA electronic health record system, which was developed by the Department of Veterans Affairs to serve military veterans.[5] Medicare is distributing this software in a form that can be installed and used by individual users, but those users will still need to pay installation costs. According to an article in The New York Times, the cost of installing VistA is "$10,000 to $12,000 for an entire medical practice." That means that a practice of five doctors might pay $100,000 to computerize, but if the doctors used the Medicare system they might pay only $10,000 for the whole office."[6]

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[5] www.vistasoftware.org/what/index.html.
[6] Kolata, G *U.S. Will Offer Doctors Free Electronic Records System*, The New York Times, 7/21/2005 www.nytimes.com/2005/07/21/health/21records.html?ex=1279598400&en=65d75ef0b6ef2340&ei=5090&partner=rssuserland&emc=rss.

possible to do that. In fact, it's more possible [than it is to do with paper charts]. Right now we have security by obscurity… We can't get to the data, so that is how we keep it secure. Unfortunately, if you are in a hospital and [you have a paper chart], anybody can walk up and pick up your chart. And, by the way, that happens more often than it should. And, you have no record of that."

While paper files may be difficult to secure, the difference between one person picking up a chart erroneously—or even illicitly—and a hacker compromising the privacy of the records of the entire American public is dramatic. Dr. Kolodner said that, while we need to take privacy threats and breaches very seriously, "people with chronic illness want their information available to their docs, and right now, that is not possible. So we have to ensure that they have that right as well."

Who Is Allowed Access?

While many people may want their information available to their doctors, no *one* entity can make that decision unilaterally. Consumers need to be the ultimate decision makers about who can see their health information.

"There are rules set out by HIPAA.[7] Insurance companies pay for your care, and they get to see enough of your information to let them know that you received care and that you received appropriate care. But they don't get to see all of your record," Dr. Kolodner said. "They don't have that right. Now, if you are worried that they are getting too much information, I do think that it is reasonable to have that fear. I think that we need to find rules that people will be comfortable with, and [ways] that they know their privacy is being honored.

"The issue of not being discriminated against because of their health information, the issue of not having their job affected because somebody inappropriate has their health information—I think are very important, whether it is paper or whether it is electronic. And, what we are working to do is to develop a system, an electronic system, an infra-structure that is actually more secure, and that gives you more control [over] who has access to your information than you could ever possibly get from paper."

Online banking is a comparable example. Many consumers use online banking now, but, when online banking first became available, identity theft was a tremendous concern. Credit card companies have put protections in place to protect against identity theft, but consumers still need to beware a lost credit card or a sophisticated email phishing scheme. It is the coordinated effort of the software designers and programmers, combined with consumer vigilance, that have made online banking a success.

Despite the data security concerns, there is a large demand for a more efficient way to store health data, and for patients to be able to access and interact with that stored data. Last October, Microsoft unveiled HealthVault, a free website[8] that allows patients to store any or all of their health records electronically. It also incorporates the ability for consumers to download health information from their participating providers (e.g., participating doctors, hospitals and pharmacies), and it allows them to selectively upload or share data with healthcare providers who opt into the system. The service is free to the public. Microsoft makes its money from advertisers when users perform searches for health-related information.

HealthVault is a more fully voluntary process than the government's planned system, but there are some drawbacks. HealthVault is a private, for-profit service. When you use the service, Microsoft has access to (and control of) your health records. Although HealthVault puts the patient in the driver's seat, if you are not comfortable with computers, if not all of your providers use the system or if you become unable to enter new information, your record may be missing key pieces.

How would the government's planned system protect against these concerns?

"Right now, you sign a consent form when you go to your doctor, and so they have to keep a record of it, and they have to be able to pull that record if you have released information," Dr. Kolodner said. "In the same way, you may say, 'I don't want my information revealed, and I don't even touch a computer.' Just don't let it go. And, the system and the accreditation need to make sure that [your request] is honored. You should not have to be a computer geek to protect your information."

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[7] HIPAA (the Health Insurance Portability and Accountability Act) has provisions for personal health information privacy. For more information about HIPAA, visit the HHS HIPAA website at www.hhs.gov/ocr/hipaa.

[8] www.healthvault.com.

Approaching the 2014 Target

Given all that needs to fall into place, a 2014 deadline seems like a true challenge, but Dr. Kolodner is optimistic. "I think we are on target, because you need to understand that, if you look at any new technology, there is a repeating pattern. The repeating pattern is that there is a period of time where the foundation is being laid where it looks as though there isn't much happening. And then, the right factors all come together, and things start to really take off.

"We think about technologies like the Internet, and how quickly it took off in the mid-1990s. The Internet was there for 20 years before that. What we are doing right now is laying a solid foundation for things to move forward. Our delivery standards are in place, we will be having dialogues about privacy and security next year, we're getting governance into place, we're getting standards into products… and we're aligning a variety of conditions that can act as incentives. We're removing barriers to adoption. So, I think we are very much on target."

Although Dr. Kolodner sees the target within reach, he is also realistic about the need to be patient with those expected to adopt the new infrastructure. "I don't expect to see a huge jump in terms of the key mark—that is, the adoption of electronic health records in the next few years —probably not until 2009 or 2010. But, somewhere in the 2010, 2011 time frame, I expect there to be all of these pieces that have matured, so that they come together and communicate their value and there is a very rapid time frame of adoption. I really do think that we are going to hit that 2014 target that President Bush set out."

The Final Product

The national health information infrastructure is well on its way, and it will surely affect patients, as intended or not. A good system will integrate all patient health data, secure that data, improve care and reduce medical bills. But everyone agrees the finished product must respect patient privacy and protect against identity theft, insurance discrimination, job discrimination or other privacy abuses. HHS clearly articulates these goals. In fact, a working group devoted to consumer empowerment released a paper in June 2007, discussing all of the ways consumers will be able to interact with the final product.[9]

But, right now, the planning process has been a bit opaque for consumers, despite four public forums held in 2007 and at least two more planned for 2008.[10] There are also plans to involve the community more regularly in the planning stages, although it is not yet entirely clear how this will be accomplished.[11] Whatever the methods, healthcare consumers would ideally be actively involved to help ensure the system is realized in its most perfect form—for all its potential users.

Personally, this is one party at which I want to get out on the dance floor. It could be a great thing for all of us, but it could be a real disaster if we stand shyly by the door. ☑

FEATURED ATTRACTIONS

To learn more about specific electronic systems mentioned in this article, see the following websites:

VistA (template for electronic medical records database that is available in the public domain and that is being freely distributed by Medicare)—www.vistasoftware.org

ePrescribing (allows healthcare practitioners to send prescriptions to, and receive feedback from, pharmacies): www.rxnt.com

ELINCS
Standardizes laboratory data:
www.chcf.org/topics/chronicdisease/index.cfm?itemID=114774

HealthVault
Microsoft's free electronic health record database for consumers: www.healthvault.com

To learn more about the U.S. government's efforts to develop a national health information infrastructure, visit the Department of Health and Human Services Health Information Technology website at www.hhs.gov/healthit

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9 www.hhs.gov/healthit/documents/UseCaseCACI.pdf.
10 See the DHHS website at www.hhs.gov/healthit/healthnetwork/forums/ for more information on dates.
11 The transition plan is available on the HHS website at www.hhs.gov/healthit/community/background/AHICsuccessor.html.