Beyond Data Sharing: For Physicians, Optimism and Caution over Using Networked Patient Data

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by LeRoy Jones

Interoperability will change healthcare. How much depends to a large extent on what happens right at the point of care.

On July 21, 2004, David Brailer, MD, PhD, and the Office of the National Coordinator for Health Information Technology published the Framework for Strategic Action, which laid out a vision for nationwide interoperability among health technology applications, and a starter's pistol went off in the healthcare industry. Coalitions were formed. Strategies were birthed. Marketing materials were redone. New organizations sprang up, and existing organizations shifted focus. Healthcare entities large and small, from all segments of our fragmented industry, laced up their sneakers, did their stretches, and sprinted onto the track, determined to place well in this new health IT marathon.

Everyone everywhere seemed to be talking about exchanging health data as freely as some might exchange business cards. Phrases like "anytime, anywhere" and "what is needed, when it's needed" were in vogue. Conference speakers set out in search of the perfect analogy for the exchange of clinical data. The federal government's re-invigorated interest indelibly changed our collective conversation on the topic.

Yet, beyond both the buzz and the very real progress, there remain several underlying hypotheses still unproven. A fundamental one is that the electronic availability of clinical data from far-flung sources will change the delivery of care enough to realize the forecasted benefits. The degree to which physicians tap into and apply this newly available data will be a major factor.

Physicians see the benefits in data sharing, and many have plenty of optimism that health information exchange can succeed. They also express caution and uncertainty when the talk turns to investing in health IT and applying the clinical data that subsequently begins to flow.

Clear Clinical Benefits

Data sharing currently exists on a smaller scale, typically among care sites united through umbrella organizations of various kinds. The experience of using shared electronic data in these cases bodes well for the national agenda of data exchange on a wider scale.

"Once I had a patient come in unconscious; high on heroin. I yanked out his wallet and looked him up in the [Veterans Administration] global system," recounts John Cacciamani, MD. "I asked for a global summary and had access to all of the core information in his medical history, including his medications. Everything I needed to know about the patient was at my fingertips without the patient having to tell me anything."

Cacciamani recalls this experience from his days practicing medicine in the Veterans Health Administration. Now the medical director for clinical informatics at Temple University Health System (TUHS) in Philadelphia, PA, Cacciamani is leading the selection process to implement a systemwide clinical information system (CIS) that will unify information from its four hospitals, five campuses, and more than 70 physicians in TUHS-owned physician practices. "We have the opportunity to bring the same level of access to data that the VA has here to Temple through our comprehensive CIS, and that's good for patients," says Cacciamani.

Larry Garber, MD, is the medical director for informatics at Fallon Clinic, the largest private, multispecialty group in central Massachusetts, with more than 250 physicians practicing in nearly 30 locations. Fallon Clinic has done extensive work in using electronic data in the delivery of care, including integrating health records with pharmacy benefits manager (PBM) data. “Just today, I had a situation that highlighted the benefit of our having a link to PBMs,” Garber says. “I was sitting in an exam room with my patient, and his cholesterol was higher than it should have been. I could see from his pattern of refilling that his 60-day prescriptions were lasting him 120 days. He confessed to me that he was cutting his pills in half and taking half of the prescribed amount.”

This ability to more closely monitor patient compliance with treatment plans is one of the four major areas where Garber believes data sharing will significantly improve the delivery of care. The other three major areas, in his view, are: communication among physicians, such as between consulting and referring physicians; accuracy of clinical alerts, such as not triggering alerts for tests that have already been ordered for future fulfillment or were completed at another healthcare facility; and utilization, such as reduced adverse drug events and reduction of unnecessary admissions.

The benefits of data sharing in care delivery are also seen in the central management of patient interactions and health reporting. Neil Calman, MD, is the president and chief executive officer of the Institute for Urban Family Health; he is also professor of clinical family medicine at Albert Einstein College of Medicine and Yeshiva University in New York, NY. Calman describes an incident involving a warning associated with a vaccine. “Because of our common electronic record and central administration, we were able to identify all patients receiving the vaccine across all sites and issue a common letter to them all with relatively little effort,” he relates. “One of the major benefits of sharing data comes with the ability to aggregate and manage certain functions centrally.”

Clear Clinical Challenges

There is a long way, however, from sovereign entities sharing data within their independent domains to the exchange of data among unaffiliated and sometimes competitive organizations. The effort to organize data sharing on a regional and national level faces issues of competition and control, and it is further challenged to develop compelling business cases and identify sources of ultimate funding once startup monies expire.

At the most local level are the physicians working at the point of care. The full benefits of data exchange rely on physician investment in interoperable health IT, an issue currently beset by barriers of cost, return, and the challenges of selecting and implementing an appropriate system. Physicians are quick to note these challenges, and they point beyond the hardware and software to the shared clinical information itself: is it complete, is it confidential, is it trustworthy for clinical decision making?

The High Cost of Admission

“Ninety-nine percent of the benefit [of health IT] will come by internal use within health organizations,” says Calman. “There will be some marginal benefit of cross-organization data sharing, but by-and-large, the concept of widespread interoperability at this time seems to be the product of groupthink. Maybe in 20 years there will be significant benefit, but right now we should be focused on implementing health IT within our own organizations to improve the quality of care,” he says.

This kind of sentiment is driven in part by the high costs of implementing health IT. Compounding the cost of investment is the negative incentive for practitioners to improve care through IT. As Calman puts it, “If we spend money to avoid a duplicate test, not only is that money sunk, but someone loses revenue from the test that would have otherwise been ordered.” In fact, a primary benefit often touted for interoperability is the reduction of revenue-generating, albeit redundant and wasteful, activities such as orders and admissions. To combat this phenomenon, many have begun to explore paying for increases in quality in care delivery, or pay-for-performance. Inasmuch as health IT is thought to increase the quality of care delivered, paying for quality compensates for technology expenditure.

“Cash incentives are important. The pay-for-performance model is valid and heading in the right direction because we need incentives to drive adoption,” says Cacciamani of TUHS. But some say that such a system, at least in its current incarnation, is inadequate. “Pay-for-performance dollars are tiny little incremental payment adjustments that don’t come close to covering the investment providers will put into the EHR effort,” says Calman.

Uneven Value from Uneven Adoption

Data-sharing value is a network externality, meaning that a critical mass of entities must adopt in order for the network to be useful. Thus cost is a key consideration because significant portions of a given region must adopt health IT simultaneously so that the network has enough users to make it valuable.

"Volume on the sharing network is key, as Metcalfe's law predicts," says Cacciamani, alluding to the principle that the value or power of a network is proportional to the square of the number of nodes in the network. "I'd say you need about 35 percent participation as critical mass," he remarks.

During the period of uptake, when some facilities are online and some are not, it is difficult to trust the data seen on the computer screen for fear that it may not be complete. This means that both electronic and paper workflows may need to be in place for a period until enough data are flowing through the electronic exchange. "What good is it to be able to see a discharge summary from a year ago if the patient has had 14 doctor visits since then that don't show up [in the network]?" asks Calman.

Vija Sehgal, MD, of Waianae Coast Comprehensive Health Center (WCCHC) in Waianae, HI, says this period of maintaining both workflows is not sustainable. "We are in that period now with our clinics, and it slows adoption," she reports. WCCHC is a multisite clinic and the largest community health center in the state, with a primary health center, four satellite clinics, and a 24-hour emergency department. Sehgal, associate medical director and director of quality assessment and peer review at the center, also serves as the physician advocate and clinical consultant to the EHR implementation team. "We've allowed our physicians to adopt at their own pace, which has definite benefits," Sehgal says, "but [it] has definite overhead, also."

"Uneven adoption is a tough problem," says Garber of Fallon Clinic, "but if you are able to get the major institutions—hospitals, labs, et cetera—that provide ancillary services to those who are slow to adopt—typically smaller providers—then even their data is in the network, enabling completeness for those who have adopted."

Confidentiality and Liability

Clinicians are also cautious of sharing data due to patient confidentiality concerns. Some states are stringent on protecting private health information, especially data such as HIV test results. This also means that clinical notes that may be shared must be sanitized in order to prevent unintentional release of sensitive patient information.

"While I feel objective information should be shared, I am more careful about subjective and confidential information, such as physician notes," says Sehgal. "A patient may share something with me in confidence, and I have an obligation to respect that confidence. This kind of subjective information is less likely to hold value for anyone except me anyway."

Garber concurs and enjoins the need to get patient consent on record: "The biggest challenge we have is the willingness of patients to share their data and the potential limitation their reluctance may put on the free flow of information. We will have to be conservative in the release of data, especially annotations such as the clinical history in a radiology report, which could contain sensitive or legally protected material."

The confidentiality issue raises the specter of liability and accountability. Are clinicians liable for acting upon information that shouldn't have been shared, or are they responsible for the accuracy or completeness of the electronic data presented to them? Are they responsible for protected data that are shared when they are, at best, only part of the value chain that produces data for electronic sharing? "The degree of accountability should be clear for doctors sharing or using electronic data," says Cacciamani. "Ideally there would be some central process to ensure that core data is ready for use."

Trust the Data or Rerun the Test?

The reduction of duplicative tests and therapies is cited as a major benefit of health information exchange. Savings, though, depend on clinicians trusting the data that flow across their screens. If clinicians largely take the posture that they need to have their own sets of results because they feel those generated for others are largely unusable, the case for sharing data electronically is significantly weakened.

David Kibbe, MD, director of the Center for Health Information Technology of the American Academy of Family Physicians, notes that the prominent examples of data exchange in the country right now provide evidence that data sharing does reduce duplicative tests, therefore showing that clinicians use shared data during treatment. He notes, however, that these are tightly controlled, closed networks. Their successes may not be transferable to environments that are more loosely federated with autonomous, competitive network participants. “Eighty to 90 percent of the healthcare world is not in that kind of situation,” Kibbe says, “and it will not be as easy to foster that kind of trust among participants.”

John Halamka, MD, chief information officer of both the CareGroup Health System and Harvard Medical School, chairman of the New England Health Electronic Data Interchange Network, and an emergency physician at Beth Israel Deaconess Medical Center, comments, “Healthcare is local, and many providers know each other. If a test such as an MRI is produced by a locally reputable institution and read by a known colleague, clinicians will trust it. If the same MRI was done at an out-of-state imaging center and read by an unknown clinician, it will likely be repeated. Medical-legal concerns are such that clinicians would be reluctant to base decisions on image interpretations of unknown quality.”

Cacciamani takes a pragmatic stance toward the issue of trust, likening it to what currently happens in the world of paper medical records. “If you’re handed a piece of paper on a patient with ‘Quest Labs’ on the top, you put it in the chart and make decisions based on your evaluation of the content of the paper,” he notes. Cacciamani says that TUHS is wrestling with how it can have a system of classification for data included in its EHR, but says that workflow issues will likely result in all the data going in. “In the end, it will probably be left to the user of the data to make the judgment about its quality,” he says.

Difficult, Not Insurmountable

The electronic sharing of clinical data seems to be having a positive effect on the quality of care even now. Physicians are using the data, and patients are benefiting. It may be too early to predict how these local successes might translate to broader initiatives like those advocated by the federal government, but many microcosms are coming to light along the way, providing valuable experience and insight.

While there are barriers to widespread data sharing, it is difficult to imagine them as insurmountable. Indeed, each of the physicians interviewed in this article has a leadership role in some form of multi-entity clinical data-sharing effort, despite any concerns he or she expressed with the concept. There is enough industry momentum to make great progress, and the industry is approaching the challenge with its eyes wide open. In fact, many call the current movement toward data exchange unprecedented, and it is certainly difficult to argue against the entire notion of sharing clinical data. Garber sums it up this way, “In general, physicians are bright people, and given the right information at the right time, they can make good decisions to improve the health of patients; health data exchange is the vehicle to bring them that information.”

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