

Personal Health Information: Data Comes Alive!

BY ESTHER DYSON

When we first wrote about personal health information last January, pressures for consumer access to personal health information and specifically to personal health records (PHRs) were beginning to be felt, but not much was happening. The larger vendors of hospital-as-enterprise software were offering electronic medical records, and some even offered an option for the health-care provider to offer PHRs to individual patients, but take-up was low.

Now, the situation has changed. Like it or not, individuals are becoming more and more responsible for their own health (care) financially. That is creating a new market of vendors interested in catering to them, and a beneficial ancillary market of consumer-oriented “system navigators” interested in helping them understand other vendors’ offers and figuring out the best deal for themselves (financially and fundamentally). Most personal health information out there is messy and fragmented, but now individuals are beginning to see the need for a PHR that consolidates all their information. Entrepreneurs who have been toiling for years to fill latent needs are now seeing real demand (though they may still be underestimating their marketing challenges) and investors are ready to fund them.

The rhetoric has changed, too. The US government has made personal health information a priority (though without much funding), and, tragically, Hurricane Katrina has illustrated the importance of reliable access to medical records in a way that will no doubt drive many people to start collecting their records. But then what?

The Back-ends: Who’s Got the Data?

We’ve looked at the front-end applications that organize data around individual patients, and at one aggregator, Resolution Health, which uses large sets of data to analyze individuals’ care. But how will all the data be integrated – across plans, across providers, and following individuals as they change their locations and their employers and providers? And especially, how can it be managed in a way that each individual’s record can be assembled from multiple sources? Currently, most health-care institutions are linked for financial-transaction purposes, through the country’s banking system. But exchanging administrative (claims, etc.) and especially clinical health data isn’t so simple. Over time, health-care institutions have started exchanging administrative and clinical records among themselves, usually in an

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ad-hoc way, mostly following business arrangements such as common plan memberships or referrals from institution to institution (as allowed by HIPAA when they are caring for the same patient). Some of these arrangements are being formalized into RHIOs. When they need records for a patient outside the “home” network or plan, providers or plans will make a phone call, go direct to the patient or give up. Indeed, the health-care industry is probably the nation’s single biggest user of fax services.

In the long run, however, there are two new models growing up. One is for administrative and clinical data to be “owned” and managed by health-care institutions and exchanged much like financial data. This generally happens through a third party such as FirstData, which currently does that on behalf of credit-card issuers and is moving aggressively into health care. Call that the banking model.

Call the second a clustered patient-centric model: Each individual patient’s data will be aggregated, on behalf of that patient, in one of many databases organized around patients’ data rather than belonging to a single institution.

We believe these two models will coexist.

There are two other, more centralized models being advocated by others in the industry: a single centralized database, which is just not likely to happen – whether it’s government-controlled (for privacy and other reasons) or private (as propounded by Patient Command (below). Finally there’s the master-index model, in which data would stay where it is and patients’ records would be assembled in real time on demand (by patient or practitioner) by database requests to all the locations/institutions that hold the data. (A number of companies, such as Resolution Health, are providing the medical equivalent of credit bureaus (not in real time), but for the *consumers*. This can be done for a limited number of patients, but it still suffers from limited data and incomplete records.) We believe that attempts at these centralized models will not emerge anytime soon, despite their seeming elegance. (That may be their problem; they can’t emerge incrementally.)

The banking model

The Medical Banking Project (SEE **RELEASE 1.0**, JANUARY 2005), is trying to help the banking industry move into health care in a big way. It sees a huge opportunity – and a market where its members’ familiarity with real-time, geographically distributed transaction-processing and with scale could be big competitive advantages. A number of banks are entering this market. More significantly, so is the biggest player in interoperability and transactions among all banks in the US, FirstData Corp. (below). As in banking, FirstData sees its mission as providing a neutral, real-time service that allows independent institutions to provide an almost seamless experience for its institutional customers.

In the banking model, the originators keep the data and it’s assembled as needed for transactions, using indexes and links and real-time data transfer. However, this model doesn’t really envision a personal health record for consumers, just as the banks don’t really envision integrating all of a consumer’s financial records into one. Customer-centric data is stored at the three credit bureaus, but for now, that data is batch-processed and held on behalf of credit grantors, rather than for the individuals it concerns. Despite new free-access laws and increasing consumer empowerment, the credit bureaus still operate for those who pay them the most – the financial institutions. By analogy, the health data network FirstData envisions would operate on behalf of payers and providers.

eHealthTrust: Man with a plan

Right now Bill Yasnoff is just a health-care consultant with an idea at NHII Advisors, the so-far one-man firm he founded early this year after leaving the Department of Health and Human Services, or HHS). But he is collaborating with eight interested colleagues; he has the requisite experience and pedigree to help execute his idea, and also some good client prospects such as the health-care communities of Spokane, WA, and South Bend, IN. At HHS, he served as senior advisor, NHII (National Health Information Infrastructure) and initiated and organized the activities leading to the President’s \$50-million health-care budget request for the 2005 fiscal year (even though it was never in fact funded). He also established the NHII as a national goal – though he no longer believes in the architectural model he initially propounded.

More practically, he built the (still successful) immunization registry in Oregon, a complex, large-scale, multi-stakeholder project similar to the eHealthTrust concept he’s working on now. Before that, he worked on three IT start-ups (one as founder), and he has both an MD and a PhD (in computer science) from Northwestern. But

now, he says, he wants to make some of his ideas happen, and he has moved back to the private sector to do so.

His plan is to foster the creation of eHealthTrusts – health data banks – that would store and manage personal health records on behalf of patients. His vision is that there would be multiple such eHTs, and probably similar competing data banks with other names (though using his business-model patent; more later). An eHealthTrust would take charge of collecting patients’ records from all sources – doctors, plans, labs and the like. Each patient’s records would be physically stored in one of a number of community-owned and operated databases (with backups) rather than just linked to, and would always be available.

As noted, that contrasts with the purportedly cheaper, less disruptive idea of simply building a master index that would know where all the records are – and that could assemble them on demand in real time. This concept, propounded by Markle and the HHS’s David Brailer, among others, is appealing technically and could work, but only when – or if – standards to make it easy have been established and all institutions are tightly connected. It’s a good approach for tracking terrorists, for example, but less suitable for giving patients (or terrorists, for that matter) access to their own data. We believe less ambitious approaches are likely to succeed first.

Centralized into local clusters

Indeed, Yasnoff is expert at debunking the real-time index idea. “I should know,” he says. “I was one of the people who helped develop it” at HHS. Originally, it seemed like the appropriate alternative to a central database that would be, almost by default, government-controlled. But the idea of multiple databases built around individuals’ complete records, collecting data from institutions, rather than multiple institutional databases with subsets of individuals’ records, makes much more sense – as long as the privacy questions could be handled. We agree, although this approach has yet to percolate through the industry.

There are three major problems with the index approach, Yasnoff points out: First, building a comprehensive index system that would allow instantaneous access from anywhere to all the records in the country is probably even more complicated than building a set of heterogeneous data stores that serve individuals: i.e., each patient is the center of his own universe, rather than a short-term, multi-part database join. The first kind of system needs all the data sources to work at once; the second can be rolled out for hundreds of thousands rather than hundreds of millions of patients at a time. Moreover, it would be hard to agree on standards for such a system. In prac-

tice, standards emerge as one or two market contenders win. Unfortunately, there's no real way around the redundancy and duplication that imposes.

Second, argues Yasnoff, there's no system of incentives for the linked system until it's fully operational. The investment is too great for it to be funded on spec.

And third, we'd argue, the data in an indexed system wouldn't be liquid; it would be kept in silos until it was assembled for transactions, rather than integrated for continuous monitoring, either for the patient or for more general analytical work.

Patient at the center

By contrast, the eHealthTrust model, while it is just a data store, could easily send the data for any patient to a rules engine for processing, to a drug compliance system for monitoring, and so forth. To ensure patient control, eHealthTrust plans to rely on You-Take-Control (SEE **RELEASE 1.0**, JANUARY 2005) for its HIPAA-style permissions workflow, which is granular enough to expose only certain records or subsets of records to any particular person or role within an institution. It would keep individuals' records in one secure database connected to the Internet, with a front-end that allowed only one person's record for any query. That is, a user couldn't ask for records on a group of people or make any other kind of general inquiry. And of course, each query would have to go through the permission process that the eHealth model (and HIPAA) imposes.

That database would also be copied periodically into an air-sealed machine with no direct connections to the Internet, and with only keys to the names and IDs in the source database. Here, authorized institutions (for a small fee) could send in queries for eHealthTrust to run on records patients have agreed can be queried: everything from a manufacturer who wants to send a message to all users of a suddenly recalled or withdrawn drug or device (as if that ever happened!), to a researcher looking for the incidence of colon cancer by geography, to a pharma company interested in finding patients with advanced prostate cancer for a clinical trial of a promising new drug. Longer term, that same database could be used to cross-reference various genetic patterns with diseases and other anomalies.

Of course, notes Yasnoff, people's data (or subsets) would be in that second database only with their permission, and even then it would be anonymous (except to eHealthTrust, which could pass alerts, fees and requests for more information back to the individuals involved). Most of the fees collected for data access would go to the patients who provided the data, giving them an incentive to do so.

“I’ve spent enough time on this that I know many of the policy problems it will unearth. It won’t *create* them,” Yasnoff stresses, “but it will create possibilities that make policy choices necessary.” For example, since individuals can black out any part of their records from scrutiny even by their own doctors, what about people who make a career of getting controlled substances from a multiplicity of doctors

EHEALTHTRUST INFO
Headquarters: Arlington, VA
Founded: March 2005
Employees: 9 people working on project
Funding: undisclosed
Key metric: visited 18 communities in 15 states so far
URL: www.ehealthtrust.com

and selling the surplus? Although law enforcement has access to those records through pharmacy records anyway, all authorized viewers of the patient’s record would see a notice that one or more controlled substance prescriptions had been suppressed, answers Yasnoff. Or what about psychiatric as opposed to physical health records? Yasnoff believes his system should not as a rule include detailed psychiatrists’ notes. As for regular doctors’ notes, he says, doctors are just going to have to learn not to write things such as “hypochondriac whiner – muscle pains from hauling too much weight around.” Of course, Yasnoff hastens to add, “It’s not that they don’t respect their patients. These are just keys to jog the memory.”

We suspect that the mere physical act of typing rather than scribbling on paper will help doctors to keep their politics correct.

The more fundamental issue beyond discretion – of actual disagreements between patients and doctors – can’t be resolved by the system, but they can be flagged, and both parties can contribute their versions. Any third party can make up his own mind whom to believe.

He who pays for lunch gets to choose the menu

The second major feature of eHealthTrust is its business model; Yasnoff has filed for a patent on it – not so much to generate royalties, he says, as to control use of the concept and to foster standards for submitting data to eHealthTrusts. Yasnoff believes these data standards are necessary make the concept more attractive to vendors, who will integrate the standards into systems sold to providers. Yasnoff’s idea is that patients will pay for the service, perhaps \$49.95 a year or \$9.95 a month (potentially offset by fees for selling their data to researchers). Meanwhile, eHealthTrust will pass on part of those fees to physicians at \$2 to \$4 per encounter record submitted to eHealthTrust – presumably with some provisions to make sure that doctors don’t generate multiple records per visit. That, plus the force of law – HIPAA requires that any holder of patient data provide it to the patient (or designated intermediary) on the patient’s request – should do the trick, he says.

He adds, “You tell a doctor that if he buys a new electronic system, he’ll get \$20,000 a year for, say, a busy internal medicine practice, and they’ll listen to you. Before, they were told they had to buy the equivalent of a Lexus so their health plan could save money. This way, *they* make the money!” (And, he claims, the health plan also saves long-term, on likely reduced demand for duplicate tests and x-rays as well as expensive remedial care from patients getting better preventive care).

We’re a bit more skeptical. Providers will get fees, and there are time limits and specifications of format in the law, but there are no penalties and enforcement is weak. Moreover, Alice the doctor isn’t worried just about money. She’s worried about retraining Juan, the office administrator, and getting all the nurses and assistants to adopt the new system, which inevitably will demand more process and screenwork (in lieu of paperwork) than the old system. Yes, there’s a huge savings in time once all the data is entered, but entering it the first time is quite a hurdle.

And despite Yasnoff’s citation of an Accenture study reporting that more than 50 percent of people queried would pay more than \$5 per month to have electronic medical record, the numbers (SEE TABLE, PAGE 14) show slow uptake when people are actually presented with the opportunity. Perhaps they were expecting more. Perhaps they don’t trust the ones offered. Perhaps they really need to be marketed to like regular consumers, as RealAge and HealthExpo have demonstrated. But it’s clear it’s not that simple.

Currently, Yasnoff is calling on a number of regional communities, ranging from Vermont to Washington State – many of whom he has served as a consultant. First, he had helped them to understand their problems. Now, he’s offering a solution. The idea is that he will advise them on the implementation of an eHealthTrust for their community, which that community – or local investors – will own and operate. His income comes from advice; the license fee for the patent-pending business model is more a way of ensuring the system’s integrity (and enforcing the use of common standards for data transmission) than of making money, he says.

We love this idea, and we think the business model of paying doctors may indeed be more effective than one that simply says, “The government wants you to.” And we also think that most individuals can and should pay. That will encourage transparency and healthy competition, and will shift power away from subsidy-wielding health-care institutions. ■ R 1.0

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