The Benefits, and Potential Side Effects, of Sharing Medical Records Online

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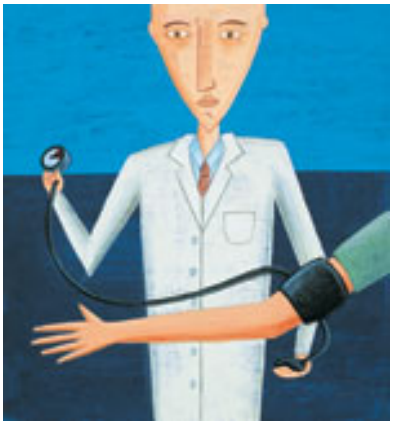

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On October 4, Microsoft launched HealthVault, a free web-based service that allows users to store their medical records online and eventually share them with doctors and health care professionals. On October 17, a Google executive stated that the search giant was also interested in the area of health information services. And on November 19, 23andMe, a startup focused on web-based personal genetic analysis, announced a program that will allow consumers to pay $999 for the privilege of exploring their own genomes. These latest developments -- and dozens of similar initiatives -- could push the online sharing of personal health information into the mainstream.

These efforts could make personal health records (PHRs) more popular, say experts at Wharton. PHRs give patients control of their medical records so they can share information as needed with physicians. The goal is to ease the burden on what Microsoft's Peter Neupert, corporate vice president of the software giant's health solutions group, calls the "family health manager," the mother in many families. In the October 4 announcement, Neupert said that HealthVault can be a repository to store data, such as a cholesterol test result or vaccination history, that could then be distributed, as needed, to multiple parties like doctors, athletic trainers or nutritionists.

"Remember, it's about the mom, the family health manager, and creating an information system that works for them," said Neupert at a press briefing outlining HealthVault. "It starts with this shared data repository, the opportunity to collect data, because we need to make information reusable. We need to make it accessible. [People] need to know that they can get the right decisions made. We're all frustrated ... by the simple, stupid things, like having to fill out the clipboard [every] time, or why we have to go get [our] x-ray, when it's right across from the doctor's office. Why can't [one] doctor figure out how to get it to the other doctor?"

Experts at Wharton agree that Neupert's assessment is on target. Medical information is too difficult to share. However, there are numerous hurdles -- privacy concerns, a lack of a single standard for sharing medical information, and a health care industry that is reluctant to change -- that hamper PHRs and similar efforts. "Health care is one big area of our economy, and it is slow and resistant to modernization," says David Hsu, a management professor at Wharton.

Technology companies are angling to change that prognosis. Marissa Mayer, Google's vice president of search and user experience, said at the Web 2.0 Summit on October 17 that the company has "a broad interest" in health care information. Indeed, as Arnold Rosoff, a Wharton professor of legal studies and business ethics, notes: "Technology has moved on, but the health care industry hasn't. Microsoft and Google have the clout to lead to a tipping effect" to accelerate electronic medical record adoption.

Leading technology companies, such as Microsoft, could help create standards so that medical information can be readily shared, Rosoff says, adding that connecting information systems inside health care institutions with personal health records would help eliminate the paper chase that ensues when a

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patient changes doctors, sees a specialist or visits different health care systems.In return, these technology giants could generate advertising revenue. HealthVault will be ad supported, and experts at Wharton expect Google's potential service to rely on targeted search results to make money. It's unclear, they add, whether consumers will view targeted health ads as intrusive.

Today, there are two forms of electronic medical records. The relatively new web-based PHRs are designed to be individually controlled and potentially portable. Electronic medical records (EMRs) are used by industrial strength information systems that are being adopted by health care institutions and hospitals to share lab tests, X-rays, MRIs, medication history and other items internally. These EMR systems have been deployed by the Veteran's Administration, the University of Pennsylvania's Health System and other major health care providers. But information is still hard to share outside of those respective health systems, says David Asch, professor of health care management at Wharton.

According to Asch, a physician aligned with the VA and University of Pennsylvania Health System, the problem is that electronic records are hard to push on independent doctors. In the VA's system, doctors are employees and there is more centralized control. Convincing independent doctors to go electronic is like herding cats. "The VA invested in electronic records and had economies of scale as the largest integrated health system," says Asch. "It also had a bunch of physicians and clinicians [accustomed] to being employees and following orders. That's harder to export outside of the VA when each physician is independent."

Meanwhile, a single standard doesn't yet exist for sharing information between EMR systems. Peter Gabriel, medical director of clinical information systems at the University of Pennsylvania Health System, is implementing an EMR system from Epic Systems, one of the leading players in electronic medical records. The project, which has proceeded off and on since 1998, should cover 50% of the University of Pennsylvania's Health System by the summer of 2008, says Gabriel. While Gabriel's EMR system can yield benefits among the University of Pennsylvania's hospitals, the electronic record ends if a patient goes to another health care network.

"On a national scale, you have the problem that EMRs don't talk to each other. If a patient at Penn is taken to Jefferson [Thomas Jefferson University Hospital in Philadelphia], that hospital has no good information about him without phone calls, time and faxing," says Gabriel. "This means that tests are repeated and costs rise."

Forgetting the Triglycerides

Experts at Wharton say that PHRs, in theory, could be a bridge between the various electronic records found at hospitals. For instance, a patient could take a health record from a hospital, store it on a web-based service and then share that information with other doctors or specialists. However, experts were mixed on where PHRs fit in relative to other electronic records.

To Gabriel, PHRs are a complement to existing EMR systems. For example, the University of Pennsylvania plans to use its EMR system to provide a patient portal that would view records and interact with physicians. "To me, the terms PHR and EMR are fuzzy," says Gabriel. "But where EMR systems are incompatible, the PHR could be the bridge. The ideal would be a shared repository under patient control or records stored on a device."

Asch says it is unclear how PHRs would meld with institutional electronic medical record systems and how this information would be shared in an emergency. If a patient were incapacitated, how would he provide access to his web-based medical record?

There is also a quality issue, Asch adds. "Patients aren't the best judge of what should be in there. It's hard to know how useful these PHRs will be on the physician side." A patient could record popular tests, such as a cholesterol score, but omit a lesser known result, such as the triglyceride level. "If you go to a doctor's office, you are given an enormous check list and you document as much as you can. People will be just as good or bad with that process on a web-based program."

Rosoff echoes those concerns. He says that patient controlled medical records are only as complete as the information entered. Selective disclosure could be commonplace. He also notes that there may be emerging incompatibility problems with PHRs. Microsoft's HealthVault is entering a market where there

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are dozens of PHR products. For instance, Steve Case, former CEO of AOL, has started RevolutionHealth, a health care portal and community site. For a $129 annual fee, customers get a health care adviser, help finding doctors, and tools to facilitate expense and medical record keeping. Microsoft is offering its service for free to encourage more adoption by consumers, says Neupert. Meanwhile, the American Health Information Management Association lists 15 free web-based PHR services, 47 Internet services that charge a fee and 28 software programs.

According to Hsu, one promising aspect of Microsoft's HealthVault announcement is that the company has more than 40 partners, including Allscripts, which provides EMR systems, the American Heart Association, Healthways, which provides wellness and disease prevention services, and New York Presbyterian Hospital. Other partners include health device makers, which will import HealthVault information.

Hsu, however, adds that the personal medical record market will need more than Microsoft and its partners to make web-based health information the norm. "There will probably have to be some partnership between the private sector and the government. I don't think Americans are prepared to turn over their health information to any one organization. If there were tools endorsed by a branch of the federal government and professional associations, that would help. This may be bigger than any one company."

Privacy Pitfalls

Anita Allen, a law professor at the University of Pennsylvania and an expert on privacy law, says no matter what entity endorses personal online medical records, privacy issues will loom large. "Anyone's health records should be regarded as personal and sensitive," says Allen. "People need to be mindful of discrimination from employers and insurers."

One issue with HealthVault and similar efforts is that they aren't covered by HIPAA (the Health Insurance Portability and Accountability Act). HIPAA, passed in 1996, created standards for electronic health care transactions and addressed security and privacy issues. Under HIPAA, a patient's medical record and payment history can't be linked to an individual by an unauthorized person. These rules apply to health plans, health care clearinghouses -- such as billing services and information providers -- and health care networks.

Although HIPAA covers the institutions installing EMR systems, Allen says that regulation wouldn't cover entities like Microsoft, Google or any other web service that allows medical records to be stored online. "HIPAA doesn't prevent you from uploading information and accepting terms of an agreement. Anything that happens to those records is routine and covered in courts under privacy law."

For instance, Microsoft promises that HealthVault records will only be controlled by the patient. In a "frequently asked questions" document, Microsoft outlined that the consumer decides what information is stored in HealthVault, access is granted on a case-by-case basis, and health records aren't used for commercial purposes unless authorized.

The genetic testing outfit 23andMe makes a similar promise. According to the company: "23andMe provides a service: linking you to your genetic data. Though we store and help you interpret it, your genetic information is yours to have and explore. 23andMe provides you with all your data and will never withhold it from you. It is our job to present it with as much context as we can. Since it is your data, it is also your option to share it as you wish with your family and friends."

"I think it's a great idea to enable consumers to maintain their own health information," says Allen. "But when they do that and use third party providers, they are taking risks." Allen's advice: Read web providers' terms and conditions carefully and realize that they aren't covered by HIPAA. "One can enter a contract with a firm and use a service, but that means you have to trust the party -- Google, Microsoft or anyone else," says Allen. "Also, realize that other parties, including the government, may have access to that data under subpoena power. Companies can make promises, but they may not be able to keep the government out of your business."

Looking Ahead to the Future

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Hsu expects concerns about the electronic transfer of personal medical information to fade over time. While medical information is guarded more closely than financial data, there are similarities. Initially, financial data was largely paper-based and consumers were reluctant to share information electronically. Today, web-based banking and financial transactions are commonplace. Personal health records may follow the same path, says Hsu.

"Electronic banking faced initial resistance too," he notes. "Remember, it is still quite early in the Internet age. So there will have to be education about electronic medical records, a clear value proposition and a lot of selling before people are prepared to make the transition."

Gabriel says one big challenge in the future will be applying electronic and personal medical records to groups that need it the most. For instance, a PHR for an elderly person would be helpful as would a three-month trend of blood sugar levels for a diabetic, but those patients have to be diligent record keepers. "Only a certain segment is capable and motivated to do it," says Gabriel. "Socioeconomic and education factors also play a role. Some of the people using PHRs may be the ones who least need it."

Rosoff suggests that those issues could be resolved if records were automatically shared between devices that test for chronic conditions such as elevated blood sugar levels or high blood pressure, institutional systems and web-based services. "For chronic diseases, you could see PHRs linked to medical providers, data updated once or twice a day and email reminders about medications," says Rosoff. "We're not far away from people having biosensors that transmit data into the record. It's not science fiction. It's definitely coming. That's why Microsoft and Google are interested."

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