Perspective

Personally Controlled Online Health Data — The Next Big Thing in Medical Care?

Robert Steinbrook, M.D.

Most physicians in the United States have paper medical records — the sort that doctors have kept for generations. A minority have electronic records that provide, at a minimum, tools for writing progress notes and prescriptions, ordering laboratory and imaging tests, and viewing test results (see line graph).[1] Yet electronic health data are poised for an online transformation that is being catalyzed by Dossia (a nonprofit consortium of major employers), Google Health, Microsoft HealthVault, and other Web services that are seeking expanded roles in the $2.1 trillion U.S. health care system.

Online repositories will allow patients to store, retrieve, manage, and share their health data — such as lists of medical problems, medical history, medications, allergies, immunizations, test results, insurance information, and

doctor's visits — over the Internet. It remains uncertain, however, whether people will wish to assume these responsibilities, whether physicians and health care institutions will facilitate the process, and whether the long-term result will be improved health care and decreased costs — or simply the creation of new business opportunities.

Online repositories typically promise consumers, in the words of Google Health, "complete control over your data," meaning that personal information won't be sold or shared without the consumer's explicit permission. Repositories may have comprehensive privacy policies, and people can always de-

lete their data or cancel their accounts. Unfortunately, promises about data privacy and security may lack legal force. Policies about advertising on repository sites vary from complete prohibitions to allowances for targeting ads and searches to users with specified personal characteristics. Data storage is usually free; there may be a fee for additional services provided by other companies or organizations.

Physicians may have little awareness of the changes that are afoot. Nonetheless, they may soon need to figure out how to work with the new services. Physicians with electronic records will have to decide whether to allow their patients to receive this information in standardized electronic formats online and use it as they wish — for example, to share it with a competing medical group or a doctor in another part of the

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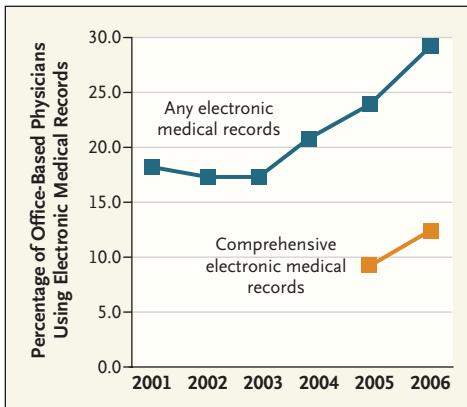
Percentage of Office-Based Physicians in the United States Using Electronic Medical Records, 2001–2006.

Data are from Hing et al.[1] Comprehensive electronic medical records systems include, at a minimum, computerized orders for prescriptions and tests, test results (laboratory or imaging), and clinical notes.

country. In turn, physicians will be able to receive electronic data from patients seeking care or a second opinion.

Since the 1990s, a few academic researchers have sought to develop personally controlled health records. In 2003, a working group sponsored by the Markle Foundation defined such records as "an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment."

In an online survey conducted in November 2007, 91% of respondents agreed that "patients should have access to their own electronic medical record," and 60% agreed that "the benefits of electronic medical records outweigh the privacy risks" (see bar graph).[2] At present, however, few people have personal health records, and even fewer have personally controlled electronic health data; only 1% of respondents use a personal health record that is accessible through the Internet.

Nonetheless, many patients use the Internet to e-mail their physicians, receive test results, request referrals, schedule appointments, or refill prescriptions.

If personally controlled records take off — and despite the enthusiasm of proponents, there is no assurance that they will — the electronic records maintained by physicians and hospitals will be only one component of a larger Web-based information system with national interoperability standards, in which patients increasingly control their own health data. Patients will be able to download their data from medical records, laboratories, pharmacies, and insurance-claims databases, and add data, such as measurements of weight or blood pressure. Without carrying paper records, they will be able to share data with multiple doctors, an emergency department, or family members as necessary; renew prescriptions; manage their fitness, diet, or a chronic disease such as diabetes or congestive heart failure; communicate with people with similar health problems; or find clinical trials to participate in.
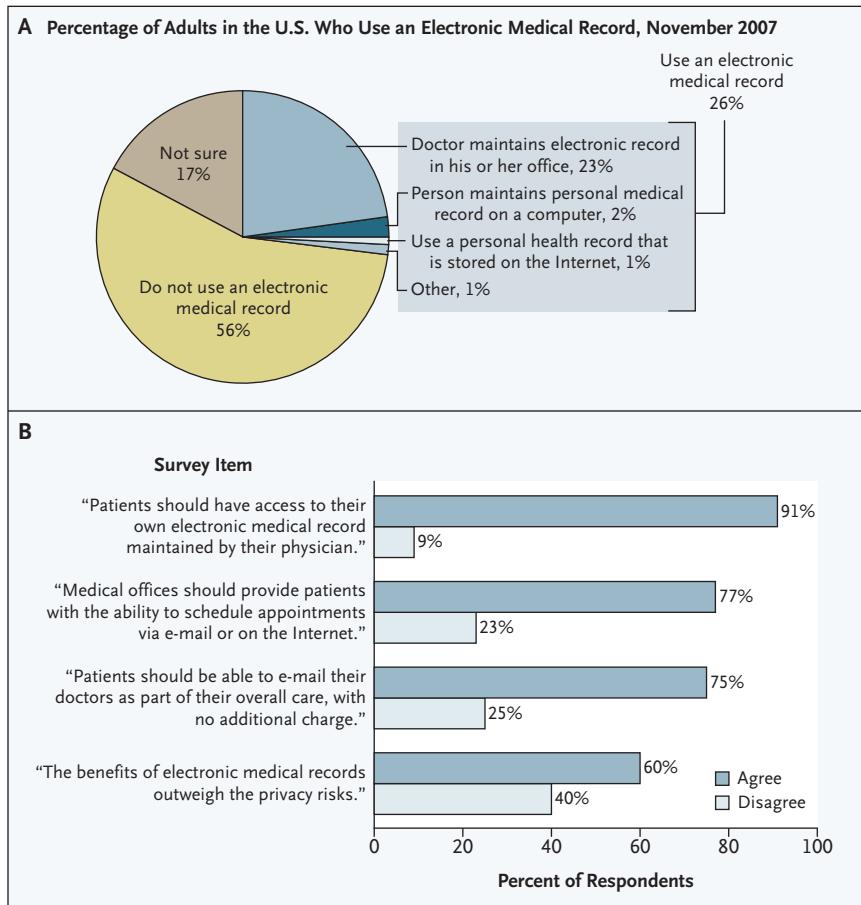
Dossia (www.dossia.org), founded by AT&T, Intel, Wal-Mart, and five other large U.S. employers, plans to offer a voluntary means of storing personally controlled health data to about 2 million employees and 5 million dependents and retirees, as well as making other services available. The platform uses an open-source technology, Indivo, developed at Children's Hospital Boston. Dossia's long-term goal is a portable and secure lifelong record that will be available regardless of a person's employer, insurance plan, or physician; employees who leave a participating organization will

still be able to use the system, possibly for a fee. Pilot testing is ongoing.

Microsoft HealthVault (www.healthvault.com) allows patients to "collect, store and share health information with family members and participating healthcare providers." HealthVault, currently available only in the United States, includes a search feature, services (such as an emergency health record) to which information can be sent, and a connection center permitting the direct upload of data from compatible devices, such as those that measure heart rate, blood pressure, blood glucose, or peak airway flow. New York Presbyterian Hospital is working with Microsoft HealthVault on data exchange; however, the feature is not yet available and the exact data types are still under discussion. Microsoft indicates that it does not "use your health information for commercial purposes unless we ask and you clearly tell us we may."

Google Health is not yet publicly available. In February, the Cleveland Clinic and Google announced a pilot program that will enroll 1500 to 10,000 patients to test the platform's ability to exchange data with an electronic medical records system. Such exchanges could eventually allow patients to store all their medical records in one place and to communicate with providers, pharmacies, and online health applications.

In theory, personally controlled online health data could help to improve health, doctor–patient communications, and the coordination and quality of care and to avert medical errors — and thereby reduce the cost of care — though of course this all remains to be seen. The users who

A Percentage of Adults in the U.S. Who Use an Electronic Medical Record, November 2007

Use an electronic medical record 26%

Doctor maintains electronic record in his or her office, 23%

Person maintains personal medical record on a computer, 2%

Use a personal health record that is stored on the Internet, 1%

Other, 1%

Not sure 17%

Do not use an electronic medical record 56%

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Survey Item

"Patients should have access to their own electronic medical record maintained by their physician." — 91% / 9%

"Medical offices should provide patients with the ability to schedule appointments via e-mail or on the Internet." — 77% / 23%

"Patients should be able to e-mail their doctors as part of their overall care, with no additional charge." — 75% / 25%

"The benefits of electronic medical records outweigh the privacy risks." — 60% / 40%

☐ Agree
☐ Disagree

Percent of Respondents (0, 20, 40, 60, 80, 100)

Use of Electronic Medical Records in the United States, November 2007.

Data are from a Wall Street Journal Online/Harris Interactive Survey of 2153 adults, conducted online in the United States, November 12–14, 2007.[2] Percentages in Panel A do not sum to the total because of rounding.

may benefit the most may be patients with complicated chronic conditions and those with episodic needs for extensive care or treatment.[3]

Because patients generally won't have to pay for storage or other costs of maintaining online health data, funding plans are largely based on anticipated revenues — revenues for hospitals and health plans from the recruitment and retention of patients who want such records, and revenues for the likes of Google and Microsoft from lucrative advertising on health-related searches. There are also anticipated savings — for in-

surers in the form of reductions in claims as a result of coordinating care and enrolling patients in disease-management programs, and for employers in the form of increased worker productivity and decreased health care costs for employees who become more aware of their health care needs, use wellness programs more fully, and have better-coordinated care. Of course, it is too soon to say what revenues and savings will actually materialize.

Personally controlled electronic health data may also raise new problems. The data may be incomplete, inaccurate, or difficult to

verify, resulting in liability concerns for physicians who rely on them. Online data stored outside the health care system are not subject to the federal Health Insurance Portability and Accountability Act (HIPAA), which established minimum privacy and security standards for individually identifiable health information controlled by a "covered entity" — a health care provider, a health plan, or a health care clearinghouse. Because online data repositories such as Dossia, Google Health, and Microsoft Health-Vault and some of their business partners are not covered entities, the data they store may not be as private as consumers assume, and a person's "control" could turn out to be limited.

Under HIPAA, every person "has a right of access to inspect and obtain a copy of protected health information," with certain exceptions (for example, psychotherapy notes). Providers, health plans, and clearinghouses must provide the information "in the form or format requested . . . if it is readily producible in such form or format," although electronic medical records are typically printed out and given to patients in paper form.

Perhaps the most widely used personal health records are hospitals' or medical groups' electronic medical records reached through a secure Web connection, or "patient portal." The portal is part of the provider's information system, and as long as patients' health data remain there, they are covered by HIPAA. Depending on state laws and organizations' policies, patients may have access to lists of their problems, medications, allergies, and test results. Progress notes are usually not

available because of the level of explanation required and physicians' concerns about sharing their personal thoughts, although the patient has the right to examine the entire chart.[4] Examples of portals are PatientSite, developed at Beth Israel Deaconess Medical Center in Boston, which has about 37,000 active users, and MyChart, outpatient medical records developed by Epic Systems. Versions of MyChart are used by an estimated 2.4 million patients,[4] including about 120,000 at the Cleveland Clinic and 103,000 at the Palo Alto Medical Foundation, nearly half of all adult primary care patients. Portals can allow for secure messaging, including prescription, referral, and appointment requests, but they typically do not support data input from the patient or outside pharmacies, laboratories, physicians, or hospitals, nor do they communicate with portals at other institutions or work at all sites of care.[4]

Other personal health records, including some being established by Aetna and WellPoint, are based on insurance claims. After portability standards are implemented, patients who change coverage should be able to transfer their data between companies. Although insurers can provide data from administrative claims and can sometimes supplement them from other sources, such records lack detailed clinical information.

Dossia was announced in December 2006, Microsoft HealthVault in October 2007, and Google Health in February 2008, so their collective impact is not yet measurable. Although some physicians and patients will embrace increased use of the Internet for health care, others may prefer to watch from the sidelines as the bugs are worked out. Moreover, because legal protections have not kept pace with technological advances, Congress may wish to amend HIPAA or enact new legislation[5] to safeguard personally controlled electronic health data. If concerns about privacy, security, and commercial exploitation can be allayed, this nascent enterprise should have a smoother birth.

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5. Technologies for Restoring Users' Security and Trust in Health Information Act, HR 5442, 110th Cong. 2nd Sess (2008).
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Off the Record — Avoiding the Pitfalls of Going Electronic

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Many of us remember searching frantically for a lost chart or misfiled laboratory result in the wee hours of the morning as we cared for a sick patient in the emergency ward, or requesting in vain the most recent note from a specialist about a patient who returned to our office after a consultation. The ultimate goal of the electronic medical record — a technological solution being championed by the Bush administration, the presidential candidates, and New York Mayor Michael Bloomberg, as well as Google, Microsoft, and many insurance companies — is to make all patient information immediately accessible and easily transferable and to allow its essential elements to be held by both physician and patient. The history, physical exam findings, medications, laboratory results, and all physicians' opinions will be collected in one place and available at a single keystroke. And there is no doubt that these records offer many benefits. We worry, however, that they are being touted as a panacea for nearly all the ills of modern medicine. Before blindly embracing electronic records, we should consider their current limitations and potential downsides.

As we have increasingly used electronic medical records in our hospital and received them from