

Building a Health Information Network

by David B. Kendall

Information technology (IT) has so pervaded our lives that we often take it for granted. Tens of billions of emails pass through cyberspace every day. Anyone with a credit card or an ATM card has access to cash 24 hours a day, seven days a week, in most countries. Thirty million U.S. workers now telecommute.¹ These developments have made our lives more productive and more convenient.

One glaring exception, however, is the health care sector. There, IT is used only in a piecemeal fashion—for limited tasks like scheduling appointments and accounting—not as a means of streamlining all health care processes. Rather than sending prescriptions to pharmacists electronically, for example, most doctors continue to scribble them on paper, sometimes illegibly. Similarly, most doctors use paper medical charts instead of electronic records. Most hospitals do not mine data to find patterns of poor quality care. And health insurance plans and government programs like Medicare generate a massive flow of paper back to patients for processing routine medical claims instead of authorizing payments automatically.

Although some pioneering health care providers have launched comprehensive IT systems, patients are becoming impatient. Four of every 10 Americans have sought

answers to their health care questions online instead of contacting a doctor, despite knowing that such information may not be reliable.² Patients would do much more online if they could. Surveys show that most patients would like to check and refill prescriptions online, get test results, and email their doctors.³ As any patient who has carried X-rays from doctor to doctor knows, there has got to be a better way.

President Bush's proposed solution is a 10-year project, launched in 2004, that urges all doctors to keep their patient records electronically rather than on paper. So far, however, less than one-quarter of the country's doctors have begun doing so. In fact, only 9 percent have computer systems with the features that health care experts recommend.⁴ And none of the nation's doctors are connected to a network for sharing patients' records with other health care professionals

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providing care to the same patients.

Doctors are not connected to a national health information network, because no such network exists in the United States. What is more, the administration has dropped the ball in creating one, according to the U.S. General Accountability Office.⁵ That is unconscionable. A national health information network would provide the essential foundation for modernizing the U.S. health care system at a time when the system's soaring costs and retrograde inefficiencies constitute a dangerous drag on the country's economy and a glaring flaw in its social contract.

Merely asking doctors and other medical service providers to begin digitizing the records they keep on patients is insufficient because that will only create a series of disconnected electronic silos of patient information in doctors' offices, hospitals, medical testing labs, pharmacies, and elsewhere. Fragments of an individual patient's medical history will be spread far and wide: X-rays and MRI films in a medical lab here, a primary care physician's diagnostic notes in an office there, a specialist's notes in another office somewhere else, and so on. What is needed instead is a networked system that allows medical service providers to securely feed those disparate pieces of information into a single electronic history that is owned and controlled by the individual patient, and that represents the patient's complete medical record.

When a patient sees a doctor, she should be able to give the doctor an access code and a password to her private medical history. The doctor should then be able to view all of the key information contained in that history, ideally on a single computer screen. In the course of providing treatment, the doctor should be able to feed new information into the system to keep the patient's medical history up to date. Eventually, these patient-controlled electronic medical histories could become hubs at the center of a national health information network that seamlessly

connects not just doctors and patients, but also hospitals, pharmacies, medical labs, and health insurance companies—that is, all entities that offer medical services of any kind to American consumers. Such a network would give doctors more comprehensive patient information that they could use to improve the quality of care they provide. It could increase efficiency by expediting billing processes, cut costs by eliminating the need for redundant tests, and reduce medical errors by making it easier to flag dangerous drug interactions, for example. More generally, it would allow people to take greater control of their own health care.

Experts have been calling for such a system of secure, patient-controlled electronic health record (EHR) accounts for several years. In fact, a pilot EHR system, administered by the nonprofit organization Patient Safety Institute, is already up and running in three Seattle-area hospitals.⁶ Similar EHR systems are operating in Indianapolis, Kansas City, and Spokane, Washington.⁷ Under the leadership of Gov. Chris Gregoire (D), Washington state is expanding such pilots as part of a statewide health IT strategy.⁸

It is noteworthy that these pilot EHR systems have been undertaken by organizations that are not medical service providers themselves. One reason President Bush's electronic health records plan is not likely to lay the groundwork for a national health information network is that it relies on doctors to take the initiative in going digital. But doctors do not have enough financial incentive to make the substantial IT investments necessary to create patient-controlled electronic health record accounts, because entities other than themselves—especially the insurance companies and government programs that pay most of the country's medical bills—will be the chief beneficiaries of the resulting efficiency gains.⁹

Achieving 100 percent adoption of full-featured EHR systems will require an investment of approximately \$115 billion.¹⁰

That is simply too much to ask of doctors and hospitals. Yet researchers at RAND estimate that the potential return on investment in EHR systems for the nation as a whole could be \$5 for every dollar invested over a 15-year period—about \$500 billion in total.¹¹ That creates an enormous opportunity for third parties to step into the breach, put up some investment capital, and make a profit by delivering efficiency gains. Commercial ventures or membership organizations like the AARP could finance the creation and maintenance of EHRs at no cost to patients by charging insurers, the government, and others a small fraction of the large benefits they will accrue as widespread use of EHRs produces new efficiencies and cost savings in the health care system.

But before such a health information market can emerge, PPI believes government must establish a regulatory framework that protects people's medical privacy and requires the players to use interoperable technologies, among other matters. For starters, there must be a highly secure means of administering EHR accounts and authorizing access to the data they contain. An analogy would be to the functions that VISA and MasterCard perform in administering credit card accounts and authorizing payments.

Just as financial institutions compete to offer consumers credit cards with different perks, PPI envisions a number of government-certified health record trusts competing to offer people their electronic health record accounts. The trusts could compete for people's business by offering EHRs with highly personalized features. For example, a trust might offer people with diabetes EHR accounts that automatically notify them when it is time to have check-ups on their eyes, feet, blood pressure, and blood sugar to prevent unnecessary blindness, amputations, heart disease, and other complications that are commonly related to diabetes. In fact, just as computers and the Internet have driven

transformation in other sectors of the U.S. economy, the emergence of health record trusts offering EHR accounts will trigger the development of a host of revolutionary new computer applications for patients and health professionals.

The main responsibility for all health record trusts will be to gather patients' medical records into EHR accounts and authorize doctors, hospitals, pharmacies, insurance companies, and other entities in the health care sector to access the data according to patients' specific instructions. That level of patient control over medical data would be substantially stronger than current federal law, which generally does not require health service providers to ask permission before sharing patient records with other organizations. In addition, health record trusts should be required to provide patients with regular reports of who has been accessing their accounts, just as credit card billing statements list all charges to an account every month. Patients should also be able to view their medical records and correct inaccurate information.

The federal government can be a prime catalyst for electronic health records, since it pays for nearly half of the nation's health care bills through Medicare, Medicaid, and other programs, and since it subsidizes most private health care spending through tax breaks.

Congress should take the following steps to give all Americans access to a network of EHR accounts within the next three years:

- 1. Set federal rules for independent health record trusts.** These standards should include privacy and security protections for patients, and interoperable IT standards for health care providers to transmit patient information back and forth with health record trusts. In addition, the government should create a certification process that bestows a regulatory seal of approval upon trusts that are verifiably adhering to these government standards. Just as the banking industry benefits from federal regulation that protects consumers' deposits,

trusts will need federal regulations to assure patients that their health records will be permanently available according to their privacy preferences. Federal regulation also needs to assure doctors that they will have easy access to reliable information about their patients. Trusts will be responsible for working collaboratively to develop protocols for the private, confidential, and secure storage and transmission of patients' health records among all the players in the health care system. Reps. Dennis Moore (D-Kan.) and Paul Ryan (R-Wis.) and Sen. Sam Brownback (R-Kan.) have proposed legislation to promote such organizations.¹²

2. Give patients a legal right of access to medical records that are already being stored electronically. Current federal law only gives patients a right to a paper copy of their records. Congress should require doctors, hospitals, health plans and other entities with electronic patient data to give a patient's health record trust access to that patient's information so it can be gathered together in an EHR account. The Moore-Brownback legislation and another bill by Reps. Patrick Kennedy (D-R.I.) and Dave Reichert (R-Wash.) would patients this legal right.¹³ In addition, Sen. Tom Carper (D-Del.) and Rep. Jon Porter (R-Nev.) have proposed legislation to require health plans in the Federal Employers Health Benefits program to give federal employees access to records stored in the computers of the health plans.¹⁴

3. Strengthen patients' privacy rights. Regardless of where or in what form health records are stored, federal law should give patients the right to control who has access to them, review a list of people who see them, and be notified of any security breaches. These EHR accounts would give providers an inexpensive and easy way to protect patients' privacy and to follow their privacy preferences.

This paper examines the obstacles to health IT adoption; the creation of independent health record trusts; the use of patient health information that is "stranded" in the computers of medical testing labs, pharmacy benefit managers, and

health insurance plans; and finally, changes in federal law needed to protect patient privacy.

The High Hurdle for Health Information Technology

Health care is the great outlier in the digital revolution. Your local oil change mechanic has better access to your car's service records than doctors have to those of their patients. As a result, doctors sometimes make well intended, but harmful decisions—even deadly ones—based on incomplete information. They push up health care costs by ordering duplicative tests and procedures because they lack easy access to patient records from other doctors. They inadvertently make errors that computers could help guard against.

Of course, doctors' offices use computers to make appointments and file medical claims, but they generally do not use them to record patient office visits, log test results, track preventive care plans, submit prescriptions, or communicate with patients.

Today's system of paper records makes it very difficult for anyone to ensure that patients receive all the care they need. For example, patients with diabetes need annual check-ups to have their eyes, feet, and blood examined. If they don't get these check-ups, then they are much more likely to end up in the hospital for more serious—and expensive—medical problems or procedures such as an amputation, eye surgery, or a heart attack. Paper record systems, unlike computers, cannot generate automatic reminders to patients to get these checkups.

The president's strategy of getting doctors to adopt electronic health records independently poses a high, one-time hurdle for physicians. A group of Philadelphia physicians report on their struggles and satisfaction in adopting an electronic system:

"Its financial impact is not clearly positive; workflows were substantially disrupted; and the quality of the office

environment initially deteriorated greatly for staff, physicians, and patients. That said, none of us would go back to paper health records, and all of us find that the technology helps us to better meet patient expectations, expedites many tedious work processes (such as prescription writing and creation of chart notes), and creates new ways in which we can improve the health of our patients."¹⁵

Indeed, in a survey of family doctors with electronic records, 87 percent said they would not go back to paper records even if they could get their money back.¹⁶ So why are more doctors not adopting electronic record systems as the word gets around about their benefits? The principal reason is cost.

An electronic health records system typically cost between \$15,000 and \$30,000 per doctor.¹⁷ Doctors can expect to recoup only 10 percent of the savings from using electronic record systems that allow them to order prescription drugs and tests electronically.¹⁸

Though costs are coming down—a new web-based system costs only \$3,500 upfront and \$600 per month per doctor, and open source software inspired by the Linux computer operating system costs as little at \$5 per month¹⁹—converting to electronic records still has high costs in terms of workflow disruption for doctors. Considering that doctors bill hundreds of dollars per hour, anything that slows down a physician is expensive. Even if an electronic record system saves a doctor's time in the long run, any change requires a substantial upfront investment of time.

Another problem is that electronic records by themselves do not give doctors complete patient records. Just as today's paper records are scattered across many doctors and other providers, so too would a doctor's electronic records be incomplete, since there is currently no way for doctors to share electronic records

among themselves to give every physician a complete record for every patient.

Step One: Creating Independent Health Record Trusts to Spur a National Health Information Network

To use a national health information network, patients will need an EHR account to authorize the transmission of their records to and from health care professionals and health care facilities and organizations. Patients' accounts would contain a complete digital copy of their records from all sources. Physicians and other providers would continue to keep their own records and send copies to patients' EHR accounts. These accounts would be issued by independent, government-certified health record trusts that can perform administrative functions similar to the ones credit card companies perform.

Credit cards allow consumers to authorize payments on their behalf. The VISA credit card network, for example, enables individual banks and other organizations to issue credit cards while maintaining a broad network that any merchant or any consumer can use. Similarly, an EHR account would let patients control who has access to their health records. Organizations ranging from WebMD, the online health care service, to the AARP could issue health record accounts as long as they used a broad network open to any patient and any health care provider. The trusts will have a fiduciary duty to protect the interests of patients, which is the highest legal standard of responsibility for acting on behalf of another person. For example, an employee of a trust who releases a patient's information without the patient's permission could be personally fined and jailed.

Health insurance plans and employers have already begun to issue personal health records that are similar to the EHR accounts envisioned in this proposal. By next year, more than 70 million Americans will have access to a personal

health record that contains records gleaned from medical claims data.²⁰ Dossia, a collaboration of several large employers, including Intel and Wal-Mart, will begin offering employees personal health records that include data from medical testing labs, medical insurance claims, and other sources.²¹

Sens. Tom Carper (D-Del.) and George Voinovich (R-Ohio) have proposed legislation to provide federal employees with a personal health record through the Federal Employers Health Benefits program (FEHB).²² This bill would require health insurance plans that participate in the FEHB to offer their members a personal health record to use at their option. It would include clinical information from the health insurance claims submitted by providers and additional health history from patients. Representative John Porter (R-Nev.) introduced a similar bill in the U.S. House.

One potential obstacle for the personal health records offered by health plans and employers is that doctors and patients may not trust them to oversee medical records. Trust is vital because no one will participate in a network if they believe it will work against their interests. Nonetheless, the role of health plans and employers is important because they will be the first to benefit from the elimination of duplicative testing and other savings and can thus provide financing for a health information network.

The Independent Health Record Trust Act, proposed by Reps. Dennis Moore (D-Kan.), Paul Ryan (R-Wis.), and Sen. Sam Brownback (R-Kan.) solves the trust problem by calling for federally certified independent health record trusts that are accountable directly to patients.²³ Patients would choose a trust to open and maintain their EHR just as they would chose a bank to open a checking account. Trusts could compete for patients based on health care services that are related to information in patients' records. For example, a trust could alert patients with untreatable conditions to clinical trials for experimental therapies. Or they could provide patients with the latest research about their health care problems.

All trusts would be obligated to follow federal rules for handling patient records as stipulated in the Independent Health Record Trust Act. Access to a patient's records would remain under the patient's control at all times. The trust would be obligated to transmit all or portions of a patient's records electronically to any doctor the patient designates. The patient's records would be portable from trust to trust, so patients could in effect "fire" a trust and move to a different one. But patients should not be able to alter their health records; doctors would lack faith in records that patients had been able to change. Patients should instead be able to add their own notes or request corrections to their records from the original source of the information.

Health records trusts will be self-financing from the savings they generate. For example, when a trust sends a patient's EHR to an emergency room, doctors will not need to duplicate any recent lab tests because they will have all of the patient's current lab test results. This one step alone could save health insurance plans and government health care programs as much as \$60 billion annually.²⁴

Health plans and government programs will be eager to pay for the use of EHRs once the health record trusts prove their economic worth.

Given the potential for EHRs to generate savings, health record trusts will have an incentive to pay doctors to use them, driving more physicians to use EHRs to get more data. Trusts could even help finance EHR systems for doctors.²⁵

In addition to savings, EHRs will generate other benefits as doctors widely use them. They will help doctors improve the care they provide to patients. For example, when EHRs are combined with specialized computer software, doctors will have new tools to help decide if a patient has had all the appropriate tests and procedures for a given health care problem. To be sure, doctors will continue to treat each patient as a person and not as a collection of digits, but an EHR will help them make it the best care possible. One diabetes

patient whose doctor's office monitors her condition digitally says that getting an email from a nurse practitioner when her blood sugar numbers go awry is like having a "guardian angel, that's worth everything—you can't put a price on that."²⁶

With large databases of medical records held by health record trusts comes great potential for research and other uses in both the public and private sectors.²⁷ People should be able to remove their identities from their EHRs and lend the data anonymously to researchers, who would examine the information, along with the records of millions of other people, to find new ways to improve health care and lower costs. This aggregated information will have substantial economic value for both public and private purposes, but patients should have a say in the use of their information and benefit directly whenever possible.

Health record trusts would have to seek patients' permission to share their data for any purpose, including financially beneficial ones. For example, a trust could ask patients with high cholesterol to participate in program that monitors their adherence to their doctor's instructions for prescription drugs. Drug companies should be eager to pay these patients a modest amount because according to one study, two-thirds of patients with high cholesterol stop taking their medications after two years.²⁸ Such financial incentives could help a patient's health and pocketbook, but the decision to share their data and participate in such programs should be the patient's.

Step Two: Liberating Stranded Data with EHRs

To win quick, widespread adoption by patients and physicians, a national health IT strategy must meet two initial conditions. First, it must create a health information network that links every patient's record regardless of where it exists. And second, it must be easy and inexpensive for physicians to use.

Both conditions can be met by linking together existing electronic records that doctors would find useful. A lot of important patient information has already been converted into electronic form by organizations other than doctors. For example, medical testing labs and pharmacists have already converted from paper records to computers in order to make their own operations more efficient. But this patient data is isolated or "stranded." It is not widely available electronically for either patients or doctors to use.

The EHR accounts would liberate this stranded data for use by patients and the physicians they authorize to see it. As a national health information network is first getting off the ground, EHRs could contain patient information that is already in electronic form somewhere and that would be valuable to doctors during a patient's first visit with them or an emergency trip to the hospital: a list of previous diagnoses, lab results, an indication of radiological testing, hospital admissions and other treatment history, prescriptions, and vaccinations. As more information comes online, EHRs could expand to contain brief case summaries; links to imaging and scan records; non-prescription medications; and allergies. Each bit of information should include the name of health professional or associate, and their contact information. All of these disparate pieces of information are routinely exchanged today, often by patients themselves, but not in a simple, digital format.

Congress should grant all patients the right to an electronic copy of the kinds of information listed below. A patient's EHR account would then serve as the means for transmitting it all to doctors. Under the current federal law known as HIPAA (the Health Insurance Portability and Accountability Act), patients have a right to a copy of their records, but they generally receive those copies on paper. Digital copies of electronic information would make it much easier for patients and doctors to assemble complete

medical records and to use the information to improve care.

Health care history. Health plans do keep computerized records of the tests and procedures performed on their customers, because they have to pay the bill. But such financial records do not always show the results of such tests. Nonetheless, if doctors knew what tests and procedures had been done, they could get the results themselves and make treatment decisions based on more complete knowledge of their patients' medical history. Such information can be especially critical for patients who are lying unconscious in an emergency room.

Lab results. Clinical testing laboratories have also computerized their operations to make themselves more efficient. As a result, lab results are generally kept in an electronic format. Clinical labs have also been in the forefront of communicating electronically with doctors. For example, a large national lab, Quest Diagnostics Inc., uses the Internet to receive 40 percent of its physician orders for tests and to send back 60 percent of its test results.²⁹ If doctors could send the results directly to patients electronically, then both doctors and patients would save time and could act more quickly on the results if need be.

Prescription drugs. Pharmacy benefit managers, who process payments for most of the nation's prescription drugs bills, have digitally recorded the prescribed medications in order to process insurance claims more efficiently. But they have not made this information available to doctors. With EHRs accounts, doctors would be able to automatically check whether patients are using the prescribed drugs and prevent harmful interactions between drugs.

Vaccinations. State vaccination registries for school age children have been computerizing their records for more than a decade. But they are not designed for optimal use by health professionals who need to make sure children's vaccinations are complete. They generally require an extra effort by health professionals to gain access to the records

using a special authorization. This extra step makes it more likely that doctors will rely on the parent's memory, which may or may not be accurate. But with an EHR account, vaccination records would be readily transmitted to the treating physician with a simple authorization that works for all of a patient's data.

The idea of creating a health information network based on these kinds of existing electronic patient records has already been tested in the Seattle area. Since 2003, three hospitals with 600,000 patients and 675 doctors have been successfully using a network created by the Patient Safety Institute (PSI), a nonprofit collaboration of national patient, physician, and hospitals groups. The PSI network displays for doctors on a single computer screen most of the critical information that a doctor first needs when treating a patient. As one participating doctor said: "The PSI network is incredibly useful and time saving, especially in the ER, where you immediately need to sift through a myriad of factors and charts."³⁰ Surgeons, too, have found the system a godsend because it delivers lab test results within seconds.

The drive to use EHRs will come from patients as well as physicians. EHR accounts will give patients more convenience and control. Patients will be able to refill their prescriptions and get lab results online. Such online patient tools have proven very popular at Kaiser Permanente, the California-based HMO. With over 8 million members, Kaiser has digitized all medical records including key information about patients. In less than a year of operation, Kaiser has enrolled one out of five of its patients for online services, and the program is growing at an annual rate of 40 percent.³¹

Digital records can also help patients keep track of the care they need. They can use automated prevention schedules to receive care reminders for the services their digital records show they haven't yet received. Patients with chronic illnesses can benefit especially by getting the care they need without duplication. In addition, digital records can feed intelligent search engines for both doctors and patients

to find the latest and best scientific research on specific health problems. Having digital records can reduce the time it takes to fill out medical history forms at a doctor's office, and also reduce errors and inconsistencies. Patients seldom remember everything off the top of the head and worry about forgetting something that may turn out to be important. Relying on a patient's memory can also be wasteful. For example, anyone who shows up in an emergency room for stitches gets asked if they have had a tetanus shot during the last 10 years. Few patients remember with any certainty, so many get a duplicative shot.

Kaiser and other organizations from the U.S. Department of Veterans Affairs to the Group Health Cooperative of Puget Sound have invested heavily in information technology systems because they can capture the savings from more efficient health care delivery. These large organizations provide health care and pay the bills, so they have a strong incentive to help doctors save money. In contrast, an insurance plan that shares providers with other insurance plans would hurt itself financially by spending money on IT that benefited their competitors. But insurance plans with their own providers are less popular than insurance plans that share providers, because they limit patients' choice of doctors. That is why we cannot rely on competitive forces alone to stimulate the spread of IT in the health sector.

Step Three: Protecting Patient Privacy

The success of health information technology ultimately depends on widespread patient approval. Just as patients feel vulnerable when they are naked in an examination room, they do not want their health information to be available to prying eyes. When patients do not have control over who can see their personal health records, they will try to withdraw from the system and there will be a political backlash.

Patients will balance the risks of losing privacy with the benefits of health IT, but the risks will only increase over time as medical science advances its understanding of disease especially genetic causes, which will require genetic profiles to become part of EHRs.

Patient-controlled EHRs would give consumers privacy protections in the following ways:

1. Participation would be voluntary.
2. Patients would control access to their electronic records.
3. Patients would control particularly sensitive segments of their records, so they are not shared in the same manner as the rest of the health record.
4. Health record trusts would provide patients lists of everyone who has had access to their records.
5. No one with access to a patient's records could re-release the information without patient permission.
6. Employers would not have access to patient records.
7. Security breaches would have to be disclosed to patients.³²

These privacy protections are included in the Moore-Brownback legislation and would be much tighter than the protections offered under HIPAA, which has many gaps in privacy protection that will grow ever larger as health information technology becomes prevalent. The most significant gap is the failure to require patients' permission when providers share their health records. This basic principle, which dates back to the Hippocratic oath from ancient Greece, remains a key ethic for medical professionals because it enables patients to confide in their doctors. It is also the basis for medical privacy laws in many states. The HIPAA requires that providers only offer patients a disclosure statement about privacy rights, which patients can sign to acknowledge they received it. Under HIPAA, doctors, hospitals, health insurance plans, and companies that work with providers and plans can see personal medical

information without patients' permission. With paper records, the number of people with access to personal medical information is self-limiting, but with electronic records, access is virtually limitless.

Some providers are concerned about the extra work involved in getting patient permission to share records, but with an EHR, granting permission can be as simple as clicking a button on a computer screen, pressing a number on a telephone keypad, or checking a box on the existing HIPAA disclosure form. The vast majority of patients agree to let providers share personal health information when asked clearly and directly, according to work done by the PSI and others.

An EHR account would make the adoption of these rules relatively straightforward. A patient's privacy preferences would be coded into the EHR as a kind of traffic light that would signal green or red according to the patient's preferences about who should be able to access their personal medical information. Patients could authorize some or all of their information for sharing and could limit the use of their information to one-time or continuous use. No personal information could flow through a health record trust until a patient set up an EHR account.

The Moore-Brownback bill does not attempt to plug all the privacy protection gaps in HIPAA, but it will have a profound effect over time. For example, doctors will continue to have their own records that could be shared without patient permission because they fall under the jurisdiction of HIPAA and not the Moore-Brownback bill. But once a patient signs up for an EHR account, any information that flows out of a patient's account would remain under a patient's control. As more patients signed up for EHR accounts and more health information

flowed through them, the stronger privacy protection under the Moore-Brownback bill would supersede the weaker HIPAA protections. The Moore-Brownback bill would create national standards for privacy protection because its standards would preempt and supersede state laws.

To fully protect patients' privacy, however, Congress will have to amend HIPAA. Once health record trusts are established and EHR accounts are widely available, Congress should give patients the same privacy protections under HIPAA as they will enjoy through their EHR accounts. In the meantime, Congress should give patients the right to limit the health information that providers disclose without their permission. Currently under HIPAA, patients have a right to request that providers not disclose their information, but HIPAA does not require providers to comply with patients' requests. Patients should be able to vote with their feet for better privacy protection.³³

A surprising political hurdle for privacy protection is the abortion issue. Anti-abortion forces are afraid that giving patients control over releasing personal medical information will gut state laws that require parents to be notified when minors seek abortions. Pro-choice forces are against a compromise that would preserve parental notification laws in the states because they believe these laws put underage victims of sexual abuse and incest at risk for retribution by adult perpetrators. Generally, parents should be involved in their children's medical care and have access to their medical records. In cases of suspected incest or child abuse, however, parents should not be able to control their children's access to health care. In any case, privacy protection and promoting health information technology are simply too important to be sidetracked by ancillary issues.

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