Improving Health Care: Why a Dose of IT May Be Just What the Doctor Ordered

BY DANIEL CASTRO | OCTOBER 2007

It is time to reinvigorate and renew our national strategy for improving health care through the use of electronic health records and other health IT.

Information technology (IT) is a major driver of innovation and economic growth.[1] Health IT promises to revolutionize health care by improving the quality and containing the costs of care. For the American health care system to benefit from advances in IT, it must adopt electronic health records (EHRs). An EHR[2] contains the complete medical history of a patient, including a full listing of illnesses, laboratory tests, treatments, drugs administered, and allergies.

Health IT is not just about merely digitizing medical records to create a paperless office, although doing this will achieve considerable savings—it is also about fundamentally transforming the health care system so that both doctors and patients have access to information and tools that allow them to better manage their care. This new IT-enabled model of health care has the potential to improve preventive health care and chronic disease management and reward medical practices with financial incentives for effective and efficient care. It has the potential to give health care researchers the data they need to identify and deliver best practice care and continuously improve the quality of health care. Finally, health IT has the potential to empower consumers to better understand and manage their own health care conditions, needs, and treatments.

Recognizing the importance of IT to health care, President Bush issued an executive order in 2004 calling for the rapid deployment of a nationwide interoperable health information technology network, including EHRs for all Americans, within 10 years. The U.S. Department of Health and Human Services (HHS) has led this effort. Unfortunately, the results of the national health information network initiative to date have been disappointing. So far, for example, HHS has not established comprehensive standards for the network.

The strategy of building the network from the bottom up by establishing many regional health information organizations (RHIOs) throughout the country is not working. More than 100 RHIOs have been established across the country, but the majority are financially unsus-

tainable.[3] In the absence of clear national standards for sharing medical data, achieving system interoperability for RHIOs has been difficult.

Many medical practices are choosing to wait on the sidelines until national standards for EHRs emerge. Moreover, in part because most of the benefits of health IT accrue largely to parties other than health care providers, there is no convincing value proposition to encourage providers to make long-term investments in EHRs. In addition, medical privacy advocates have objected to efforts to move to EHRs, because they are concerned that existing privacy protections for patients are insufficient.

It is time to reinvigorate and renew our national strategy for improving health care through the use of EHRs and other health IT. Although the private sector will continue to engage in a number of projects to bring about change, the federal government also has an important role. Now is the time for action, and Congress should commit to a new strategy.

To help accelerate the transformation to an IT-enabled health care system, we propose that Congress take the following steps:

- **Pass legislation to promote the use of electronic health records and national health data standards.**

- **Create a legal framework for health record data banks.**

- **Leverage federal resources to ensure access to health record data banks.**

- **Require medical practices to disclose patient health information electronically upon request.**

HEALTH CARE IN AMERICA
The American health care system has some of the world's best doctors, hospitals, and medical research facilities, and there is no question that top quality medical care is available to those who can afford it. Nevertheless, our health care system also has many problems, including costly and inefficient health care, improper or inadequate care, inequitable access to care, and difficulty obtaining complete medical records.

With health expenditures of $2.0 trillion per year,[4] the United States spends more on health care than any other nation.[5] Sixteen percent of our gross domestic product is spent on health care, translating to approximately $6,697 per capita. Yet for all this spending, in 2000, the World Health Organization ranked the health care system in the United States as 37th in overall performance.[6]

Many factors contribute to our low ranking in health care. Unhealthy lifestyle choices such as poor diet, physical inactivity, and carrying excess weight contribute to the high cost of health care and morbidity rates. Currently, for example, nearly two-thirds of all U.S. adults are overweight.[7] One study estimates that reducing obesity rates could generate productivity gains of $254 billion and save $60 billion in direct health care spending.[8] Another problem is that many people do not have access to affordable health care. Almost 47 million Americans, or 16 percent of the U.S. population, do not have medical insurance.[9]

Quality of care issues also plague our current health care system. Some individuals do not receive the proper amount of care.[10] Those who receive too much care or the wrong kind of care waste resources, while those who receive insufficient care may develop additional health problems. In many instances, the health care that people receive is not based on the best available scientific evidence. A study in 2007 found that children receive the recommended care less than half the time.[11] A related problem is patient safety.[12] In 1999, a study by the Institute of Medicine estimated that between 44,000 to 98,000 people die every year as a result of medical errors.[13] This statistic has since been disputed,[14,15] but there is little question that more progress is needed to improve patient safety.[16]

Furthermore, many individuals with chronic illnesses do not receive adequate or proper care in the current health care system. Chronic conditions are those that "last a year or longer, limit what one can do, and/or may require ongoing medical care." [17] More than 125 million Americans have a chronic illness and more than 88 percent of the population aged 65 years and older has at least one chronic condition.[18] As the population ages, this number will continue to rise. Care

for chronic conditions differs substantially from care for acute illnesses or infectious diseases. Furthermore, chronic conditions are the leading cause of death and disability, accounting for 70 percent of all deaths in the United States.[19] Poorly managed chronic illnesses such as cancer, heart disease, or diabetes lead to unnecessary suffering on the part of patients, as well as to inefficient uses of the health care system. Approximately 75 percent of all U.S. health care spending is for the treatment of chronic conditions.

Access to medical record information is also problematic under the current health care system. Many Americans see multiple health care providers—the average Medicare beneficiary, for example, sees seven different physicians each year[20]—and their health care records are fragmented. The fact that consumers do not have a single, consolidated health care record makes it difficult for patients to participate in managing their own health care. It also means that many health care providers have incomplete information when they treat their patients. For health care providers, this lack of information sometimes results in medical errors. Incomplete patient information about allergies or other drug usage, for example, sometimes results in medication errors.[21]

Finally, the practice of medicine is still based in part on expert judgment rather than on evidence-based medicine. It is often difficult for doctors to know what the best standard of treatment is, particularly as new research comes forward. Moreover, the lack of data on treatment results makes it difficult for providers to determine which treatments deliver the best results and are most cost-effective.[22]

BENEFITS OF HEALTH IT

Information technology (IT) has transformed industries such as finance, retail, and telecommunications by enabling greater efficiency, better performance, and more consumer choice. Unfortunately, the potential benefits of IT have yet to be realized in the U.S. health care sector. Health care providers have lagged in their adoption of electronic health records (EHRs) and other health IT, even though many studies have demonstrated that health IT offers societal benefits such as increases in efficiency and health care quality. Furthermore, the lack of interoperability between EHR

databases has minimized the potential benefits of IT for early adopters of the technology.

One area where the health care industry has successfully implemented IT is in electronic claims processing. Currently, the majority of medical practices use IT for electronic claims processing. Title II of the Health Insurance Portability and Accountability Act (HIPAA) required the U.S. Department of Health and Human Services (HHS) to establish national standards for transmitting electronic health care data and national identifiers for providers, health plans, and employers. The successful transition from paper-based claims processing to electronic claims processing illustrates the potential for improving other health care business processes. A survey in 2006 found that 75 percent of claims were received electronically, compared with 44 percent in 2002.[23] Electronic claims processing resulted in greater efficiency and lower costs. Health insurance plans processed 98 percent of claims within 30 days in 2006, up from 94 percent in 2002.[24] The average cost to process a "clean claim" received on paper is $1.58 versus only $0.85 for a comparable electronic claim.[25]

Researchers estimate, for example, that the annual savings from health IT could average almost $81 billion over 15 years.

Unfortunately, the medical community has not implemented EHRs at anywhere near the same pace as it has implemented electronic claims processing. Estimates show that only 25 percent of doctors use some form of EHRs, but less than 10 percent of doctors use a "'fully operational' system that 'collects patient information, displays test results, allows providers to enter medical orders and prescriptions, and helps doctors make treatment decisions.'"[26] There are no reliable estimates on the adoption rates of EHRs in hospitals, but some researchers estimate that only 5 percent of hospitals have fully implemented a computerized physician order entry system, a key tool used to improve patient safety.[27]

Although EHRs are by no means universal, a growing body of evidence summarized below shows that interoperable EHRs and other health IT will reduce health care costs, improve the quality of care, and give

consumers more access to their personal health information and more control over their treatment options.

Reduced Medical Costs

One reason EHRs and other health IT initiatives have received widespread bipartisan support is that they promise to reduce future U.S. health care costs. Estimates of the societal cost savings vary, but most studies show the benefits of implementing health IT greatly exceed the costs. RAND researchers estimate, for example, that the annual savings from health IT could average almost $81 billion over 15 years.[28] Other researchers have estimated national savings of $78 billion per year.[29]

Much of the estimated national savings comes from increases in efficiency such as shorter hospital stays because of better coordination, better productivity for nurses, and more efficient drug utilization.[30] In addition, EHRs provide doctors with more complete information about their patients, which reduces the need for duplicative and unnecessary medical tests. RAND predicts that implementation of EHRs by all medical practices would cost approximately $8 billion per year over 15 years. Thus, the rewards from investing in EHRs would far outweigh the costs.

Investments in health IT such as clinical decision support systems (CDSS) also have the potential to improve care and reduce costs by increasing patient safety. CDSS, which include automated diagnostic programs, computerized test result interpretations, and drug management systems,[31] provide health care workers with real-time information to aid with treatment and reduce medical errors. EHRs feed CDSS the medical data they need to deliver timely and accurate results. Thus, for example, an EHR could provide a comprehensive record of a patient's allergies and medications history, which a CDSS could then analyze to detect known problems, thereby reducing harmful and costly medical errors. Adverse drug events account for 19 percent of injuries in hospitalized patients in the United States and cost hospitals alone over $2 billion per year, not including malpractice costs or the costs of injuries to patients.[32] One study found that health IT could eliminate around 200,000 adverse drug events at a national savings of $1 billion annually.[33]

In addition to using EHRs and CDSS to improve patient safety, hospitals can use health IT in the form of operational decision support systems to analyze clinical and financial information. Operational decision support systems can be used, for example, to evaluate resource utilization levels, component costs, and clinician performance.[34] Operational decision support systems that support administrative decisionmaking can help to ensure higher levels of efficiency and improved business processes.[35] Hospitals and other health care providers can use health IT to increase operational efficiency. Some hospitals, for example, have implemented self-service kiosks for patient registration and providing copayments, thereby reducing patient wait times and decreasing staff utilization.[36] Similarly, hospitals that use telemedicine for patients with chronic diseases generated significant cost savings.[37] This type of automation also generates substantial monetary and time savings for patients, who benefit from more efficient health care encounters.

Improved Medical Care

EHRs are a prerequisite to using health IT to improve health care. EHRs ensure that medical data are available, organized, and legible. They also provide health care providers with real-time access to their patients' health records. Moreover, EHRs can help improve medical care by making it easier for doctors to provide evidence-based medicine. Evidence-based medicine is the use of treatments deemed to be the best practice for a certain population, based on the evidence of expected benefits and risks. Without sufficient data, health care providers lack the knowledge necessary to effectively apply evidence-based medicine.[38] CDSS use information from EHRs to help doctors improve medical care by increasing patient safety.

The spread of EHRs is a classic example of a network effect, where the value of a product to one individual depends on the number of customers already using that product. Health care providers, researchers, and consumers will reap the greatest benefits from EHRs once EHRs have been widely adopted. At that point, EHRs will improve the quality and quantity of information available to medical researchers and public health officials. In addition, health care providers will be able to use rapid learning systems to develop new

clinical evidence from the data in EHRs, which can then be applied immediately to improve medical care. Physicians will be able to spot dangerous drugs and problems such as those that emerged with Vioxx more quickly.[39] EHRs will also yield information that can help in evaluating the effectiveness of various treatment protocols, especially for specific patient populations. Health care providers will be able to use this information to improve evidence-based medicine available to all patients. Public health officials will be able to use information from EHRs to identify possible outbreaks of infectious diseases and monitor treatment efforts.

The goal of these applications is to give consumers the tools they need to manage their health information online as easily as they can manage their finances.

EHRs also promise to help improve Americans' health by providing opportunities for improved approaches to disease prevention and chronic disease management. Health care providers and health plan issuers can use factors identified in patients' EHRs to automatically target specific high-risk patients for disease prevention programs. Thus, for example, a health care provider might automatically e-mail educational material on nutrition to any patients who become overweight. Alternatively, a health care provider might wish to automatically alert a set of patients identified using factors in their EHRs about the availability of new preventive services, such as vaccinations and screenings.[40] In addition, EHRs can allow doctors to easily and efficiently inform their patients of new medical research as it becomes available.

EHRs can also make it easier for patients with chronic conditions to take an active role in their health care and routinely monitor their symptoms and treatment. One reason that some individual are not more actively involved in managing their own health care is that they have bought into the idea of the doctor as the expert where "the doctor knows best." EHRs, specifically when coupled with secure web portals, help give patients a stronger sense that they have control of and responsibility for their own care. Certain EHR appli-

cations allow patients to track health markers such as their blood pressure, cholesterol, and body mass index to see how it changes over time and how they compare to "healthy" levels. Thus, patients can use medical home monitoring devices to track and compare their health between office visits.

Health care providers can also use EHRs to improve care to patients with chronic diseases by offering services such as remote vital-sign monitoring, automated appointment scheduling, and medication reminders. By combining continuous monitoring with remote health monitoring, health care providers can identify potential problems and recommend preventive treatment. Medtronic, for example, currently produces a number of implantable cardiac resynchronization therapy and defibrillator (CRT-D) devices that support remote monitoring.[41] Using a wireless data reader that connects to standard telephones, patients can securely transmit the medical data recorded by these medical devices to their health care provider. Their physicians can then review the patients' health information remotely, thereby reducing the number of office checkups. Remote monitoring also gives patients more flexibility to travel because their physicians can access their health information when they are away from home.

New applications of remote monitoring will likely build on existing devices that provide continuous health monitoring. Currently, for example, there are several devices on the market that permit continuous monitoring of glucose levels in patients with diabetes. The traditional approach to monitoring blood glucose levels, using finger sticks, provides only a few data points. Continuous monitoring allows diabetic patients and doctors to track the patients' glycemic patterns over time and also helps patients better understand the effect of certain behaviors on their glucose level.[42]

Increased Patient Access to Personal Health Information
Unlike paper medical records which most patients never see, EHRs provide individuals with ready access to their personal health information. Comprehensive EHRs reduce paperwork and enable patients to view a consolidated record of their entire medical history, including health information from different sources. With information in electronic form, consumers can

access their critical medical information even in emergencies such as natural disasters or illnesses while traveling. Because they can easily access their EHRs, they can review them for accuracy and take steps to correct errors.

Many Americans have multiple doctors, each with his or her own specialty.[43] Interoperable EHRs ensure that when patients see a new doctor, they can provide their full medical history to that physician. The ability to supply such information will also help individuals with employer-provided health insurance who must switch doctors when they change jobs. The average American worker will have held 10 jobs between the ages of 18 and 40.[44]

The health care industry can potentially use EHRs to provide consumers more detailed information on the cost and effectiveness of various treatments. These data will allow consumers to make better judgments on the value of their treatment options and reward quality care. Patients can use better data on infection rates and complication rates, for example, to make more informed decisions about their own health care treatments. Some people, such as Andrew L. Stern, president of the Service Employees International Union, have expressed doubts that the average American has the capacity and interest to analyze this information,[45] but such doubts are not supported by the facts.

A survey in 2005 found that 80 percent of Internet users have looked for health information online.[46] In addition, many online applications, including WebMD, Revolution Health, and Microsoft HealthVault, have emerged to allow consumers to track and analyze their personal health information. The goal of these applications is to give consumers the tools they need to manage their health information online as easily as they can manage their finances. Thus, for example, secure web portals will allow consumers to book their doctors' appointments online, make copayments, get insurance reimbursements, and get their prescriptions filled. Consumer demand for EHRs is growing, and many people have embraced the technology when it is available. One of the leading EHR software companies reports that its product is used by more than 58 million people, mostly in large multi-specialty practices.[47]

One of the nation's leading EHR systems has been implemented by Kaiser Permanente, the nation's largest not-for-profit health plan. This system, called KP HealthConnect, allows patients and providers instant access to their medical information. Physicians use the system to place orders, review laboratory results, and access their patients' medical histories. Health plan members access the information using a secure web portal that allows them to review laboratory results and office visits, as well as to communicate with their providers. As of mid-2007, 1.4 million Kaiser Permanente members had signed up for online access.[48] One study found that after introducing EHRs, Kaiser Permanente reduced visits to primary and specialist outpatient care by 5 to 9 percent.[49] Another study found that annual adult primary care visits decreased between 7 to 10 percent among patients who communicated with their providers electronically.[50] Kaiser Permanente intends to deploy additional functionality to the web portal in the future to allow health plan members to make copayments and schedule their appointments online.[51]

Kaiser Permanente serves a dual role as health care provider and insurer that gives it a stronger incentive to invest in health IT than some other entities and allows it more easily to implement and benefit from IT investments than some other entities. Nevertheless, KP HealthConnect demonstrates the potential for EHRs to improve health care for both consumers and health care providers.

OBSTACLES TO HEALTH IT ADOPTION

Given all of the potential benefits of EHRs and other health IT, it is perhaps surprising that the rates of EHR adoption and use in the United States are not higher. Three major obstacles have delayed the widespread adoption of EHRs: the asymmetrical relationship between the costs and benefits of adopting EHRs, the absence of a national standard and consensus for interoperability requirements, and concerns about the security and privacy of personal health information. Fortunately, all of these major obstacles can be addressed through improved federal policies.

Asymmetry of Costs and Benefits Associated with EHRs

The asymmetrical relationship between the costs and benefits of adopting EHRs, coupled with the general lack of competition in the health care marketplace, has reduced the incentive for health care providers to invest in the needed IT systems. A 2006 survey found that 94 percent of hospitals considered the initial cost of EHR adoption as a "significant barrier or somewhat of a barrier." In addition, hospitals reported ongoing cost as the second greatest barrier to health IT adoption.[52] From the standpoint of medical practices, especially solo or small group practices where more than two-thirds of U.S. physicians work, cost is an even bigger issue.

Although the net social benefit of investing in EHRs is positive, the return on investment for individual medical practices is less certain. One of the biggest problems is that medical practices incur most of the costs of adopting EHRs, but health insurers and patients receive most of the benefits. One industry observer estimates that medical practices "bear 80 percent or more of cost and cultural change burden, but payers get 80 percent or more of the savings."[53] Another estimate is that physicians receive only 11 percent of the financial savings, with the rest going to "insurers, laboratories, and patients."[54] This asymmetry of risk and reward makes it difficult for many medical practices to justify an investment in EHRs, where they are slow to reap the benefits.

Solo and small group medical practices have been slower to adopt EHRs than large practices. Adopting EHRs requires a substantial initial expenditure for equipment, software, installation, and training. One study found the average cost of initially implementing EHRs was approximately $33,000 per physician.[55] Medical practices paid on average an additional $1,500 per month per physician for maintenance costs.[56] Often these capital expenses come directly from the physician's take-home pay, because most practices do not have retained earnings to cover these types of expenses.[57] Apart from bearing such costs, medical practices must integrate EHRs into their workflow so they can benefit from the technology. The process of adapting workflow is often difficult. Some health care workers resist using the new technology, and productivity can suffer during the transition period. One study found

that physicians lost 10 to 15 percent productivity for the first few months after implementing EHRs.[58] Even with such costs, one study found that the average medical practice generated enough benefits from adopting EHRs to pay for its investment after 2½ years.[59] On the other hand, some practices did not fare nearly as well.

For solo and small medical practices in particular, investing in EHRs is a risky proposition, because such practices face the possibility that the benefits of adoption will not cover the cost of implementation or that the initial costs will jeopardize the practice's financial solvency. Many medical practices lack managers with the skills and experience necessary to make strategic investments in health care IT. One study found that the costs involved with deploying EHRs was heavily influenced by the negotiating and technical skills of the employee charged with implementing EHRs, typically a physician or office manager.[60] Similarly, the amount of benefits accrued by an office after adopting EHRs depended on the business and technical skills of that same employee.

Many early initiatives by hospitals reflected a naïve vision of how IT should be integrated into their workflow processes. In many cases, hospitals began developing IT systems without defining clear strategic goals and metrics for measuring performance.[61] IT systems are not simply "plug-and-play" products and hospitals must consider the extensive training, support and workflow process development that need to accompany these investments.[62] As a result, hospitals have wasted millions of dollars on health IT systems that failed to generate cost-saving benefits. The Cedars-Sinai Medical Center, for example, spent $34 million to develop its own in-house computerized physician order entry system that ultimately had to be shelved after a few months of use because clinicians found it to be too cumbersome.[63]

The average cost per physician of adopting EHRs is higher for solo and small practices than for large practices. Larger practices can reduce the average cost of expenditures for hardware, software, and training by spreading them across multiple doctors. Similarly, hospitals have the potential to achieve greater benefits from EHRs by taking advantage of economies of scale.

Unfortunately, with two-thirds of U.S. physicians working in solo or small group practices, the barriers to the adoption of EHRs for small group practices are a major impediment to the transformation to an IT-enabled health care system.[64] Eventually, some of the smaller medical practices may consolidate into larger practices to take advantage of the cost savings.

Lack of National Interoperability Standards

The absence of national standards for interoperability and the exchange of health information has hindered the development of a national health information network. Interoperability is necessary for medical data to be exchanged between health care systems. Medical information must be shared between multiple entities including hospitals, clinics, laboratories, pharmacies, insurers, and patients. The development of standards such as HTML for web pages and SMTP for e-mail, for example, facilitated the growth of the Internet. These standards run at the application layer of the computer, so they can work on any operating system or hardware. The same level of standardization is needed to allow interoperability and the exchange of health information.

Medical data is complex and requires precision. Health records must use a standard health vocabulary to ensure consistency and interoperability. National standards for record structures, data formats, and protocols used to exchange information are a critical prerequisite to the development of interoperable EHRs. Various standards development organizations have emerged to classify and organize health information, but national standards have yet to emerge.[65]

Currently, many individuals' medical records are fragmented into multiple, disparate systems. Thus, for example, a patient's lab reports may be stored in one system, diagnostic images in another, and observation notes in a paper file. Interoperability standards that allow the exchange of health information will give patients and their health care providers better access to such information. It will also enable patients to transfer their medical data to a new doctor or share their information with all of their health care providers. In addition to making sure that new systems comply with health IT standards, it will be essential to ensure that proprietary legacy applications are updated to support interoperability.[66]

Few economic incentives exist to promote interoperability. The benefits of interoperability are spread over many stakeholders in the U.S. health care system. The adoption and implementation of standards-based, integrated, and interoperable EHR systems, for example, has the potential to benefit society by facilitating public health monitoring and medical studies.[67] Despite such benefits, some health IT companies are reluctant to adopt open standards, because they rely on the lack of interoperability to retain customers. In addition, as a result of the network effects of interoperability, there are first-mover disadvantages with respect to adopting interoperable data standards.[68] In fact, 79 percent of hospitals reported that interoperability issues with current systems are a "significant barrier or somewhat of a barrier" to health IT adoption.[69]

Fears About the Privacy and Security of Personal Health Information

Many medical privacy advocates object to implementing EHRs because they have concerns about the security and privacy of personal health information. Health care providers own and manage the medical records they create, so patients expect their providers to enact appropriate safeguards to protect the privacy of their personal health information. Current polls indicate that 70 percent of U.S. adults "are generally satisfied with the way doctors and hospitals handle personal health information in terms of protecting its confidentiality and security."[70] Similarly, a majority of people believe that the increased use of EHRs can be accomplished without harming patient privacy.

On the other hand, approximately one-quarter of U.S. adults do not believe that the move to increased use of EHRs can occur without tradeoffs in privacy.[71] The belief that EHRs may compromise patient privacy is in part a perceptual issue, as studies have shown that EHRs are as secure, if not more secure, than paper-based records.[72]

Many medical privacy advocates have indicated that they will continue to resist the adoption of EHRs until Congress strengthens medical privacy rights for pa-

tients and restrictions on the use of medical data by health care providers. As noted earlier, the Health Insurance Portability and Accountability Act (HIPAA) required HHS to establish national standards for transmitting electronic health care data and national identifiers for providers, health plans, and employers. The HIPAA privacy rule sets a federal minimum standard of medical privacy for personal health information. Under this rule, patients have the right to access their medical records, to dispute inaccuracies in their medical records and note any disagreements, and to request a disclosure accounting of who has accessed their records. The HIPAA privacy rule also imposes a number of restrictions on health care providers. One is that health care providers give patients notice of their privacy practices. Another is that health care providers train employees and implement data safeguards to protect private medical information. HIPAA sets additional limits on the use and disclosure of health information. Finally, it creates both civil and criminal penalties for violations of a patient's privacy.

The adoption of a federal privacy standard that preempted complex and competing state regulations would ensure all Americans had equal protection for their health information.

The enactment of HIPAA marked a major step forward in protecting the privacy of personal health information, but some medical privacy and patient advocates believe that HIPAA law and regulations did not go far enough. They note, for example, that the HIPAA privacy rule does not apply to certain entities that may have personal health information. The rule does not apply to health care providers who do not submit electronic insurance claims, a shrinking percentage of providers. The rule may not apply to other entities that have access to health information, including certain group health plans, employers, and insurers.[73] The rule also does not apply to many web-based health services, such as web sites providing information about health conditions and treatments, online mental health counseling sites, and web sites selling nonprescription drugs.[74] Such web sites are opt-in services, though, and consumers can make decisions about whether to use

these products based on the web sites' stated privacy policies.

In addition, some medical privacy and patient advocates object to HIPAA's language authorizing entities to use and disclose "protected health information for treatment, payment, and health care operations."[75] They believe that there should be more restrictive language that would require the patient's consent for the disclosure of information. Some privacy advocates also object to the fact that HIPAA allows health care providers, under certain conditions, to disclose private medical information for public health and research purposes without the patient's consent. Some advocates even object to researchers sharing such information when the data are stripped of personally identifiable information.

Policymakers should recognize that such objections are not objections to EHRs per se but to existing regulations governing the privacy of health records generally. Medical privacy and patient advocates want to increase patients' control over the disclosure and use of their personal health information regardless of what form the information is in. Still, federal privacy regulations do influence efforts to develop an interoperable national health information network. The HIPAA privacy rule establishes a national baseline for a medical privacy right, but states can impose additional restrictions to ensure the privacy of health records. This situation has led to a patchwork of differing state policies, which makes building a national health information network difficult. Currently, for example, health information systems must be customized to meet the privacy requirements of each state.[76] The lack of uniformity in state requirements reduces the interstate portability of EHRs.

The adoption of a federal privacy standard that preempted complex and competing state regulations would ensure all Americans had equal protection for their health information. It would also ensure interstate portability of EHRs. One additional way to address privacy concerns might be to strengthen laws that prevent discrimination on the basis of personal health information. Such laws could help ensure that privacy risks remain low and concerns about privacy

do not impede the progress of health IT and its life-saving and cost-saving benefits.

WHY A NEW FEDERAL DIRECTION IS NEEDED

Most people agree on the goal of creating a national health information network in which all Americans have EHRs by 2014, but progress toward this goal has been slow. Thus, a new strategy to develop an IT-enabled national health information network is needed. As discussed below, the three competing models for the proposed network are (1) a distributed health information system, (2) a centralized health information system, and (3) a hybrid known as health record data banks (or independent health record trusts).[77, 78]

Distributed Health Information Systems

One model for an IT-enabled national health information system is a distributed, peer-to-peer model. In a distributed health information system, no data provider maintains a complete medical record of any patient. Each data provider—hospital, clinic, laboratory, or insurer—maintains its own database of health information. Thus, each provider must be able to interface with every other provider to exchange information. Patients and providers use a single user interface to access information from each data source and to construct a virtual health record.

Many proponents of RHIOs advocated a distributed network topology. The Markle Foundation, for example, recommended building a national health information network incrementally by developing a non-proprietary, interoperable, standards-based "network of networks."[79] The idea was that there would be no national health ID or a central repository for patient medical records; rather the national health information network would be a distributed system that would facilitate the identification and exchange of patient health information, with appropriate authorization, in a private and secure way. RHIOs were supposed to lay the foundation for a national health information network by allowing communities to develop their own interoperable health networks and EHRs. Unfortunately, as discussed below, the strategy of building the network from the bottom up by establishing many RHIOs throughout the country is not working.

One drawback of a distributed health information system is that such a system can be technically difficult to build and manage. One major technical challenge, for example, is searching for data from multiple, heterogeneous databases. A distributed health information system requires the extensive use of middleware—that is, software used to interface between incompatible databases and data formats. Another technical challenge in a distributed system is identifying patients correctly. If there are two John Q. Smiths living in the same region, for example, a computer system may have a difficult time matching records; similarly it may have trouble verifying that the records for John Smith and John Q. Smith belong to the same person. A record locator service must be used to ensure patient records are correctly matched from each database. Yet another technical challenge is to ensure that each data provider's database provides an acceptable response time. In addition, developers must work with data providers to ensure a harmonious data retention policy.

In recent years, coalitions of hospitals, insurers, vendors, and nonprofits have sponsored and made valiant efforts to develop RHIOs. Despite this enthusiasm, few RHIOs have succeeded in establishing a sustainable business model. More than 100 RHIO initiatives have begun in the United States, but most rely on seed funding and support from grants. One study found that only seven RHIOs were considered "operational,"[80] and another study found only two RHIOs were self-sustaining.[81]

The failure and lack of sustainability of RHIOs suggest that HHS is not on track to meet the goal of having a national health information network established by 2014. Thus, it is important to understand the technical and other challenges that led to the setbacks and failures experienced by RHIOs built using this model and to adopt a new national strategy that can overcome these challenges.

One of the more prominent RHIOs that failed was the Santa Barbara County Care Data Exchange, which eventually served as a model for many RHIOs across the country. The Santa Barbara project, which was begun in 1998, was proposed and designed by David Brailer, CEO of CareScience, who later became the

first National Coordinator for Health Information Technology at HHS. The Santa Barbara County Care Data Exchange was intended to be a secure regional network for electronically sharing health care data among hospitals, physicians, and other providers at the point of care. In 2006, after a number of setbacks, including Brailer's departure from the project in 2002, the board decided the project was unsustainable and voted to shut it down.[82] The project ceased operations on December 31, 2006.

Observers have attributed the collapse of the Santa Barbara County Care Data Exchange to a number of factors, including poor project management, software issues, and the lack of a compelling business case. In its initial proposal, CareScience, the company chosen to run the program management office, stated that existing commercial off-the-shelf products could deliver all of the needed functionality. After the project began, though, CareScience found that existing software was insufficient to enable interoperability between legacy health information systems.[83] As a result, CareScience took on the role of software developer. This move limited independent project oversight, because that company also operated the program management office. Furthermore, Brailer criticized the project management (including himself) for focusing on delivering the latest technology rather than on addressing users' needs.[84]

The Santa Barbara project also failed to establish a business model that appealed to the providers. Although nobody questioned the net societal value of establishing a health information exchange, the lack of a convincing value proposition for providers made many participants passive, unenthusiastic, and little invested in the project's success. Critics have blamed this result on the easy access to grant money, which enticed health care providers to participate regardless of their interest level and tolerance for risk. When the grant money ran out, these providers were unwilling to continue the project on their own given the uncertain economic benefits.[85]

To be fair, the Santa Barbara County Care Data Exchange provided many useful lessons to the health care community, and Brailer has defended the effort as a constructive experiment.[86] Unfortunately, though, it is hard to see how the lessoned learned from the Santa Barbara project have been applied to the national health IT policy. The federal effort to building a national health information network continues to focus on a bottom-up approach in an attempt to allow community control. One problem is that consumers are unable to influence these regional projects through traditional market forces. Although RHIOs are developed at the community level, RHIOs are by definition regional, so they have very little competition, and consumers have few alternatives if they dislike the quality of service offered by the RHIO. Moreover, federal policy has not sufficiently addressed the three main failures of RHIOs: the lack of a convincing value proposition, the technical difficulties of searching for data from multiple, heterogeneous databases, and the lack of portability for health information when consumers move outside the system and have to join a different RHIO.

Centralized Health Information Systems

In a centralized health information system, all data on a particular patient are stored in a single centralized database. Technically, this model is simpler to develop than a distributed model. Health care providers populate the central database with their patients' medical data, and developers need to create just a single interface for this database. Many medical privacy and patient advocates oppose centralized health information systems, because patients have little control over who manages their personal health information. Many also object to health information networks with a single centralized system that patients are forced to use.

A centralized health information system works well in a single-payer health care system like the United Kingdom because ultimately all of the health care expense data will be transmitted to a single entity. One of the few successful RHIOs, the Indiana Network for Patient Care, built its system using a centralized database that includes information from five major hospital systems, the county and state public health departments, and Indiana Medicaid and RxHub. Data streams from these health care data providers are transmitted in HL7 to one central system, which is then standardized and linked to a specific patient ID.[87] The Com-

munity Health Management Information Systems and Community Health Information Networks, popular in the 1990s, used a centralized model with a single data network and a single data repository.[88] Most of these efforts failed for a variety of reasons, including a lack of cooperation between health care providers. In a centralized model, providers fund the information network by charging participants for transactions. Many providers invested in their own information networks but were hesitant to participate in community databases for fear of losing their competitive advantage. As a result, they failed to develop a central database, so the funding models for these projects never materialized.[89]

Health Record Data Banks

The health record data bank model has recently emerged as an alternative to the distributed and centralized health information system models. In this model, multiple data banks compete to manage the EHRs of individual patients. Patients or health insurers pay health record data banks a fee to manage their electronic health information. Each patient's data is stored in a single repository maintained by the health record data bank of the patient's choosing. Patients access their EHRs through a user interface designed by their particular data bank.

Whereas the centralized model forces patients to use a single database, the data bank model gives patients a choice of data bank providers. Providers of health record data banks could conceivably include membership groups like AARP, health care providers, employers, health plans, or other trusted entities such as companies that emerge with specialized health care web portals.[90]

In the data bank model, all of a given patient's data is stored in a single bank's repository. Thus, the health record data bank's architecture eliminates many of the technical problems of compiling a virtual EHR for a patient from multiple databases in a distributed system. In a distributed system, to assemble a complete EHR for a single patient, every database that contains a piece of that record must be accessible and responsive.

In addition, health record data banks eliminate many of the interoperability problems experienced with a distributed health information system. In a distributed data sharing environment, each system must be able to interface with all other systems.[91] With N systems, this environment would require a maximum of N * (N-1) interfaces. With health record data banks, the maximum number of interfaces is only N, the number of systems.
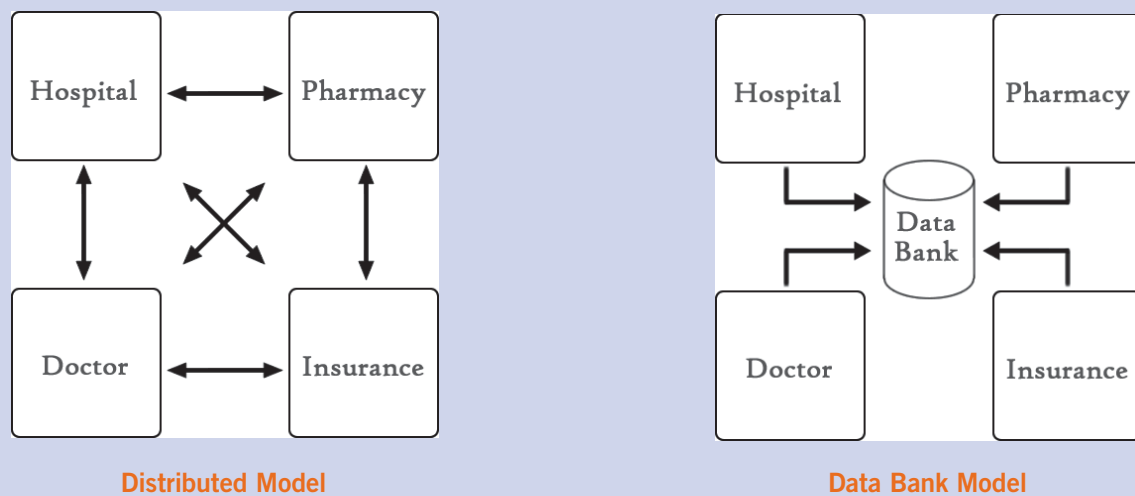

Distributed Model   **Data Bank Model**

Figure 1: Building an electronic health record in a distributed health information system versus a data bank.[92]

THE CASE FOR HEALTH RECORD DATA BANKS

Health record data banks have the potential to foster customer-driven health IT. With RHIOs or a centralized model, there are few market incentives for the participating organizations to respond to customer demands. With multiple health record data banks, though, the data custodians will have to answer directly to their customers to stay in business.

Another advantage of health data banks is that they give consumers full control and ownership of their personal health information.[93] Thus, for example, individuals can review anything from their most recent blood tests, to their immunization records, to the list of their current medications. Individuals may add personal health information to their own EHR, but they may not change any data submitted by another authorized user (such as their doctor). Any entries added to the EHR by the consumer would be labeled as such. In the event of an error in the record, consumers may request that the record be corrected or submit an amendment to any information that may be in dispute.

Health data banks also provide consumers with the tools they need to manage their EHRs. Once patients have established an EHR, they control the access rights to their EHR. Health record data banks provide the tools to allow patients to control access to their EHRs. All users must be authenticated to access the health record data bank, and every transaction is logged. At any point, patients can monitor and track who has accessed their EHRs. If patients choose to share this information with their doctor, their doctor can access in real time a complete EHR of their patient. After every office visit, the doctor submits to the patient's chosen health record data bank an electronic record of the office visit, including any clinical notes, test results, and prescriptions in a standard electronic data format.

Overcoming Existing Barriers to EHR Adoption

Health record data banks have the potential to help overcome the three main obstacles to EHR adoption—namely, cost, interoperability, and privacy concerns. As discussed earlier, many health care providers are reluctant to invest in health IT, even though the net social benefits outweigh the costs, because many of the benefits of health IT go to entities such as insurers and

consumers rather than to providers. Health record data banks fix this problem by creating a sustainable business model that encourages health care providers to participate.

If consumers or health insurers pay health record data banks a fee to manage their electronic health information, these payments would provide a steady stream of income to the health care providers to cover the cost of investing in health IT systems.[94] Health care providers who electronically transmitted their updates to a health record data bank would receive a small payment from the data bank after every health care encounter. Such providers would also benefit by simultaneously using the investment in IT to lower their costs and provide better quality care.

Consumers would benefit from being able to better manage their personal health information and being able to control access to that information.[95] A 2005 survey found that the majority of U.S. consumers were willing to pay at least $5.00 per month to have electronic medical records.[96] Health record data banks could also offer consumers the choice of using an advertisement-supported web portal to reduce or eliminate the access fee. Insurers would have an incentive to sign up their beneficiaries for EHRs because EHRs will increase efficiency and help reduce medical errors, thereby benefiting insurers.[97]

Health record data banks would simplify interoperability by storing all of an individual's medical information in a single repository. This repository allows individuals to create a single, lifetime health care record, which they can share with their health care providers. Currently, under HIPAA regulations, all health care providers must provide patients with a copy of their health records upon request. Patients can use this requirement to request copies of their medical records from all of their health care providers. Patients can choose to submit these records to the health record data bank where they can be digitized and used to create a complete electronic medical history. Looking forward, as health care providers adopt EHRs, the data they submit to a patient's EHR will be in a standardized and structured electronic format. This will ensure that patients' personal health information is interoperable with third-party applications.

Finally, health record data banks would help ensure the privacy of consumers' personal health information.[98] With health record data banks, consumers own the medical information in their health record, and the data bank operator is only the data custodian. Because consumers will own their medical records, they will be free to select the health record data bank of their choice. As there will likely be multiple health record data banks, competition between these companies will ensure the highest levels of security and privacy. Moreover, health record data bank operators, as the data custodian, will have a fiduciary responsibility to protect all of the private medical information stored in their database.

Once a patient's medical information is digitized in a usable format, the applications and possibilities for innovation are limitless.

Individuals would have full control over their personal health information in a health record data bank. Individuals could control, at a granular level, which providers access the information in their EHR, what information they can access, and under what conditions. This level of control would allow individuals to customize their EHR to adhere to the privacy policy that best fits their individual needs. In addition, individuals would be provided a complete audit log of who has accessed their EHR. With this level of transparency, individuals would be able to monitor any inappropriate or unauthorized access.

Additional Benefits of Health Record Data Banks
Congress should ensure that the health information network model encourages other desired characteristics such as competition and innovation. In addition to overcoming the current barriers preventing the widespread adoption of EHRs, health record data banks have the potential to help achieve these goals.

Health record data banks would create a competitive market for EHRs and ensure that health IT innovations are customer driven. In a health data bank model, each consumer has an EHR and owns his or her own personal medical data. Because there are multiple

health record data banks, consumers are not locked in to a specific data bank provider. If they choose, they can easily move to a new health record data bank. This competitiveness will help ensure that patients receive the tools they want so that they can effectively manage their health care data.

Health record data banks would have to compete for business, because patients would select the health record data bank they believe provides them the best quality and value. Thus, customer demand would encourage them to develop innovative interfaces and applications to help their customers more easily access and understand their personal health information. In addition, health record data banks may target niche markets. Patients wanting additional security and privacy controls, for example, could choose a health record data bank willing to provide that service.

RECOMMENDATIONS
Health IT will bring significant benefits to our health care system. The health care sector has made progress, but now is the time to commit to making the goal of building a national health information network a reality. We recommend Congress take the following steps:

Pass Legislation to Promote Electronic Health Records and National Health Data Standards
Federal leadership is needed to respond to the various challenges of promoting the widespread adoption and use of EHRs. Congress should work to pass additional legislation that supports the adoption of EHRs and national health data standards. Bills such as S. 1693, the Wired for Health Care Quality Act, introduced by Sen. Kennedy (D-MA) and Sen. Enzi (R-WY), and H.R. 3800, the "Promoting Health Information Technology Act," introduced by Rep. Eshoo (D-CA), would provide new leadership, funding, and organization at the national level to promote health IT.

Specifically, this legislation would make permanent the HHS Office of the National Coordinator for Health Information Technology, which is responsible for coordinating federal health IT initiatives, policies and investments. It would authorize funding for grants to promote the adoption of health IT, to develop and test quality measures, and to foster telemedicine. It would create the public-private Partnership for Health Care

Improvement, which would be responsible for developing and recommending national standards for the electronic exchange of health information. Finally, this legislation would extend the health information privacy requirements found in HIPAA to cover any operator of an electronic database of health information.

Create a Legal Framework for Health Record Data Banks

Congress should pass legislation supporting the creation of health record data banks.[99] H.R. 2991, the Independent Health Record Trust Act introduced by Rep. Moore (D-KS) and Rep. Ryan (R-WI), for example, would establish federally regulated health record data banks. This legislation establishes a fiduciary duty for each health record data bank to act for the benefit of its participants and prescribes penalties for a breach of these responsibilities. In addition, the bill prohibits the data bank operators from charging fees to health care providers for accessing or updating an EHR to which they have been given access. The legislation specifically states that all participation in the health record data bank is voluntary, and no entity, including employer, health insurance issuer or health care provider can compel participation.

To ensure continued innovation in applications that can add value to health record data banks, Congress should require that all health record data banks allow customers to share their EHR electronically with any third party. Health record data banks create the necessary market incentives to implement EHRs, but Congress should enact policies to ensure these data banks do not become data silos. Specifically, this requirement should specify that customers may allow third-party applications to access their health information. Patients may wish to use software programs on their home computer or online services that will help them better utilize their health information. Services may be offered by insurers, employers, or other companies investing in health IT applications. Thus, for example, patients may choose to subscribe to services that allows them to create a customized exercise program based on their fitness level or alerts them when new medical trials begin on a certain health condition. Once a patient's medical information is digitized in a usable format, the applications and possibilities for innovation are limitless.

Leverage Federal Resources to Ensure Access to Health Record Data Banks

The federal government is the single largest health care payer in the United States spending over $600 billion annually on 80 million Americans through programs such as Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP).[100] Congress should use the federal government's substantial buying power to create change by covering the monthly access fees to participate in a health record data bank to all Medicare, Medicaid, and SCHIP enrollees.

Because adopting EHRs will lead to cost savings for health care payers, in this case the federal government, this strategy will ensure an effective investment of federal health care dollars.

The strategy of leveraging federal resources has a history of success for creating dramatic change. In 2003, the Centers for Medicare and Medicaid Services began a voluntary program, the Hospital Quality Initiative, for hospitals to report quality performance information. At first, few hospitals participated. Shortly thereafter, Congress passed the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, which tied an annual 0.4 percent payment increase to participation—and now virtually every hospital reports quality performance data.[101] In addition, Congress can require that health plan issuers for federal employees include coverage to health record data banks as part of their covered services.

Require Medical Practices to Disclose Patient Health Information Electronically Upon Request

HIPAA established the right for individuals to obtain a paper copy of their health care records from their doctors. Congress should update this legislation to require doctors to provide patients with an electronic copy of their health information upon request.[102] Under the current law, health care providers can charge reasonable fees associated with the cost of copying and mailing paper health care records, but they cannot charge fees for the time spent searching for or retrieving the records.[103]

We propose establishing a threshold date after which patients will no longer be charged fees when they request electronic copies of their health records created

after this threshold date. Patients will be charged only for requests for paper records from before this date. This mandate would protect patients' right of access to their medical information while also providing an economic incentive for medical practices to move to EHRs.

CONCLUSION

EHRs and health IT hold the promise of transforming health care in America by improving quality and lowering cost. Unfortunately, progress in adopting EHRs in the United States has been slow. Thus, it is important for Congress to find new strategies to accelerate their adoption. Health record data banks are one of several strategies to overcome many of the current barriers in EHR adoption including cost, interoperability, and privacy concerns. In addition, health record data banks will eliminate the fragmentation in medical data in today's health records. Moreover, data banks will give patients more control over and access to their personal health information. Congress should act now to help accelerate the digital transformation of the American health care system.

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