Consider this irony of modern life: in a medical crisis, emergency physicians would have an easier time accessing a patient’s bank account using his or her automatic teller machine card than they would finding critical medical history using his or her medical insurance card. Medical records, including crucial electrocardiograms, drug allergies, or medical conditions, are typically stored on paper and are often inaccessible in emergencies.

The ability to access medical charts electronically, in emergency situations or in routine medical settings, has not paralleled the growth of financial networks or indeed of the Internet. Although several commercial sites are now selling space for individuals to put their medical records online and numerous institutions have local electronic medical records (EMRs) in place, most clinical records are still kept in paper charts that are stored at a single location.

The challenge of building an integrated EMR system has proved to be more than technological; 25 years of attempts to formalize the terms and concepts of medical practice has exposed some fascinating philosophical conundrums. What belongs in a medical record, and how should medical conditions or ideas be encoded? Which tasks are best performed by physicians, and which by the computer? Is it possible to encapsulate the medical encounter in digital form?

A number of centers have had local EMRs available for decades, providing evidence that thoughtfully implemented EMRs improve medical care through adjunct technology like error checking and allow easier study of trends in a clinic population. New links are being forged between individual patient data and the information in digital libraries or the tools of computerized decision support. While the potential for ease of access and error reduction seems obvious, new technologies should be held to the same standards of evidence as new treatments are. Research in this field has started to look not only at efficiency and institutional satisfaction but also at health outcomes and impact on the patient-physician relationship.

As researchers measure the gains made by using EMRs, they should also consider potential losses. Will physicians rely too heavily on the safety nets of automatic warning systems, losing the ability to think through the problem—just as many who rely on calculators cannot compute answers on their own? With full histories available at the touch of a button, will tired interns and residents cut corners, neglecting to ask their own questions? EMRs must be a tool for improving patient care rather than a crutch or a hindrance to the primary work of caring for patients.

This month, MSJAMA examines the legal, ethical, and technical challenges of EMRs. With a new generation of physicians accustomed to working with computer technology, we may see some of the promise of the past 3 decades of research in this field come to fruition in the coming years.

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Patient Participation in Electronic Medical Records

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Electronic medical records (EMRs) hold great promise for improving the practice of medicine by facilitating communication between members of the health care team. The most profound influence of EMRs may lie in their ability to encourage patients’ involvement in their own care. Potentially, patients could use EMRs to access their medical records online, learn about their health conditions, communicate with physicians, and even contribute to the chart itself. Certain hurdles to such access have yet to be overcome, such as ensuring privacy of personal medical data and determining the ways in which patients should be able to influence their charts; once these challenges are met, patients can look forward to a future of increased participation in and control over their own care.

Prior innovations in telemedicine provide the foundation for interactive EMR projects. Telemedicine uses remote transmission of video, audio, and text data to provide subspecialist care or consultation to patients who might not otherwise have access to it. In teleradiology, for example, a neuroradiologist working remotely can diagnose brain pathology by looking at a digital image.1 Telemedicine can also facilitate the practice of cardiology, orthopedics, dermatology, and psychiatry.2 Telemedicine has been used to provide medical care to underserved rural communities, disaster areas, and military operations.3

Interactive EMR builds on the telemedicine framework by making the medical chart, traditionally the province of the health care provider, a shared document that patients can access and update themselves. Numerous projects already allow patients to read specified portions of their charts online, manually enter data, and verify their medication dosages or track what doses they have taken. The Patient Clinical Information System (PATCIS) project provides patients with the ability to view laboratory results and text reports through a Web interface and to enter data such as vital signs.4 The Patient Centered Access to Secure Systems Online (PCASSO) project focuses on developing a robust security architecture for direct patient access to an EMR.5

The largest project combining telemedicine with patient access to an EMR is the Informatics for Diabetes Education And Telemedicine project (IDEATel).6 Begun in February 2000, the IDEATel project is a 4-year, $28-million randomized clinical trial designed to maximize Medicare patients’ control of their diabetes by providing them with a computerized link to their caregivers. Patients use a home telemedicine unit (HTU) that allows them to interact in multiple ways with their online charts. When patients measure blood pressure or fingerstick glucose with devices connected directly to the HTU, the results are automatically encrypted and transmitted securely over the Internet into the Columbia University Web-based Clinical Information System (WebCIS) and to customized case management software. Patients can also view and enter other data including diet, medication, and exercise information through the EMR. Patients and diabetes case managers can communicate through a secure clinical email system as well as via video-conferencing; case managers also receive alerts when patients’ transmitted values exceed set thresholds. By allowing direct patient interaction with the EMR, case managers and physicians have much more accurate and up-to-date information for managing therapy. Patients learn to monitor their own condition by receiving immediate feedback after finger sticks and comparing blood glucose values over time.

No new health care technique will be implemented unless it is demonstrated to be cost-effective, whether by improving health outcomes, or decreasing costs, or both.7 Several studies have suggested that telemedicine is able to decrease costs while maintaining quality in the management of congestive heart failure, chronic obstructive pulmonary disease, cerebral vascular accident, cancer, diabetes, and anxiety.8

Patient interaction with EMRs has the potential to reduce the frequency of clinical visits and improve health outcomes. Yet, one concern is that telemedicine interactions will replace clinical encounters, thus deteriorating the patient-physician relationship. It remains to be seen whether the face-to-face clinical encounters that supplement interactive EMR will be more productive and satisfying because of the long-term connection between physician and patient that can be provided by the EMR system.

As telemedicine becomes incorporated into chronic disease management across the United States, patient-oriented EMRs may become a part of the standard of care of outpatient management in all medical specialties. Soon, third-year clerks may spend part of their ambulatory care rotation videoconferencing with patients and reviewing EMRs with them remotely.

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My colleagues and I originally built an electronic patient record at the Beth Israel Deaconess Medical Center (BIDMC) in 1989 simply to facilitate sharing of information over geographically dispersed practice locations.1 However, the introduction of an electronic patient record has fundamentally changed the practice of medicine in ways that we never foresaw. This type of highly interactive program tailored to medical workflow improves the quality of care,2 reduces medication errors,3 saves physician and nurse time, improves resident and medical student clinical precepting,4 and supports collaboration in complex organizations.5

While the electronic patient record seems to be the holy grail of clinical computing, the idea is straightforward: take the physician’s paper chart and make it electronic. Of course, since paper records are not standardized neither are electronic records. An informal count finds more than 400 companies that claim to have such programs for physicians. Any implementation of an electronic medical record requires certain decisions about how medicine is practiced, and making such a system work is not as simple as taking a paper chart and making it electronic. For instance, can 2 people in the same office look at a patient’s chart at the same time? Is the physician part of a health system that needs to share patient records more broadly? How well can the data collected by the system support quality improvement with alerts or reminders? How do the data get into the record?

BIDMC is served by the Center for Clinical Computing (CCC) system, a mature system that began to evolve in the late 1970s to support the clinical information needs of staff and the administrative needs of the hospital.6 This system is now one of the most widely used in the United States. Physicians use the computing system to look up the results of all diagnostic studies, to send and receive electronic mail, and to perform a variety of decision support tasks, including online literature searching, computer-assisted expert consultation, and online clinical calculation.

As a part of this heavily used CCC system, in 1989 colleagues and I at the CCC developed an extensive online medical record (OMR) for use in an ambulatory primary care practice with the goals of facilitating workflow, supporting collaborative practice models, delivering clinical practice guidelines, and making the ambulatory office paperless. Clinicians interact directly with the computer system, increasing the accuracy of data capture and providing an opportunity for education, documentation, and action.

Since the system was first introduced, more than 1000 different staff physicians, nurses, resident physicians, and psychiatric social workers have entered 1278484 progress notes and 391897 medical problems and written online 1367450 prescriptions for more than 53000 patients. Clinicians have also documented health promotion and disease prevention tasks, such as recording a patient’s blood pressure. Confidence in the well-published security measures is so great that even psychiatric notes are kept online.

With such a heavily used system in place, we had the opportunity to change medical practice as McDonald8 and others have done. We developed computer programs to alert the clinician about clinical events, to help the clinician to act on the information, and to document the clinician’s response in the medical record. A nonrandomized, controlled, prospective trial performed during an 18-month period found that the presentation of a set of alerts and reminders as part of computer-based medical record resulted in significantly faster and more complete adoption of practice guidelines by a group of clinicians treating patients with human immunodeficiency virus infection.2

With fully functioning electronic patient record systems to monitor care, computers can perform many care coordination and documentation functions, freeing people to concentrate more on interpersonal interactions and provision of health care services.4,5 With shared electronic patient records, busy health care providers can collaborate and asynchronously update plans and progress; for instance, several specialists participating in the care of a patient can share medication lists, exchange notes, and alert each other to problems.

The promise of the electronic patient record is real and proven, but the reality for physicians in the United States has been largely unrealized. Perhaps the emerging generations of physicians with computer skills and consumers of health care who demand digitally ensured quality will spur adoption of a technology that saves lives and improves the quality of care.

Financial Disclosure: Dr Safran has an equity interest in Clinician Support Technology, an e-health application service provider.

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The age of computers has heralded the slow replacement of the paper medical chart. Although it may be irrational to fear more for the privacy of a cyberchart than that of its paper cousin, in recent years concerns about protecting electronic medical records have mounted. Perhaps the unease is this: the paper records were tangible, locked away in an office or a basement, while with a few mouse clicks, computerized records could be bouncing all over the Internet into the hands of anyone, from an employer to a teacher to a friend. At least, that may be a common fear. When even Microsoft’s “impenetrable” databases are vulnerable to hackers, abstract concerns about an inviolate chart seem closer to a disturbing reality.

Patients, not surprisingly, are worried about how their medical information will be used—so worried that they may withhold details from providers or forgo medical care altogether.1

Legislators, too, are concerned. At the state level, legislatures have begun to map the largely uncharted terrain at this intersection of medical records and technology.2 Yet, in the “laboratory of the states,” these laws are inherently varied and may offer spotty coverage.3 Federal legislators have also been struggling to provide uniform protections for computerized medical records. As electronic medical records gained prominence, policymakers began to notice legal oddities in the current protections for computerized records. Notably, the law protected videotape rental records, but it left electronic medical records vulnerable. In 1996, partly in response to that “blockbuster phenomenon,” Congress included a provision to create strong federal privacy protections, with a 3-year deadline for congressional action, in the Health Insurance Portability and Accountability Act.4 When ensuing legislative proposals became mired in genuine disagreements over language and substance, as well as partisan politics, Congress missed that target date. The task of creating comprehensive legislation to guard the nation’s medical records fell to the US Department of Health and Human Services (HHS).

At the twilight of the Clinton administration, HHS offered its Final Rule on Standards for Privacy of Individually Identifiable Health Information and effectively created the first extensive federal regulations for medical records.3 The rule, which would preempt only weaker state laws, offered sweeping protections for electronic and paper records, as well as spoken communication. Some key provisions: patients may inspect their medical chart and request corrections; health plans and physicians must obtain written consent in many instances before disclosing identifiable information; civil and criminal penalties may follow compliance failures and wrongful disclosures.

While the rule has been widely praised, it has also been roundly criticized as onerous, costly, overreaching, and incomplete. Patients do not own their records, and they have no new right to sue those who illegally obtain and use their medical information. Plaintiffs are still limited to theories based on, for example, a constitutional right to privacy or a common-law duty of confidentiality. Also, there is an exception for using identifiable chart excerpts in direct-to-patient marketing. Rather than require written informed consent for that disclosure, the rule employs a different mechanism—companies may contact a patient at least once about a product, at which time the patient may exercise a right to “opt out” of future mailings. While direct marketing may be an effective way to alert patients to new and useful products, this loophole could stamp the federal government’s imprimatur on a practice that, without stringent safeguards, may be ethically problematic.5

Today, national protections for electronic medical records float in a kind of nether world, somewhere between the proposed rule, a Bush administration review, and its enactment. Meanwhile, researchers have recognized the need for standards and have created secure record-keeping systems based on the National Research Council guidelines.7 Still, ethical questions remain. How should physicians balance the need for record keeping and data collection against patients’ pleas to leave medical histories, physical findings, or test results out of the electronic chart? Who should be responsible for confidentiality breaches, from the loudly whispered elevator gossip to the discriminatory uses of ill-gotten information? Where can patients turn for recourse?

Federal protections for cybercharts may eventually become as comprehensive and as balanced as those on the front lines would like, but the evolution of law is often a slow, even maddening process. The medical community may need to address issues of privacy on its own, without waiting for a perfected federal mandate to safeguard a seemingly simple ideal: that patients will be able to share their most intimate secrets with physicians, confident that they will remain safe within a very private world.
Grassroots Computing: Palmtops in Health Care

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Palmtop computers first arrived on the market nearly 10 years ago. However, it was not until the last few years that they started to be widely used. A combination of technological advances, improved form, and diverse applications has led to a 169% increase in sales from 1999 to 2000.1

Originally designed as personal organizers—a replacement for bulky and inefficient day-planners—these pocket-sized devices are quite versatile and can support a wide variety of functions. From medical references, to prescription writing, to electronic medical records, palmtop computers may be key to the ever-elusive adoption of health care information technology by physicians.

In the past, most information technology in health care was imposed on physicians by the institution in which they practiced. This often led to an “us vs them” mentality that has severely hampered physician adoption of new technology. In contrast, palmtop computers have been brought into health care by physicians looking to improve their productivity. This grassroots movement towards a new technology is unprecedented in health care.

When personal computers (PCs) were first made available to the general public, they were shunned by large enterprises, including health care institutions. The enterprises were already entrenched in mainframe-based computing, and personal computers were not seen as suited for the workplace. However, as PCs became more and more popular with individual users, large enterprises had to adapt; networking technology was created to connect individuals’ computers and to allow them to access server applications. Despite these developments, PCs were never as widely adopted in health care as they were in other industries. Since physicians do not often practice at their desks, large, immobile desktop PCs did not fit into the physician workflow.

The adoption of palmtop computing in health care is in many ways analogous to the adoption of PCs in other industries in the 1980s. In contrast to the PC revolution, nearly 15% of physicians are already using palmtop computers.2

While most of these individuals are still using their devices for simple organizational tasks, many are beginning to investigate how to use the devices to improve their professional productivity. Small group practices and departments within large health care institutions have even started purchasing devices for all of their members.3

There are many reasons palmtop computers have had a larger grassroots movement driving them into health care than other technologies. The first is mobility. For physicians used to wearing white coats filled with reference books, index cards, and hundreds of scraps of paper as their ad hoc mobile filing system, the promise of 1 pocket-sized device that could simplify and organize all of their clinical responsibilities is invaluable. The second is cost. Most palmtop devices, equipped with all necessary software, cost well under $500. This puts them within the price range for the traditional early adopters of technology—young physicians and physicians-in-training—and has further facilitated the rapid growth of the palmtop movement. Third is the large breadth of applications available. Individuals can download current reference information that is automatically updated to their devices at no additional cost. Furthermore, there are hundreds of niche applications that can be used to solve specific clinical problems.

However, the biggest hurdle for adoption of palmtop devices by individuals and enterprises alike is the ability to connect them directly to clinical information systems. As was the case with PCs, the technology that most significantly impacted their adoption and functionality was networking—the ability to connect to local intranet and global Internet resources. For mobile, disconnected devices, the analogous technology to networking is synchronization—updating new information from the palmtop to the existing information system, and sending new information from the existing information system to the palmtop. Palmtop computers will only reach their true potential when they can connect to any and all clinical information systems the physician uses. For example, while in the clinic, the palmtop must connect to the physician’s practice management system to check patient information and record visits.

While at the hospital, the device must connect to the hospital’s information systems to obtain lab results or enter orders. Institutions and companies are now addressing the technical challenge of connecting to these disparate systems.

Palmtop computing promises to help finally realize the benefits that health care information technology has been promising for years. Physicians will be able to perform all of their information management responsibilities from individual palmtop devices that are with them at all times. From prescribing medications and checking formulary restrictions, to ordering labs and viewing test results, physicians will soon be able to interact with both personal and professional information and improve their productivity, their income, and ultimately, their patients’ care.

Financial Disclosure: Dr Shah owns stock in PatientKeeper Inc, a company that develops palmtop medical applications.

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The Patient-Owned, Population-Based Electronic Medical Record: A Revolutionary Resource for Clinical Medicine

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The Integrated Electronic Medical Record (EMR) is the next step in the evolution of health care delivery. There have been many attempts to create this tool. Nevertheless, an EMR that contains all of a patient's health data and allows information to be extracted for anonymous population-based epidemiologic studies remains elusive.

Inevitably, this record will change the everyday practice of medicine both for the individual and the population, but it will also revolutionize clinical research. It will allow researchers to ask questions about diseases that were previously impossible to ask, and it may well lead to the discovery of tens or even hundreds of new diseases and allow reclassifications of existing ones. Although smaller subsets of data have been extremely useful and form the basis of traditional epidemiology, the real value of the integrated EMR is the ability to ask these types of questions on routinely collected clinical data from whole populations of millions of people. Gene chip–based molecular analyses of patients with complex clinical phenotypes will soon become commonplace, and researchers will need to be able to search across the EMRs of all patients to find those with the same subtle constellation of clinical features.

It is essential that there be an open and informed debate to determine where the balance lies between the use of patient data for research and public health management and the right of the individual to control personal privacy of the medical record. Much has been written on both sides of the argument; legislation has in general empowered the individual and caused anxiety among researchers. Nevertheless, objective studies of patients' views are sparse and find that most patients realize the value of well-controlled access to records. For example, a study of more than 200,000 patients at the Mayo Clinic, conducted in response to new legislation in Minnesota in 1997, found that more than 95% of patients, when fully informed, were willing to have their clinical information used in EMRs. Health care communities in industrialized countries are confronted by the technical, ethical, and social challenges created by these issues.

Standards that support data integration and security are inherently scalable to the size of a whole population will need to be developed. These standards must also be able to evolve quickly to embrace new technology or statutory changes in data access control rules. Researchers will require new search tools with algorithms capable of trawling this type of relatively "messy" clinical data.

Researchers, clinicians, and health care providers are seeking a suitable social and political environment in which to develop a prototype population-based, patient-owned record. The United States leads in the overall investment in infrastructure and the general level of acceptance by clinicians of the value of information gathering in clinical practice. Unfortunately, in the United States, health record systems are focused around the financial drivers in health care and consequently the clinical population data are bakanized among individual health care providers. In contrast, in the United Kingdom, as in much of Europe, a unified health care system in the National Health Service has led to the introduction of a unique patient identifier for everyone in the population. New European legislation ensuring patient empowerment mandates that there is specific consent obtained for how clinical information may be used both in medical care and research. This, when combined with a number of British government imperatives establishing data communication standards and the Health and Social Care Bill currently before the UK Parliament to address the issue of control of anonymized access to population data, serves to create the ideal environment to develop an integrated EMR.

The United Kingdom has begun to capitalize on these opportunities with a number of initiatives at the local level coordinated nationally by the National Health Service Information Authority, which will develop and test the necessary prototypes. The Electronic Record Development and Implementation Programme and others such as the Eastern Region Electronic Health Record Consortium, a partnership of academics, industry, and the health service led by the University of Cambridge, are closely linked with national public debates on the ethical use of data for clinical studies and patient care. These can succeed only by combining public debate with the introduction of technology.

It is still early, but during the next decade some form of patient-owned EMRs for entire populations will likely be introduced. The impact this will have on clinical practice and our understanding and classification of disease could possibly be greater than the effect that molecular biology has had on medicine during the last 10 years.

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