

FROM THE FIELD

The Missing Link: Bridging The Patient-Provider Health Information Gap

Electronic personal health records could transform the patient-provider relationship in the twenty-first century.

by Paul C. Tang and David Lansky

ABSTRACT: Widespread adoption of information technology is now regarded as a pathway to improving health care and achieving the Institute of Medicine's highly regarded six aims for redesigning care. Achieving these aims requires fresh approaches to health system design, including continuous healing relationships between physicians and patients and provision of tools to help patients be more active participants in their own care. Personal health records (PHRs) might allow patients and providers to develop new ways of collaborating and provide the basis for broader transformation of the health care system. Federal policies can be key catalysts in accelerating PHR development and adoption.

FOUR YEARS HAVE PASSED SINCE the Institute of Medicine (IOM) issued its six aims for redesigning health care for the twenty-first century: providing safe, effective, patient-centered, timely, efficient, and equitable health care.¹ The current enthusiasm for adoption of electronic health records (EHRs) and broad connectivity across the health care system reflects the belief that information technology (IT) can hasten the nation's ability to achieve these six aims.

Less often mentioned are the IOM's ten design rules: care based on continuous healing relationships; customization based on patients' needs and values; the patient as the source of control; shared knowledge and the free flow of information; evidence-based decision making; safety as a system property; the need for transparency; anticipation of needs; continuous decrease in waste; and cooperation among clinicians.

The first four of these rules imply that the IOM's worthy aims will not be achieved unless we build a system in which patients share information and control with professionals. The mere installation of EHRs—even with comprehensive interoperability—will not sufficiently engage patients in the health system.

Patients As 'Copilots' In Their Care

Patients have little access to information and knowledge that can help them participate in, let alone guide, their own care. The IOM design rules propose that patients have shared knowledge and free flow of information. At a minimum, they need access to information from their providers' EHRs—their own diagnoses, medications, allergies, lab test results, visit summaries, and other findings over time. A continuous healing relationship is a two-way interaction (whether electronic or face-to-face) between patients and their providers.

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Patients should be able to send information to their doctors or other health professionals and receive advice, reminders, and alerts from them. A simple, nonurgent exchange of questions and answers is often all that is required. Yet information that could prevent deterioration in a chronic condition or obviate an unnecessary visit too often goes undelivered because of the high barriers to in-person access.

Using information about a patient, a personal health record (PHR) can customize linked content based on a patient's needs and values. In a study exploring the information needs of patients, patients wanted to receive personalized, physician-endorsed health information relevant to their own health conditions and treatment recommendations. Study participants felt that being better informed increased their understanding of their treatment plan, motivation to comply with the plan, and satisfaction with the office visit.²

Finally, the IOM notes that patients should be the source of control, by having "the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them."³

The IOM vision is unattainable if it depends on a paper-based record-keeping and communications infrastructure. Even in a digital information environment, these "design rules" can be realized only if the patient is a full information partner with the health care professional and institution. With properly designed public policy, adoption of advances in IT can be accelerated; without basic changes in policy, effective use of IT will wane, and the opportunity to efficiently apply scarce resources to a growing demand for health care services will pass us by. Which technologies must be embraced and rapidly adopted?

EHRs And PHRs

In April 2004, President George W. Bush set a goal that most Americans have their medical information maintained in EHR systems within the next ten years.⁴ How does an EHR differ from a PHR? One way to view the difference is to consider the intended user.

An EHR is a collection of health informa-

tion that has been gathered by and is managed by an enterprise—typically a doctor's office, a hospital, or an integrated system. In today's health care system, one patient might have several EHRs under the control of various organizations. No one EHR has all of the patient's health information. Fully integrated systems, such as those of Kaiser Permanente and the Veterans Health Administration (VHA), come closest to having comprehensive information on their patients.

In contrast, a PHR is meant to address the health information needs of the individual patient or consumer. In addition to the provider-centric recording of the patient's interaction with the health care system, a PHR would include information, entered by the patient, about daily symptoms, over-the-counter medicines taken, personal exercise programs, special diets, or data from home monitoring devices. By combining personal health information with knowledge about diseases and their treatment, a PHR system can provide tools to help patients become more active participants in their own health care.

■ **Optimal characteristics of PHRs.** As innovators have begun to implement technologies that address the four IOM design rules highlighted above, they have identified five key attributes of an optimal PHR.⁵

First, the PHR should be lifelong and comprehensive. These two items have major policy implications. To be a lifelong record, the technical standards and design used in developing both EHR and PHR products must support information exchange and portability. In our fragmented health care system, it is often up to patients and their primary care providers to consolidate information from the various participants in their care. A PHR can help patients and their families cope with the disjointed way their information is being handled.

Second, the PHR must be accessible from any place at any time. This is particularly vital to glean the widely understood benefits of emergency room (ER) access to a new patient's health history. Third, the PHR must provide health management tools that assist patients in understanding the information contained in

their record along with recommendations for improving their health.

Fourth, the PHR must be private and secure. Recent revelations of improper releases of personal information from information clearinghouses, credit bureaus, and researchers understandably heighten public concern about online health information.⁶ The PHR system must be transparent—in terms of both information sources and information access. Fifth, patients must be able to control who has access to the information in their PHR. In a 2000 survey of online Americans, 78 percent wanted “to be able to make choices about how their personal health information is used.”⁷

■ Consumers’ attitudes about PHRs.

Even as policymakers discuss the value of PHRs, it is not clear that the public is fully aware of the trade-offs between legitimate concerns about their privacy and the benefits of making more complete information available to providers. Today, of course, each of us chooses what to disclose during a doctor visit and what to keep to ourselves. Failing to disclose information, however, does incur risks, as doctors may inadvertently make suboptimal diagnostic and treatment decisions based on incomplete information.

Clearly, patients need reassurance that PHRs (and the EHRs they may be connected to) are secure and can protect the confidentiality of their health information. In the 2003 Markle Foundation survey, 91 percent of patients said that confidentiality of information in a PHR would be “very important” to them.⁸ Yet, patients also recognize the importance of critical information to their health: More than 95 percent said that they would be willing to provide their primary care and specialty physicians with access to their health information.

As patients are able to identify opportunities for greater engagement in their care, they also see these technologies as a means to improve and support their relationship with a doctor. A survey of online U.S. adults found that 75 percent of them would like to be able to e-mail their doctors; 69 percent, to look for possible mistakes in their medical records; 65 percent, to automatically transfer information

to a new doctor; and 63 percent, to view test results online.⁹

The high level of patient interest in using PHRs validates the policy objective represented in the IOM report. In the 2003 survey, 65 percent of respondents said that “having their medical records online would give them a greater sense of empowerment regarding their health,” 65 percent believed that it would reduce errors, and 54 percent said that it would improve the quality of their care.

How close are we to providing these tools to assist patients? For an individual patient in certain integrated health systems, this vision is within reach. But for the majority of the population who go to physicians in solo or small group practices, substantial policy changes must be implemented to achieve this vision.

■ **Classifications of PHRs.** Today there are three prevalent approaches to building PHRs. The most common is to provide the patient with a portal or view into the data contained in a provider’s EHR. Several large delivery systems that operate an EHR system offer such portals today and reach an increasing proportion of their eligible patients. Although this approach can provide fairly rich interactions between patients and providers, the information is primarily limited to what is in one organization’s medical record.

A second approach is to provide the patient with a freestanding software application either on the Internet or on a personal storage device. In this case, patients are not connected to their doctor’s EHR. Any clinical information patients might wish to store in the PHR requires their own data-entry time—opening up the risk of data-entry errors, misunderstandings, and incompleteness. There is some effort under way to allow these freestanding software applications to communicate with commercial EHR systems, but these are mostly case-by-case connections. Without reliable and standardized exchange of patient data between systems used by providers and by patients, the benefits of storing patient data electronically will largely go unrealized.

The third category of PHR is perhaps the Holy Grail to which President Bush and the

IOM aspire. A complete PHR would allow patients to capture information from every health care source, to enter their own information and share it with providers, and to fully control the use of the information. This paradigm will be hard to achieve until higher degrees of EHR adoption and interoperability are attained throughout U.S. society.

Because the definition of the PHR is still very fluid in the industry, it is hard to quantify how many consumers are using one. Probably less than 1 percent of the U.S. population is now using a fully functional electronic PHR.¹⁰

PAMFOnline

PHR systems hold promise because they can fundamentally change not only the way that health care is delivered, but also patients' health behavior. We show this transformative potential by sharing some insights developed by analyzing qualitative feedback by PHR users.

The Palo Alto Medical Foundation (PAMF), a large multispecialty group practice in Palo Alto, California, has been operating a PHR system, PAMFOnline (www.pamfonline.org), since 2002. The system is tightly integrated with the organization's EHR and provides secure access for patients to view key components of their medical records (including test results), get access to customized health information resources, request appointments, renew prescriptions, and communicate with their physicians electronically.

■ **Information transparency.** In the 2005 annual survey, 92 percent of PAMFOnline users were satisfied with the services offered.¹¹ In addition to quantitative feedback on various aspects of the system, close to 10,000 free-text comments provided deeper insight into how patients were using the new tool. Many described how having timely access to their test results and other information from their medical records made them feel like "a team member in [their] own care." They felt that transparency helped them "understand the whole

picture of [their] health better."

■ **Continuous access.** Patients quickly became used to and appreciated the continuous access to their providers. It made them feel "more connected to [their] provider," and that "changes totally the dynamic of medical care." Nevertheless, patients do not abuse the privilege. Ninety-two percent of physicians felt that patients were using the system "as expected or less," consistent with the experience of others in the industry.

■ Bridging the digital divide.

Concern over a possible age-based "digital divide" seems to be dissipating also. For example, one-third of all PAMF patients in their sixties, and a quarter of all patients in their seventies, have signed up for a PHR. One octogenarian declared that having an electronic record helps

her "keep her health record straight," while another noted how important this communication tool is for older patients: "Since I am in my eighties...the most important [factor] is a savings in physical travel to the clinic."

■ **Most popular features.** Not surprisingly, access to test results was the most popular feature commented upon. Of great interest, the second-most-common qualitative feedback was how the PHR caused respondents to act on the information they viewed in their PHR, highlighting the transformative nature of the interaction. Feedback from patients speaks to their new sense of empowerment and control: "It is important to me since I can help manage my own health." A short anecdote describes how one patient attributed the positive change in lifestyle and health risk to the information transparency of a PHR:

I always check my lab results.... Because I've had ready access to this information, I was able to tailor a diet specifically to adjust my blood lipids...I saw the improved test results two weeks ago. Not only was I hugely successful (triglycerides from 333 to 85), but I lost twenty pounds, too. Having my lab results online was tremendously helpful.

"Without the efficiencies gained by using PAMFOnline, this transformative technology would not have been adopted."

■ **Physicians' feedback.** It is largely because of the seamless integration between the PHR and the EHR systems that 90 percent of physicians were satisfied with the PHR. Without the efficiencies gained by using PAMF-Online and the reinforcing positive feedback from patients, this transformative technology would not have been adopted.

■ **Complaints.** Complaints received from survey respondents primarily focused on individual situations unrelated to the PHR. Interestingly, the most frequent complaint was about the difficulties in setting a new password. The PAMF adopted a privacy-protective approach by using an authentication process for password reset that is similar to that used in the initial sign-up, to ensure that password changes are being requested only by the patient. Some patients seemed willing to make a privacy trade-off for convenience.

Another issue that arose stemmed from a California law (which superseded the Health Insurance Portability and Accountability Act, or HIPAA) that requires additional physician and patient consent for patients to access their information electronically. This state law also says that certain results (for example, abnormal Pap smears) may not be released electronically for any reason, regardless of a patient's request. Without uniform federal policies controlling access to and protection of health information, inconsistent state laws can impede patients' access to their own information.

■ **Impact on health behavior.** One-fifth of respondents to the PAMF survey reported that they had changed their health behavior as a result of having access to PAMFOnline. Although carefully controlled clinical trials assessing the impact of PHR use on health outcomes and resource use are only now being conducted, it is the qualitative insight provided by these patients' experiences that leads us to be optimistic about the potential of this technology to improve care, enhance outcomes, and reduce waste.

Policy Implications

Despite PHRs' potential, without critical, enabling public policies, adoption of PHRs

may be limited to those patients lucky enough to live next to early-adopter institutions. The following policy actions could hasten adoption of PHRs.

■ **Strong national leadership.** The president and other national leaders should continue to educate the public, perhaps using public service announcements, about the role each of us can assume to become more informed about our own health and health care. Policy leaders should recognize that the integration of health information facilitated by the adoption of interoperable PHRs is central to the redesign of the health care system.

Strong national leadership also is needed to shepherd legislative and regulatory policies to protect the privacy and confidentiality of information held in PHR systems. Assurance of privacy protection is the only way to earn the public's trust in this information-gathering technology. State laws that conflict with federal privacy laws (such as HIPAA) can impede dissemination and use of PHRs.

■ **New physician payment policies.** Payment policies now discourage the use of online methods of delivering health care: Usually only face-to-face encounters are reimbursed. New policies that compensate physicians for delivering professional services that improve outcomes, regardless of the communication media used, should be developed. Pay-for-performance programs, Centers for Medicare and Medicaid Services (CMS) demonstration projects, and regional health information organization (RHIO) programs should explicitly include patient-facing portals or fully functioning PHRs in their requests for federal funds.

■ **National data standards.** Federal investments in PHR technologies should require the use of national standards for data coding and exchange and build toward full interoperability with the emerging network of EHRs. Creating silos of data is just as wasteful as creating silos of care.

■ **Role of federal agencies.** Several federal agencies have an important role to play in facilitating the development, implementation, and widespread adoption of PHR technology. The reimbursement policies of the CMS, the

largest payer of health care, affect not only Medicare beneficiaries but also private-sector policies. The National Library of Medicine plays an important role in data standards. The Agency for Healthcare Research and Quality's research portfolio is generating the evidentiary basis for effective use of health IT to improve quality and patient safety. To maximize the synergy among the various federal initiatives affecting PHRs, the Office of the National Coordinator for HIT should coordinate federal PHR activities, and adequate funding and staffing should be afforded that office to provide meaningful leadership to federal efforts.¹²

■ **Research agenda.** Finally, a research agenda should be developed and funded to guide the evolution of PHR technology, including the development of a taxonomy for classifying PHRs, and to quantify PHRs' impact on health outcomes and resource use.

WIDESPREAD ADOPTION of EHRs is critical for the modernization of U.S. health care. New information systems must be able to connect to each other and must be enhanced by clinical decision support to add value to patient care. The emergent, interoperable health information environment must fully embrace the role of patients as partners in care and in the flow of information about their own health. U.S. health care consumers are getting ready to accept more responsibility for managing their health and conditions jointly with their physicians to achieve better health outcomes and better quality of life. Consumer-directed health care initiatives and health savings accounts will provide increasing motivation for consumers to take responsibility not only for their choice of health plans but also for their adherence to lifestyle changes and treatment plans that affect their health.

Early experience confirms that when patients are given the chance to bridge the information gap between themselves, their health data, and their health care providers, many people enthusiastically take a more active role. The redesigned health system envisioned by the IOM can be realized only if public-sector

leaders and private innovators collaborate in building a health system that lets patients be full partners in their care and increasingly capable of managing their own health.

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NOTES

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