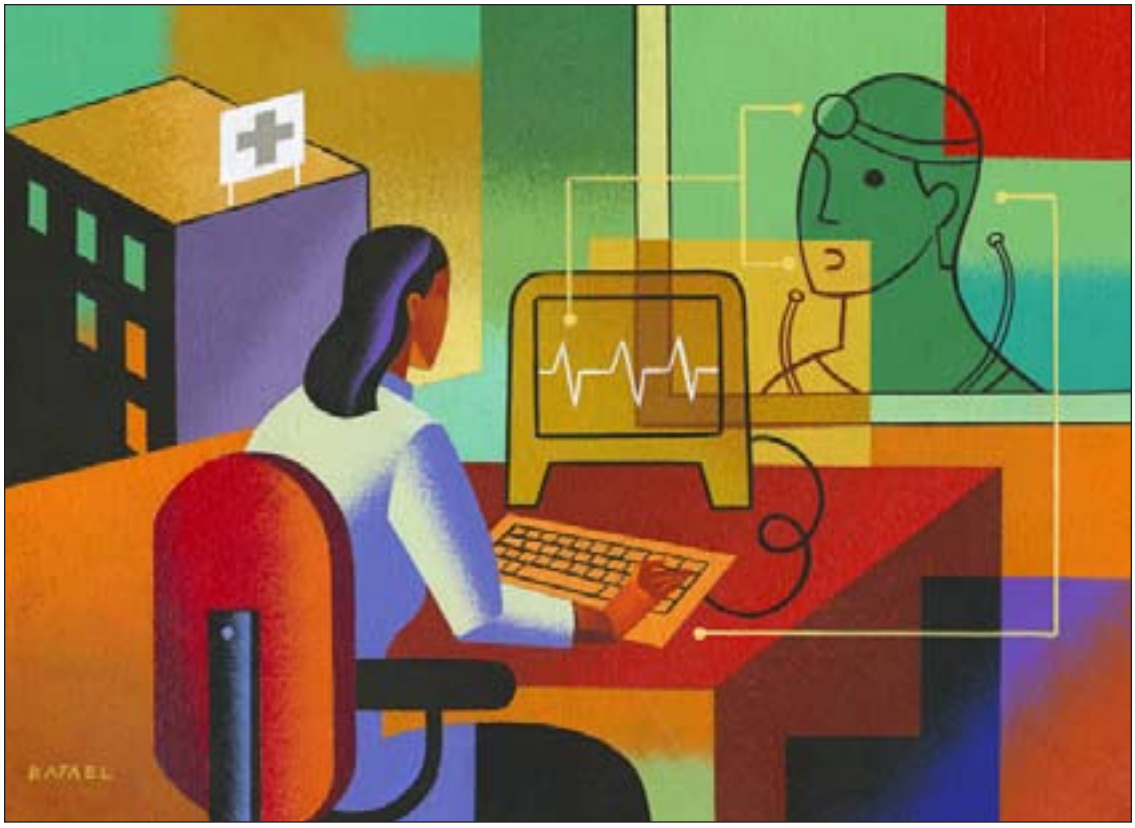
California HealthCare Foundation



Perspectives on the Future of Personal Health Records

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Prepared for
California HealthCare Foundation

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About the Foundation

The **California HealthCare Foundation,** based in Oakland, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information about CHCF, visit us online at www.chcf.org.

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I. Introduction

The Internet and other information technologies have transformed American life in the last decade, empowering consumers and the way they work, bank, shop, and travel. However, a similar, long-anticipated transformation in health care has been elusive.

Recent interest in a new kind of computerized medical record designed for consumers rather than health care providers could help speed this transformation. As a patient-centric hub of information and tools, personal health records (PHRs) have the potential to make the delivery of health care services more efficient and accessible, less costly, and safer.

But they might also be disruptive, as PHRs would be likely to alter the relationship between physicians and patients, and could affect the workflow in doctor offices. Additionally, some physicians worry they will become an unfunded mandate.

What Is A PHR?

According to the Markle Foundation, "PHRs encompass a wide variety of applications that enable people to collect, view, manage, or share copies of their health information or transactions electronically. Although there are many variants, PHRs are based on the fundamental concept of facilitating an individual's access to and creation of personal health information in a usable computer application that the individual (or a designee) controls."

"PHR" means different things to different people—there is no universally accepted definition.[1] Typically, it is an electronic repository in which a person can store his or her health-related information securely and privately, and also share that information with multiple health care providers or others at the patient's discretion. New PHR capabilities are appearing as policymakers grapple with this technology and its role in health care.

To better assess the promises, perils, and challenges of PHRs, and the impact they could have in the next three to five years, the California HealthCare Foundation invited six experts to share their perspectives. These views represent those of the technologist, informed patient, physician, employer, and the public health sector.

II. Background

A 1991 report by the Institute of Medicine, *The Computer-Based Patient Record: an Essential Technology for Health Care,* often is credited with launching the electronic health records movement. Digitizing the provider-controlled patient record, or electronic health record (EHR), has been a significant industry and public policy effort since then.

Sixteen years ago, the idea of a digitized medical record controlled by the patient was not on the radar screen. Today, even though the Health Insurance Portability and Accountability Act of 1996 (HIPAA) expressly gives patients the right to access their medical information, the concept of patient-controlled records is evolving.

As the public became enamored with stock trading and shopping on the Web in the late 1990s, two Internet start-ups presented the notion of a patient-controlled health record. The predecessor to www.followme.com sprang from a mother's desire to help keep her chronically ill son safe in the health care system. The other—WellMed, later sold to WebMD—was marketed to employers and payers as part of a health benefits solution platform.

These and other products emerged around the 1999 release of another landmark report from the Institute of Medicine, *To Err is Human: Building a Safer Health System,* which highlighted the prevalence of medical errors. The report also noted the need to electronically integrate the health care system.

Meanwhile, a resurgence of double-digit inflation in health care costs prompted more employers to abandon managed care and shift a greater share of health benefits costs to employees, giving rise to consumer-directed health care. PHRs' stature rose further in April 2004 when President Bush announced a comprehensive initiative to digitize the health care system. As part of this initiative, he said that most Americans should have a personal electronic medical record within 10 years.[2]

Since then, interest in PHRs among health care policymakers and experts has intensified, but consumer adoption remains static.

The PHR Market

Nearly 200 PHR products are now available, the Markle Foundation estimates.[3] They vary in terms of architecture, format, features, functions, and business models.[4] Health insurers, employers, hospitals, large physician groups, Internet companies, and advocacy groups sponsor some PHRs. Internet companies and vendors sell others.

First-generation PHRs were marketed as Web-based tools to help keep patients safe in what the Institute of Medicine described as a dangerous and fragmented health care system.[5] Many early adopters were people who managed their own, or a loved one's, chronic condition or who wanted to give care providers instant access to their medical information in an emergency.

Provider organizations, health plans, or employers typically offer a tethered PHR, which is integrated or connected with their information system. Persons who have such a PHR can view, for example, an abstract of their health record or parts of their clinical record. In some cases, patients may have the right to add information about their health care or health status.

Insurer-sponsored PHRs may already contain an individual's claims and pharmacy data. Employers prepopulate their tools with information culled from these sources and, increasingly, from voluntary health risk assessments.

Large integrated health systems, including the Veterans Health Administration and Group Health Cooperative of Puget Sound, frequently give members access to their medical information through a consumer-friendly Web portal. These PHRs often include functions such as secure messaging to physicians, automated appointment scheduling, and prescription refills.

Untethered, otherwise known as stand-alone, PHRs typically are not connected to other information systems. Consequently, an individual must type in, scan, or download salient portions of his or her medical records—diagnoses, treatments, medication lists, allergies, key radiology scans, the doctor's notes, and the patient's notes and observations. This type of PHR, which the individual usually owns, is portable. He or she can move it among health care settings, employers, and insurers. Care providers may or may not have the means or inclination to use the information in the PHR when they make treatment decisions.

Business Models

There are a variety of PHR business models. For example, some charge the consumer directly for a PHR, others charge the consumer's employer, and still others give them to patients or customers without charge to build loyalty.[6] Those models that generate revenue from PHRs do so through subscriber fees, advertising, or transaction or licensing fees. No single business model has proved superior and adoption remains low.

The lack of a dominant model has caused concern among some people about PHR sustainability. Others urge patience. They believe that a successful model will emerge once consumers better understand the value of having their lifelong health history electronically available.

Health industry stakeholders view the absence of health information technology standards as an impediment to widespread adoption of PHRs and EHRs. Continued development and acceptance of such standards could help resolve integration and portability issues. Increasingly, conversation is not about PHRs or EHRs per se, but about how to knit them together seamlessly and to link them with other data sources.

Small start-ups no longer dominate the fledgling PHR market. The health insurance industry, big consulting firms, and the nation's largest technology innovators also now embrace the PHR concept. They include IBM, PepsiCo, and UnitedHealth Group. The Markle Foundation's Connecting for

Health initiative advanced the debate in late 2006 by releasing *A Common Framework for Networked Personal Health Information,* which set an agenda, goals, and vision for advancing PHRs beyond the technical and policy barriers.[7]

As of early 2007, the race was on to produce PHR models that would boost consumer interest and use. Wal-Mart and Intel are leading a large employer coalition in developing a model called Dossia.[8] America's Health Insurance Plans, a trade group, also is working on a model.[9] Microsoft, Intuit, Google, and other technology giants are expected to enter the space soon.

In any case, PHRs already are becoming more than just electronic record repositories; several vendors also provide disease management content or a built-in capability to interface with providers.

III. Six Perspectives

About Patricia Flatley Brennan

In Patricia Flatley Brennan's view, today's PHR will evolve into a suite of devices and applications enabling consumers not only to acquire, store, manage, and interpret health information, but also to take appropriate health actions. Brennan is a Lillian L. Moehlman Bascom professor in the University of Wisconsin-Madison School of Nursing and College of Engineering, and national program director for the Robert Wood Johnson Foundation's Project HealthDesign.

With a background in nursing and industrial engineering, she knows a thing or two about harnessing the healing power of information technology. She developed ComputerLink, an electronic network designed to reduce the isolation of and improve self-care among home care patients, and directs a Web-based information and communications service, HeartCare, that helps cardiac patients recover faster and more safely.

Here, Brennan provides real-life examples of how PHRs of the future could impact personal health care. Before they reach that point, however, the technology must overcome many significant hurdles, not the least of which is the need for more sophisticated applications to perform complex tasks.

The Big-Picture Perspective

BY PATRICIA FLATLEY BRENNAN, R.N., PH.D.

The future for computer applications and specialized services that provide powerful support to people who are managing a range of personal health concerns is fantastic. Consider, for example, how one family might leverage such tools and services.

Mary R., an accountant and mother of two teenagers, could visit a Web portal to access the immunization records of Judy, her 13-year-old daughter, in preparation for a camping trip; to confirm the appropriate insulin dose for son Josh, 15, after a home glucose monitor checks his blood sugar; and to view her insurance records to verify recent charges for new glasses.

In addition, immunization registries coupled with recommendations from the U.S. Preventive Health Services Task Force could alert Mary that a new cancer-prevention vaccine is available for Judy. A Bluetooth-enabled blood glucose monitor

could automatically capture a sample from Josh, transmit the results to the family's computer, and launch a decision-support program confirming the correct insulin dose. Mary's cell phone could receive reports from environmental sensors that monitor pollen counts, initiate a check of her allergy history, and buzz with a recommendation that she consider increasing the amount of antihistamine medication.

In essence, PHRs will be a hub for information about and for patients. They will also give patients access to tools for managing this information, some of which patients will enter themselves and some of which will come from their clinical care provider, pharmacy, a public health authority, or other sources. All of it, including information related to population health and even climate and environmental conditions, will be stored and integrated in a way that prompts patients to take appropriate action. And the information will be accessible whenever and wherever an authorized user needs it.

Two Paths Ahead

In the next three to five years, PHRs are likely to progress along two paths. One will involve developing better links between health records containing a patient's observations and the records her or his clinician keeps. The other will entail a greater proliferation of more clinically useful home-monitoring and alert systems as home electronics mature.

When Mary steps on a weight scale, she will be able to see both her weight and basal metabolism index. The scale will then upload this information to the PHR on her computer so the PHR can determine if her caloric intake matches her health goals.

PHRs and the special-purpose health care devices they support represent a shift in the use of computers and information in health care. Recent advances in computer technology and a growing national awareness that information systems ensure safer, higher-quality, better-coordinated, and more timely care will abet a concerted effort to infuse health care with sophisticated, computerized systems.

PHRs can complement and extend the health information systems in hospitals and clinics. Through PHRs, the benefits of molecular medicine and the conversion of scientific discoveries into practical applications will accrue to both clinicians and consumers.

Capabilities

Advanced PHRs might typically include:

- Information about an individual's health states, health practices, and use of health services;
- Patient preferences for services, such as advanced directives;
- Decision logics from a person's health plan that initiate alerts, warnings, or recommendations when clinical findings exceed the desired boundaries;
- An individual's observations about her or his physical and social environments;
- Rules regarding privacy and access to, and use of, information;
- Middleware tools that manage identity, such as family relations and name changes; translate data from different computer systems into consistent forms; and ensure data integrity.

Someday, Mary might use a personal electronic activity coach to set the speed of her treadmill by comparing the results of her recent cardiac stress test and current medications with her personal fitness goals. Later, she might receive email notifying her it is time to refill her prescription for a cholesterol-lowering medication and telling her which pharmacy has the best price. While traveling, Mary's cell phone might receive an alert from the local public health authority about an outbreak of water-borne illness, warning her to avoid local tap water.

The key components for launching a new generation of PHRs—technological capacity, personal readiness, and awareness among insurers, employers, and other health care stakeholders—are in place. Evidence from early experiments with free-standing Web portals and smart home-monitoring systems supports the notion of expanding the PHR from simply an information integrator to a suite of personal tools that recommend healthy actions based on data from many sources.

Unresolved Issues

This will require policy changes—for example, deciding if caregivers can access information about a patient without her or his knowledge—as well as reconciliation of conflicting state and federal privacy laws. Such conflicts can make it difficult to transfer information into a PHR. Moreover, some institutions are reluctant to adopt PHRs because of confusion about HIPAA and its protections.

Laws and policies must give patients confidence that caregivers will heed not only the personal information in PHRs, but also patient preferences for treatment, such as life support. At the same time, however, professionals must be able to provide what they deem to be the most appropriate care.

Patients and their care providers like the PHR concept, research shows.[10] In addition to PHRs' personal health benefits, the tools will help improve health services delivery by reducing redundancies, expanding access to relevant information at the point of care and elsewhere, and aiding a doctor's interpretations of clinical observations by giving him or her a history of the patient's health states, practices, and services received. If PHRs issue reminders or guidance for action, they will extend professionals' impact far beyond the clinic or hospital.

While consumers and health professionals are now the primary PHR users, other stakeholders, such as researchers, technology developers, and insurers, also stand to benefit from them. Pharmaceutical companies and research labs could better assess the impact of approved medications on patients by capturing surveillance information in PHRs.

Deciding who should have access to the information in these tools and ensuring that consumers understand such decisions are important social issues that must be resolved.

Technical and Other Challenges

Because health professionals will play an important role in ensuring that PHRs help patients achieve health care goals, they need to learn how to incorporate patients' observations and home-sensored treatment responses into clinical encounters. Sophisticated interfaces have yet to be developed that, for example, could send Josh's clinician a relevant clinical summary of his home glucose-monitoring results rather than all results.

PHRs lack robust applications that can handle complex health data and promote data-driven health action. The decision logics necessary to guide such action, based on either a large or small amount of information, call for novel analytical techniques.

A key technical hurdle is expanding beyond the current locate-and-display approach so applications can move integrated data from diverse sources into one display and enable a computer system to read and take action on the information. To accomplish that, new types of data models will be necessary that reflect the all-important time of observations—for example, the time of day Josh got a blood glucose reading and when he ate a meal.

Creating a unified display of readings from Josh's blood glucose monitor—one that integrates those readings with findings from a clinical laboratory—is not easy. In such a display, all values must be calibrated using a common metric and not be confusing for the viewer. The display also must account for Josh's blood glucose norms, which may be quite different from those of other people.

Novel computer algorithms and decision-support systems will need to guarantee that the information in a PHR is relevant and synthesized in a way that guides the actions individuals take to manage their health. After all, Mary has neither the knowledge nor the experience to interpret laboratory results or discern which of the many guidelines for adolescent health pertain to her children. Furthermore, alerts and recommendations must be communicated in ways that everyone understands, including the many people whose health literacy is minimal.

Ensuring Security

The biggest concern about PHRs is the distributed nature of the health information they contain. Today, health professionals collect and providers store such information, and institutional policies and procedures largely protect it. PHRs raise the possibility of information storage in multiple places, which poses a challenge for current security methods.

Without agreements among institutions regarding privacy and security, data stored in more than one location might be vulnerable to unauthorized uses. Security violations could lead to blaming patients for their health condition—like the cardiac patient who, a security breach inadvertently reveals, has been smoking and eating excessively for the last 20 years—resulting in differential treatment for them. Or violations could result in marketplace prejudice—by a health insurer, for example, who learns that someone applying for coverage has HIV.

Information Management

Both clinicians and consumers should anticipate information-management challenges and risks, including information overload, given that PHRs will probably change the way data are acquired, exchanged, and used during health encounters. And some professionals will need to place greater trust in information that patients report.

Consumers, meanwhile, will have to control permissions for access, remember all the places their records reside, and know more than they do now about their state of health and the care they receive. They will also need to be educated about health data and how to interpret it.

Two necessary early steps on the education front are better basic information-science training for health professionals and expanded health literacy education for elementary school children.

Incentives for Consumers

Fundamental to PHRs is the notion that health information is a personal commodity rather than an institutional asset. However, even though consumers are increasingly responsible for acquiring and applying that information and are the ones most likely to benefit from PHRs, there are no financial incentives for consumers to use them.

Health care financing currently rewards professionals, payers, and delivery systems rather than consumers for effectively managing information, yet the greater economic payoff of PHRs will be healthier people, not more efficient health care delivery.

PHRs could shift the balance of power between clinicians and patients. Both the doctor's and patient's perspectives about patient health will be important. Somehow, PHRs must reconcile them in a way that does not overlook potentially significant information. For example, a physician who attends only to a patient's physical condition might be unaware of emotional or environmental stressors that may be contributing to symptoms.

On the Horizon

In the next three to five years, there are likely to be small pockets of integration between the health information consumers provide about themselves and the observations of clinicians. Greater public awareness of current privacy risks, and of how PHRs give consumers more control over privacy, will fuel demand for the tools.

Convincing health care stakeholders that the benefits of PHRs are worth their cost may enable a shift away

from institution-based, episodic care to continuous care that is accessible anywhere, anytime. But the willingness of stakeholders to pay for PHRs because of the economic value of data in them is not likely to increase in the near term.

Stimulation for PHR initiatives is certain to come from many of the tools that already have made it easier for health professionals to manage information, such as the Guideline Interchange Format for exchanging clinical guidelines. Soon, small experiments and special-purpose applications will demonstrate the value of PHRs.

Mary R. and her children stand to gain from a health care system that relies in part on PHRs to guide healthy living. So does society at large.

About David Lansky

As senior director of the Markle Foundation's health program and executive director of its Personal Health Technology Initiative, David Lansky is moving the PHR policy framework forward. As a patient, he knows both the limitations and potential of this technology.

Lansky recounts his own frustrating experience using a PHR in a highly fragmented health care marketplace. He sought an all-in-one product for managing his heart condition, but ended up cobbling together scattered tools for this purpose. No single tool could integrate all of his health information and satisfy his personal needs.

Before PHRs can win consumers' confidence and trust, Lansky writes, well-defined privacy policies, strong user controls, and high-level technical standards must be in place. That, in turn, would enable innovators and entrepreneurs to experiment with PHR features and strategies that meet an individual's needs and those of larger market segments.

The Consumer Perspective

BY DAVID LANSKY, PH.D.

My body had a tough 2006. First came surgery to repair a knee, then heart trouble. I started the year free of medication and behaving as if I was immortal, and ended the year taking four pills a day and moving a bit slower and more cautiously. And I was far more aware of every day, every step, every breath.

I also ended 2006 with a real, untethered PHR on my computer desktop, on a portable flash drive that plugs into the computer, and on the Internet. Unfortunately, it cannot connect to my doctor's, my hospital's, or my pharmacy's computer systems. I use their Web portals to view my personal information, but to manage and apply that information, I must enter it into the PHR.

Physician Connectivity

I have always believed in electronic health records and having access to my own health information. For the last decade, I have chosen my doctors based on whether they used EHRs.

I do not believe that any physician who attempts to deliver medical care—write a prescription, interpret a lab test, or recommend a therapy—can do good work without using computers to manage the information. After all, researchers generate about 8,000 peer-reviewed studies per month, the National Institutes of Health spends about $15 billion on clinical trials, and big pharmaceutical companies spend billions more.[11,12] I doubt my primary care doctor can synthesize and apply this body of knowledge without the help of at least some information technology.

I welcome the emergence of tools to manage all that information, as well as the trend toward evidence-based medicine. So, now that I have to deal with a number of health issues myself, including coronary disease that is probably lifelong, I got myself a PHR.

What was I looking for in selecting one?

PHR Attributes

First, I know I am at risk for more cardiac events, so I wanted my PHR to contain all of the personal information an emergency medical technician, emergency room doctor, or cardiologist would want to have—my medical history, the medicines I take, past treatments, my allergies. I am also more realistic now about my mortality, so I wanted to have my advance directives available to anyone who cares for me.

Second, I am determined to lower the chance of any future heart problems. I am trying to be smart about what I eat and to monitor my exercise habits. I also make sure those efforts pay off in terms of my functioning, health status, and biological indicators. These indicators include cholesterol level, weight, blood pressure, and exotica such as c-reactive protein level, a marker for inflammation, that many believe plays a role in cardiovascular disease.

I wanted a PHR that would track that information and add some insight or capabilities, such as decision support or graphical displays, to the raw data. For example, data from my sports watch has shown me how some medications reduce my heart rate and the pace at which I can jog.

Third, I wanted a PHR that would make my rather frequent interactions with the health care system less of a hassle. I would like to spend less time filling out forms and trying to remember my medication doses or the date of my knee surgery.

Fourth, I look for doctors who have a specific expertise, competence, and philosophy—who are likely to complement my situation. Because I prefer to use medications sparingly, I want to know if the general literature about beta blockers, ace inhibitors, and statins applies to me. A doctor who shares my philosophy, knows the literature, and has achieved good outcomes for patients would be ideal. So would a PHR that could "talk" to the Internet and help me find the right providers.

Fifth, because I am devoting substantial resources to my health care now, I wanted a PHR that could keep me informed about expenses and insurance reimbursements. I face a dizzying array of copayments, co-insurance, uncovered expenses, and out-of-pocket costs. I would like to know where I stand in collecting all the reimbursements I am due, settling what I owe, and getting whatever tax benefits I am entitled to.

Finally, I really do not want companies to market to me and I do not want persons other than those I choose looking at my personal information. So my PHR of choice would have to keep data encrypted. And an organization I trust—one that does not have relationships with others that could cause me harm, and that is adopting all of the emerging standards for information portability, in case I switch to a different PHR product at some point—would have to manage it.

As I look for PHR services that meet these needs, what do I find?

Scattered Portals and Tools

I learn that my primary care doctor has a Web portal for scheduling appointments and requesting refills, and that my neighborhood pharmacy accepts refill requests online. The two, very sophisticated hospitals I visited in the last year do not have portals or PHR capability, nor does my health insurance plan.

At www.mypyramidtracker.gov, I found a wonderful tool to manage and monitor my eating habits, courtesy of the U.S. Department of Agriculture. My sports watch and heart-monitoring strap capture interesting data on my exercise frequency, heart rate, pace, distance, and the calories I expend—and they store it all on the Web.

The PHR keeps my emergency and chronic illness information, but it cannot download information from any of my other health care resources. I must add any data I think could be important.

Marketplace Limitations

My experience reflects the PHR reality today. Our stunningly fragmented health care system has a very limited ability to electronically capture, make available, and standardize clinical data, and little interest in accessing personal health data arising from my health status or experiences. In the absence of a common technical and policy framework, it cannot make my health information portable or accessible even to me.

The easily accessible information—about my insurance claims, for example—is not of much interest to me and certainly not of much value all by itself. Some people believe that putting claims data in PHRs is a way to help advance these tools; indeed, if billing data were in my PHR, it might save me the trouble of having to enter some information manually, including drugs dispensed, diagnosis codes for recent treatments, and providers' contact information.

But claims data do not reflect my health—whether, for example, I am experiencing knee pain, eating more heart-healthy food, taking vitamins and supplements, swimming or jogging or smoking, or feeling depressed or lonely. They would be only a modest starting point for helping me manage my health or making me feel more empowered.

Personal Needs Unfulfilled

Nothing on the market really addresses my personal needs and knits all of my health care information together in a form I can easily use. Although millions of patients have the same medical conditions I do and are taking the same medications, I cannot find any studies or information sources that answer my questions, nor any information that identifies the best physicians to care for me.

In a world where consumers supply much electronic content, including content for their PHRs, and where technology allows customized services to be delivered to mass audiences, I hope a PHR product will emerge that meets my needs. Perhaps someday, the marketing capabilities of large, online, consumer-services providers and their ability to build Web tools that people can use easily and consistently will be married with the clinical expertise of health care providers or research societies to produce the kind of PHR I want.

Ideal PHR a Long Way Off

This holy grail of PHRs is at least a decade away, however. Today, my primary care doctor's EHR cannot export standardized data to any PHR I might acquire. The same is true regarding my insurance claims data. For at least the next few years, I expect to shop for individual services and features that address my personal requirements and to cobble together a set of tools that works for me.

Of course, what works for me is not likely to work for many others, and my own needs will probably change. For example, I may take on more responsibility for an aging parent to help manage medications and relationships with doctors. I may need tools that address new health problems confronting me or members of my family. I may become even less comfortable with having my most sensitive health information exchanged on the Internet or exposed to various data-mining and surveillance programs, so I would tilt toward products that give me more control and privacy.

The general use of PHRs probably first requires a personal health information environment that instills trust and confidence in consumers and that enables information to flow freely among appropriate and authorized users. Such an environment—with well-defined privacy policies, strong user controls, and high-level technical standards—would allow innovators and entrepreneurs to experiment with product features and strategies that meet the needs of various large and small market segments.

Useful Capabilities

PHRs would be even more appealing to me if:

- There were trustworthy, easy-to-use procedures for authenticating me;

- I knew I could give or retract permissions for others to see my personal information;
- I felt confident that no one could use the information to swamp me with ads and promotions;
- I could easily request and retrieve my personal health information in standardized electronic form from any entity that has it; and
- I could send information electronically to a new doctor or, for example, to my child's school when it inquires about vaccination history.

Overcoming these challenges would boost demand for PHRs. That, in turn, would make it less risky and expensive for software companies to develop new products.

Collaboration and Agreement

People like me will not drive creation of the new personal health information environment. Rather, this will require collaboration between health care institutions that recognize the value of empowered consumers, and online service providers that anticipate a new market for innovative services.

They will need to forge agreements about data portability and standardization, such that every organization where my health information resides has a bright blue download button on its consumer Web portal—like those at the Web sites of my bank and financial services companies. They also will have to work with government regulators on policies for authentication, authorization, consent, secondary use of data, and security. And they will need ways to communicate those policies to the public and enforce them vigorously and visibly.

I will not get the tools to help me manage my health better until there is a new health information paradigm that overcomes the frustrating fragmentation of today's health care system.

About Daniel Sands

Cementing relationships with patients is nearly impossible for most time-pressed doctors. For primary care physician Daniel Sands, electronic connectivity makes that challenge considerably less daunting.

In this perspective, Sands, who is affiliated with the Center for Clinical Computing at Beth Israel Deaconess Medical Center in Boston and is senior medical informatics director in the Internet Business Solutions Group at Cisco Systems Inc., also in Boston, presents two scenarios for the future of PHRs—one pessimistic and the other optimistic. Whether this technology ultimately withers or thrives will depend on a number of factors, he writes, including consumer and physician willingness to use it, technical refinements, financial incentives, and tougher privacy and security protections.

Sands is an optimist. He believes that if current efforts continue, PHRs have a bright future.

The Physician Perspective

BY DANIEL Z. SANDS, M.D., M.P.H.

Unlike most physicians who have heard PHRs are coming, I am not afraid. Physicians' fear is unfounded despite the concerns they have about patient expectations, PHR features and functions, and issues related to workflow and liability.

I have used email and electronic medical records—and have even shared patients' EMR information with them—since I started practicing primary care medicine more than 15 years ago. About 40,000 patients enrolled at Beth Israel Deaconess Medical Center can see their medical records using PatientSite, a tethered PHR that enables them to send secure email to their physicians and the physicians' staffs, request prescriptions, arrange referrals, make appointments, tap into educational tools, and enter and track their own health information.

About a quarter of the diverse patients I care for, many of whom have multiple chronic medical

problems, take advantage of PatientSite, which I have used for almost seven years. Without question, "connecting" with patients through PatientSite enables me to provide better care.

Limited Time

Like many physicians, I am frustrated by time pressures. I want to provide the best care possible but a lack of resources—time being the most precious one—constantly hamper me. Yet it takes time to build the kind of strong relationships with patients that enable me to provide the best care and education about health and wellness, treatments, and more.

Email, I have found, is the most efficient communication channel for nonurgent matters because it is asynchronous; phone calls for scheduling office visits are difficult to coordinate, resource intensive, and too often undirected.

Patients who research health information, view their medical records, and track their own health and wellness make for much better care partners, take better care of themselves, and often have better outcomes. The patient-clinician relationship fundamentally changes when there is free exchange of information, particularly the patient medical record, which for centuries has been the exclusive province of health care providers. Clinical records readily available to both physicians and patients level the playing field, educate patients, and foster trust and openness rather than secrecy.

Seeking Traction

PHRs are in their infancy—the ideal of the patient-controlled PHR as defined by the Markle Foundation and others is virtually nonexistent. Tethered PHRs, such as those that Beth Israel Deaconess Medical Center, other provider organizations, and large self-insured employers offer, have gained the most traction.

Large medical practices and provider organizations are more likely than their smaller counterparts to make clinical information available online. Some believe that communication portals and online services can help attract and retain patients, while big employers view such offerings as a way to improve employee health, thereby reducing health care expenditures and lost productivity due to illness. Unfortunately, even though these are currently the most compelling business models, they have not proved their value.

Unanswered Questions

PHRs promote information sharing among multiple interests, which raises many questions. A nervous physician might ask: Why should I make it easy for patients to take their data to another provider? Who will bear the cost of creating this capability? If I make patient information available for sharing online, won't that increase the risk of someone inappropriately obtaining it?

Furthermore, which data should be available online and in what format? Regarding format, there still are no adequate data-representation standards for information exchange outside of carefully managed data exchange projects.

Market forces and the willingness of patients and providers to adopt PHRs will propel their evolution. Although the future is far from clear, I envision two distinct scenarios for this evolution, depending on whether current efforts move forward or fizzle.

Scenario 1: PHRs Wither

In the first, more pessimistic scenario, PHR sponsors offer their products for purchase by individuals, who can buy them at a discount through the American Association of Retired Persons or other advocacy groups. However, it turns out that most consumers are unwilling to pay even modest annual fees.

Although a few very large employers subsidize PHRs, incentives for workers to use them are anemic; employers argue that the tools have not adequately proved their value. Meanwhile, few consumers are willing to maintain the information in their records

for the PHRs to be useful, and inadequate standards and physicians' poor adoption of health information technology hamper efforts by consumers to compile their data from multiple health care providers.

Health plans experiment with PHRs, but a positive return on investment is fleeting due to weak consumer use. Enrollees' distrust of health plans as custodians of their personal information, despite assurances it will remain confidential, makes the situation even worse.

In this scenario, physicians generally balk at PHRs because they must spend extra time creating patient-friendly notes and explaining the records to patients—time for which doctors are not reimbursed. Declining reimbursements, a broken health care system, and greater workloads continue to batter physicians, especially primary care physicians.

PHRs at least partially connected to other health information systems mean there is more information for doctors to review. Yet technology cannot present these diverse data streams to physicians concisely, nor is the information integrated into their other medical records. This exacerbates physicians' frustration—examining every patient's PHR is a cumbersome, unreimbursed task. A few high-profile malpractice cases cause some doctors to fear greater liability if they fail to review all of the detailed patient information from outside sources.

These issues become fodder for physicians who already are reluctant to introduce health information technology into their practices because it requires them to commit time and resources. Patients who wield PHRs often have trouble finding a physician to care for them.

Scenario 2: PHRs Thrive

Now for the second, more optimistic, scenario.

Standards mature and health information sharing becomes the norm. PHR cost-benefit studies demonstrate better health outcomes, lower health care costs, and neutral or positive impact on physician efficiency and remuneration. And patients discover that using a PHR with other health information systems is the most efficient way to manage their personal health data.

Information flows in from most of the sites where patients receive care. Services, software wizards, and regional data-sharing utilities make it fairly simple for patients to set up connections with health care facilities and health plans.

In addition, using the Web for health-related purposes becomes the rule rather than the exception across all socioeconomic strata. People increasingly use PHRs to manage information partly because of the proliferation of connectivity and tools that enable health and wellness information to be captured and displayed wherever and whenever a consumer wants it.

Patients who have incentives to take better care of themselves readily adopt wireless glucometers connected to information systems, mobile phones that manage diet logs, and physiologic monitoring and targeted health information available through television set-top boxes. Tougher legislation and educational campaigns make consumers more comfortable about the privacy and security of their electronic health information.

Also in this scenario, PHRs help chronically ill patients manage their conditions, and help the healthy maintain optimum health because, given that they now have more responsibility for health care expenditures, it is financially prudent. Health plans and employers gladly subsidize PHRs because they reap benefits when enrollees and employees engage in their health and wellness.

People enjoy closer relationships with their physicians through electronic connections. Health educators and independent practitioners—hired by patients and subsidized by health plans, employers,

and the government—help answer patients' questions, taking some of the time burden off of physicians.

Physician payments depend more on the quality and less on the quantity of care they deliver, and more on patients' satisfaction with services. Doctors can afford interconnected health information technology systems thanks to tax credits, payer inducements, Web-hosted applications, purchasing cooperatives, and other novel funding arrangements.

Doctors increasingly demand such systems so they can deliver and report on the high-quality care they deliver. They understand the value of exchanging health information with patients through PHRs and derive great satisfaction caring for those who are connected and well-informed. The physician-patient relationship grows stronger, contributing to physician satisfaction.

I believe that physicians must not be afraid of PHRs, which, if current efforts continue, have a bright future. This future is possible because the pieces are already falling into place and some doctors and patients are already reaping the benefits.

About David Kibbe

David Kibbe, senior adviser to the Center for Health Information Technology at the American Academy of Family Physicians and a principal in The Kibbe Group, a consulting firm, sees tremendous promise in PHRs. But he is also concerned they might become another unfunded mandate.

Reaping the benefits of this technology, he writes, will hinge on developing widespread, effective standards for transporting electronic patient information. Such standards would apply not only to PHRs, but also to EHRs—ideally, the two will be integrated.

Kibbe predicts that PHRs will accelerate the free movement of personal health information on the Web, and that an online giant like Google or Yahoo will be the first to win consumers' confidence in PHRs by offering an attractive product soon.

The Clinical Technology Perspective

BY DAVID KIBBE, M.D., M.B.A.

As a family physician, I am excited about the new opportunities that PHRs offer for patients and their physicians to manage chronic illnesses collaboratively, avoid unnecessary and costly treatments, enhance drug safety, and make communications with the doctor's office easier. I also look forward to having more engaged and empowered patients.

As a technologist and entrepreneur, I also see huge business opportunities to bring new tools to the market that enhance consumers' ability to directly compare the quality, convenience, and cost of health care products and services, and that use the Web as a platform for personalized, interactive health and wellness services.

Another Unfunded Mandate?

At the same time, however, I am worried that PHRs—especially in the short term—will become one more unfunded mandate, creating new bureaucratic hassles and costs for medical practices.

The last thing I want is for my office staff to have to deal with patients arriving at the front desk with multiple, proprietary PHRs in a host of different formats and containing all sorts of unverifiable information. Realizing the benefits of PHRs and avoiding their pitfalls will depend on broad adoption of effective standards for transporting patient information and sharing it among disparate computer systems and databases.

For PHRs to become widespread, at least four major constituents—employers, health plans, providers, and consumers—must agree on why and how consumers should embrace PHRs. Another issue is the absence of reimbursement for physicians and other providers whom patients trust to help them make the transition to these tools.

A Familiar Evolution

Projecting where PHRs will be in five years is akin to having asked in 1994 where the Web would be five years hence. As it turned out, the Web provided searchable content, e-commerce, and online communities, roughly in that order.

Indications are that the PHR evolution will be similar. It is likely to evolve from static collections of searchable records to systems of information-sharing that promote and support easier buying and selling of health care services at reduced prices for consumers. Then PHRs will involve whole, connected communities offering relevant and real-time information about how to live longer and healthier lives.

How quickly this evolution occurs is anyone's guess. Although traditional software applications and relational databases will remain useful for a long time to come, PHRs in the hands of consumers will rapidly boost the economic and clinical value of moving and exchanging very specific data sets and information beyond the static, privately formatted information in providers' and health plans' databases.

Information Enhancements

Applications are beginning to appear that enhance a person's health information as it moves freely on the Internet. These tools offer decision support, guidance on drug interactions, ratings of hospitals and doctors, and more. Vimo.com, for example, asks individuals to enter basic personal health information and, based on that information, returns specifics about the prices of procedures and surgeries.

Two things are moving the high-tech industry toward this new health-data liquidity: message-driven programming—such as filling out a form on the Web that, perhaps in conjunction with information already stored there, tells software to perform a certain task—and distributive computing, or Web 2.0.

"Architecture of Participation"

In distributive computing, the Web is both a platform and an application; anyone can have a Web site and control his or her own data. It is a world of news feeds, blogs, favorite content, event schedules, photo albums, and automatic software updates. Providers such as Google, MySpace, Apple Computer's iTunes, and www.salesforce.com are in the vanguard of this trend.

As this new paradigm—sometimes called an "architecture of participation"—begins making an impact on health care computing, personal health information will flow even more freely on the Web. PHRs will accelerate that freedom once consumers see the benefits.

The independence and payoffs all of this will bring to PHR users who navigate a fragmented health care system and must sift through huge amounts of health information to make it personal and relevant will be breathtaking. Of course, entities that want to be custodians of personal health information will have to address worries about privacy. The banking and financial services industry have established a good model for security and trust—one that enables the storage and round-the-clock transfer of millions

of records containing the most sensitive personal financial information.

PHR evolution and development will be slow but steady in the next year or two. Much is happening to move these tools into the mainstream of health care.

The PHR-EHR Link

Ideally, PHRs and primary care physicians' EHRs will be closely integrated. Whether one defines a PHR as merely a view or summary document of patients' clinical information, or as a software application that enables them to collect, organize, and manage their personal health information (both definitions are valid), there is a distinct advantage to linking the information physicians use with the information patients use—and doing so as seamlessly as possible.

For optimal patient value, PHRs must be able to access timely data from care providers. Physicians need EHRs that, in addition to connecting to PHRs, serve as the central nervous system of their practices.

An EHR-PHR Standard

The American Academy of Family Physicians helps doctors in small or medium-size practices acquire and use standards-based EHRs. The academy also is collaborating with other organizations and with EHR and PHR vendors to promote the development and adoption of the Continuity of Care Record standard. The collaboration is striving to make it possible for different proprietary EHR systems to share basic clinical information in a variety of settings, and to exchange a minimal data set accurately and consistently.

The Continuity of Care Record standard is equally well-suited for the realm of patient-controlled PHRs and may become the essential link between them and physician-focused EHRs. Its output is a digital file encoded in eXtensible Markup Language, or XML, a well-established Internet standard in banking and e-commerce.

The content of such a file provides a snapshot of someone's most relevant health information at a given point in time. It does not try to capture all of her or his medical history; rather, it summarizes the information in one file and in a structured way that will be useful during the patient's next medical encounter with a new or unfamiliar provider. Or it will serve as the basis for computation—for example, in applying clinical guidelines or directives.

A Continuity of Care Record can have up to 17 categories of information, regarding demographics, problems or diagnoses, medications, allergies, and so on. These sections consist of structured data elements—information that has been coded or uses a standardized nomenclature, unlike free text.

Standards are key to realizing the value of PHR technology. Whether hosted on a Web site, a desktop computer, or a cell phone or other mobile device, such records are a significant departure from traditional medical practice.

Efforts to Pare Costs

At this point, health plans and employers are primarily driving the movement toward PHRs. Buy-in from patients and physicians has been minimal. Payers tend to view PHRs in the context of consumer-directed health care—as a way to involve patients more directly and actively in disease prevention and management. The main objective of payers and employers is to reduce costs.

But they cannot impose PHRs on physicians as an unfunded mandate and expect successful integration of the technology into medical practices, where most decisions affecting the cost of care are made. Getting some physicians—particularly those with established practices—to change behavior and workflow to adapt to PHRs will be challenging enough. Forcing them to use multiple, nonstandardized tools from disparate health plans or employers would only make matters worse.

Incentives Might Help

Financial incentives such as pay for performance may spur physicians to adopt highly standardized PHRs for engaging patients in self-management. Federal legislation introduced by Rep. Patrick Kennedy is a great start in this respect. Among other things, it calls for creating standardized measures of provider performance and assessing performance yearly. Health plans would reap a significant payoff in disease management by paying physicians a small additional reimbursement for using PHRs with their patients.

Consumer adoption of PHRs is likely to be slow in the near term. No one has made it easy for consumers—perhaps the most important stakeholders—to use PHRs, nor offered much in the way of practical benefits.

A fundamental hurdle is the inexperience of health plans and employers—the stakeholders with the most to gain and the most money to spend on PHRs—in dealing directly with patients, who do not trust them to be stewards of personal health information. Indeed, PHRs sponsored by health plans and employers raise some of the biggest privacy and trust issues.

Confidence and Trust

In surveys, consumers express a clear preference for having both a physical "medical home" and greater online and real-time access to their physicians. They place their greatest trust in doctors. However, physicians are not well-positioned to build or manage the technological infrastructure PHRs require.

The demand for both technological competency and consumer trust may well be why a company like Google or Yahoo will be the first to win consumers' confidence with a widely accepted, easy-to-use, standardized, and low-cost PHR sometime in 2007.

About Michael Barrett

Facing intense cost pressures, large employers are not waiting around for fickle physicians to make decisions about health information technology, writes Michael Barrett, who analyzes health and benefits portals for Fortune 500 companies as managing partner of Critical Mass Consulting.

He says enlightened companies are giving their workers personally tailored PHRs containing some personal health information, thereby moving ahead of doctors. PHRs, these companies believe, can improve employee health and, in turn, reduce employers' financial exposure.

Commercial successes such as Quicken, a product for managing business and personal finance, provide a model for PHRs, Barrett says. However, even when comprehensive PHRs become available, the biggest obstacle could be consumers' willingness to use them.

The Employer Perspective

BY MICHAEL BARRETT, J.D.

Beginning in the post-war 1940s, U.S. corporations began building a kind of shadow health care system—nothing like the mainstream one, but still important. The first programs helped workers with alcohol problems, and widened over the decades to include on-site occupational health, behavioral and mental health, and work/life assistance. Skyrocketing insurance premiums in the 1990s changed the storyline to one involving the decline of corporate commitment to workers.

Yet many firms today remain interested in helping their employees stay well, whether it is because they have some lingering loyalty to workers or because they want to limit their financial exposure. Maintaining employee health is easier thanks to the rise of the Internet and corporate intranets outfitted with tools like the PHR.

Health Risk Assessments

As a health care consultant focused on information technology, I see this Internet/intranet trend at work

in companies such as Dell, IBM, PepsiCo, Pfizer, Pitney Bowes, and Verizon. They promote online health risk assessments as lead-ins for everything from workplace exercise and wellness activities to full-blown disease management programs. Few employees, whether well or sick, will take the time to manually insert personal health information into a PHR routinely. But a good number will complete a health risk assessment once, especially if the company offers cash-equivalent incentives, as many do.

To further encourage participation in risk assessment and protect privacy, these self-generated data are kept secret from employers. Independent third-party consultants review scores, looking for risk factors such as obesity, inactivity, tobacco use, high blood pressure, and poor cholesterol levels. At-risk workers are invited into wellness and exercise programs. In many cases, a portion of the cash incentive is contingent on participation. Assessment results are also fed into PHRs, where they serve as a data starter set.

Part of a Bigger Toolkit

Ever practical, employers seek a return on investment not just from the PHR, but from a larger toolkit that includes it, the health risk assessment, a corporate portal, health and wellness activities, and third-party health content. The PHR, situated inside the portal with its risk assessment data, supplies personalized benchmarks for the wellness and exercise programs, and helps track changes over time.

Workplace PHRs do not feed off electronic patient care records in doctor offices. Not enough are in place and they cannot interact with PHRs. Nor is there a need to tie into hospital electronic records, as most employees are relatively healthy and have few inpatient encounters. By default, workplace PHRs get their first data nourishment from health risk assessments. Recently, employers have begun to strike deals with vendors to flesh out the records with medical and pharmacy claims information.

Missing Data, Privacy Concerns

Employers give only passing grades to today's PHR technology, mostly due to frustration over the missing data from doctors. Their other worry is privacy.

Executives seem to be vividly aware that a privacy breach could cripple not only a company's PHR, but its entire wellness agenda. For safeguards, they look to internal corporate policies and practices, and to third-party subcontractors—full-service corporate health shops such as StayWell, data warehouse vendors like Medstat, and online health care and PHR vendors, including WebMD—whose job is to protect data. Many employees trust this arrangement somewhat, judging from their participation in health risk assessments. IBM and Pfizer report that more than 50 percent of eligible workers complete health questionnaires.

Multiple Storage Sites

Tethered PHRs, which subsist parasitically on a health care provider's electronic record system and expand only as information sharing allows it to, are popular. However, many company executives are beginning to think PHRs will evolve in ways that depend less on the information technology choices of unpredictable doctors. Instead, maybe people will store their data in more than one place and shift these preferences over time, depending on which venue earns and retains their trust.

Such a pluralistic market—assuming it develops with the aid of entrepreneurs, tech-literate consumers, and highly motivated employers—would keep the door open for product improvement. Employees may end up with several tools rather than just one—perhaps a comprehensive PHR at home, a summary PHR for work and travel, and a keychain accessory for calorie-tracking.

Tools like this will benefit from, but not depend on, EHRs that can interact with them. For the sake of fitness, wellness, and the self-management of many chronic problems—areas in which employers already

claim a positive return on investment[13]—risk-assessment, medical-claims, and pharmacy data will serve quite well. Additional information that employees enter manually, and even data from wireless self-monitors, will be frosting on the cake.

Health Plans' Role

Not surprisingly, health plans are responsive to employers' changing expectations. Intent on trying various strategies for controlling health care costs, health plans market PHRs to companies that do not self-insure or do not offer the tool on an employee portal.

Often a plan's biggest asset is its scale: Because it serves multiple employers, a plan can more readily finance a data warehouse for medical and pharmacy claims or create interfaces for routing information to a PHR vendor. Such scale also enables them to make records portable for employees who leave the company.

Models of Success

Commercial successes inspire optimism about the market-driven model.

Quicken, an Intuit product for managing business and personal finances, is a reminder that millions of people will pay for software that helps them gain control of time-consuming tasks. Early Quicken users were a somewhat obsessive-compulsive subgroup, but then along came the democratization of investing. Mutual funds began popping up everywhere and baby boomers found themselves inundated with information. Amid growing demand, banks and mutual funds helped Intuit develop interfaces that enabled electronic data exchange between their computer systems. Slowly but surely, Quicken sales expanded beyond the early adopters.

Early PHR users likewise hail from a subgroup: people with chronic medical conditions. As with Quicken, an era of democratization seems to be looming. Once again, boomers have too much information to track and, as they age and confront health problems, more things to do with it.

Advances on the Horizon

Even if interoperability does not arrive in a neat package, PHR enthusiasts expect leading firms to develop interfaces that will make it possible to update PHRs electronically. Among the breakthroughs they anticipate are:

Integration of claims data. In 2006, WebMD, which has the first-mover advantage in the workplace PHR market, began feeding pharmacy and medical claims into the PHRs it maintains for Dell, PepsiCo, IBM, and Verizon. These tools can check for potential negative drug interactions and for medications patients are allergic to.

Health and finance synergies. WebMD's deal with Horizon Blue Cross Blue of New Jersey in 2006 created My Health Manager. This online service combines tools for self-management (a PHR, health risk assessment, and lifestyle improvement tracker), provider evaluation (an engine that compares hospitals), and health care finance (cost calculators for 350 procedures and tests).[14]

Benefits consultants blaze a trail. Fidelity Investments, a benefits consultant, for example, sees a future in which employees evaluate health plan options with greater attention paid to PHRs, out-of-pocket costs, self-care tips, and advice on buying generics. Fidelity believes that workers with chronic medical conditions will move up to even higher levels of support, such as online health coaching and participation in disease management programs.[15]

A PHR-like product. In 2006, Intuit and Ingenix, a unit of UnitedHealth Group, announced they and other companies had launched an effort to develop and distribute a series of health care management software products under the Quicken brand. The first of these is Quicken for Health Care, which the companies say will "help simplify health care management and improve decision-making in

the same way Quicken revolutionized personal finance."[16] Quicken for Health Care is expected to be a personal health and finance tool combining medical and pharmacy claims data with copay and deductible information. Like a PHR, it also may store some personal clinical information and test results. The idea is to set up an alternative platform for online health services—one that begins with financial rather than clinical data.

Still on the drawing board are multifunctional, user-friendly, and portable PHRs and Web portals independent of any single company that can accept data from anyone, be they employees, employers, providers, plans, pharmacies, or benefits consultants. Meanwhile, information technology experts are making inroads on data standards, data mapping, and other components of a national health information network that could accommodate secure, up-to-date PHRs, although no one is promising any easy victories.

Engaging Consumers

The biggest potential obstacle is the willingness of consumers to use comprehensive PHRs when they become available. Tracking blood pressure may never be as much fun as tracking an investment portfolio.

But even if this challenge does emerge, it will spur entrepreneurs and employers to seek other ways to bring consumers into the fold. Perhaps they can learn from public health officials, who, through advertising and public relations, have persuaded people to take appropriate but not always appealing actions—to quit smoking, for example, or to get vaccinated.

Ultimately, the best PHRs will most likely be hybrids that trace their parentage back to employer promotion, consumer electronics, other health care information technologies, and media-savvy public health efforts.

About Jeremy Nobel

If, as Jeremy Nobel asserts, health care affordability is the biggest public health threat facing the nation, could PHRs help deter it?

Yes, says Nobel, an adjunct faculty member of the Harvard School of Public Health who contributed his health policy expertise to *The Computer-Based Patient Record: an Essential Technology for Health Care,* the landmark Institute of Medicine report.

According to Nobel, PHRs could make health care more affordable by, among other things, reminding consumers to get immunized and adhere to treatment, diet, and exercise regimens; directing them to less-costly caregivers; streamlining care delivery; and promoting strategies based on best practices and evidence-based guidelines—steps that would reduce use, inefficiency, and waste.

He describes the ideal PHR for public health purposes, and argues that we should begin building toward that ideal now by establishing performance benchmarks for PHRs and criteria for their effective use.

The Public Health Perspective

BY JEREMY J. NOBEL, M.D., M.P.H.

The growing affordability crisis in health care—and the barriers to access it creates—now looms as arguably the most important public health issue in the United States. Having timely and personalized health information, and an ability to leverage it to optimize care decisions and outcomes, is critical to the public's health. A Web-based, secure, and universally available PHR linked to useful guidance and support programs that can help all types of consumers would improve access to more affordable, effective care.

Properly designed and deployed PHRs will not be a silver bullet for cost containment, but they could have a significant impact. By putting consumers at the center of a network of care providers and personalized service programs, PHRs could send timely reminders to people to get immunized or adhere to self-management guidelines for

medications, diet, and exercise. They could link to resources for effective self-care and self-management guidance and support, direct consumers to less costly providers of care, and streamline care delivery, reducing waste and inefficiency.

Moreover, by providing culturally sensitive and appropriate educational information and personalized advice, PHRs could promote care strategies consistent with best practices and evidence-based guidelines, and thereby optimize quality. They also could improve quality by enhancing collaboration between patients and care providers.

Chronic Disease Benefits

A particular appeal of PHRs from a public health perspective is their potential to ease the burden of chronic disease—by reducing risk factors for cardiovascular, metabolic, and respiratory disorders, and by fostering coordination of the best longitudinal care. Chronic conditions account for more than 70 percent of health care expenditures.[17]

Because better health behaviors can dramatically pare the cost and improve the outcomes of chronic illnesses, PHRs would be a vital part of a comprehensive public health strategy for managing such conditions.

Beyond Data Storage

To deliver important public health benefits, PHRs must go beyond information storage, their main function today. They need to be linked to secure and reliable communication platforms that enable multiple health care stakeholders to coordinate decisions and promote effective health behaviors.

Physicians have been slow to adopt EHRs. But it is imperative that we not wait until they do to create the perfect PHR. We can jump start the availability of PHRs by drawing upon sources of personal health information that are already digitized.

The Perfect PHR

For public health purposes, the ideal PHR would:

- Have an easily accessible and navigable Web site that displays a range of personalized health information from multiple sources, including insurance and pharmacy claims, clinical data from EHRs, data from monitoring devices at home, lab and diagnostic test results, and information the patient has entered.
- Deliver personal clinical information accompanied by and linked to useful and culturally sensitive educational programs, given the need to accommodate different languages and to adjust the complexity of instructions and educational strategies. Decision-support systems sensitive to each patient's circumstances could steer consumers to various options for managing their care and also note the potential consequences of the decisions they make.
- Offer links to care providers who can help the consumer enhance his or her health. For example, one link might read: "Click here to schedule an affordable mammogram."
- Serve as a communications hub where consumers, physicians, nurses, health coaches and advocates, pharmacists, and others can securely exchange messages at any time using a messaging template. When appropriate, a PHR could allow multiple providers to view information simultaneously from different locations, working with the patient to optimize both decision-making and care delivery.
- Compile health data about hundreds of thousands—if not millions—of users, automatically stripping identifiable indicators from the information and aggregating it in a way that fosters an understanding of best practices and better ways to deliver care. This would enable public health experts to spot health trends early, which is critical for detecting viral outbreaks like avian flu or dangers such as bioterrorism threats.

Lessons from Katrina

The Hurricane Katrina Advisory Group Initiative impressively demonstrated how, in the absence of widespread EHRs in doctor offices, public health can benefit from already available electronic health information.

After the hurricane struck, the initiative recovered many digital prescription records for patients and health care providers in less than a week. Of course, much more digital patient information will become available from EHRs, regional health information organizations, and other sources in the years ahead—a fact that today's PHR designers must anticipate.

We must start now to establish benchmarks for measuring how effectively PHRs improve access to affordable, high-quality care, and establish criteria for their effective use. At some point, we will need to know how and to what extent consumers and providers take advantage of PHRs; whether these tools improve the health of consumers who, for example, receive immunizations or undergo cancer screening; and whether they affect use of health services.

Challenging Tasks Ahead

Numerous organizations already can host PHRs and also contribute meaningfully to the clinical, administrative, and logistical data that populates them. They include commercial health plans, the Centers for Medicare and Medicaid Services, state Medicaid programs, health plans, public hospitals, community health center networks, large physician groups, and multihospital health systems. Coordinating their activities will be a complex and challenging, but worthwhile, task.

Other big tasks will be educating consumers about PHRs' potential value to them, creating incentives for people to adopt and use the tools, and addressing privacy and security concerns. Folding incentives into the design of health care benefits is reasonable, particularly if PHRs generate significant cost savings. For example, a diabetic who adheres to a drug regimen, thanks to prompts from a PHR, could earn a waiver on copayments for diabetes medications. That would provide a behavioral reward and eliminate a barrier to medication compliance.

A Foundation for Progress

While PHRs are not a panacea, the importance of a low-cost, reliable mechanism for relaying useful health information to consumers and care providers is clear. It is time to move forward aggressively. Many of the building blocks are in place, a sizable amount of digital patient information is available now, and many health care organizations already can provide secure and timely access to that information.

Initial successes and disappointments will refine our understanding of how best to deploy PHRs over the next three to five years so they improve personal and public health.

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