Scott Endsley, MD, MSc
David C. Kibbe, MD, MBA
Anthony Linares, MD
Karen Colorafi, RN

Here's what you need to know about this growing trend to give patients access to a portable health record.

An Introduction to Personal Health Records

Meet Mrs. Johnson, a 79-year-old with diabetes, congestive heart failure and an electronic personal health record (PHR). Mrs. Johnson saw her family physician this morning, and on the way home she realized she had already forgotten his instructions for her new heart medication. Was it two pills once a day, or did he say one pill twice a day? She also wondered when she would find out the results of the blood test he had ordered to determine her potassium level, which she struggles to keep normal. She was worried but knew that her online personal health record would enable her to find the answer to both questions as soon as she arrived home.

Once there, Mrs. Johnson sat down at her computer and logged in to the personal health record Web site that her family physician offered his patients. First, she sent a secure e-mail to her physician asking how to take her new medication. She was impressed to see that the new heart drug already was on her medication list. Next, Mrs. Johnson checked her in-box, where a message from her physician was waiting. Mrs. Johnson opened the message and was relieved to read that her potassium test had come back normal. Finally, she browsed the site's patient-education area and printed an article on potassium-rich diets before signing off.

The personal health record had informed and educated Mrs. Johnson. It also had saved her and her doctor's office from one or two follow-up phone calls. But its

TIMOTHY COOK

most important benefit on this day was still to come.

That evening, Mrs. Johnson woke with severe chest pain and shortness of breath. She was able to dial 911 and was rushed to the hospital. The emergency department physician diagnosed an acute coronary syndrome and started to write Mrs. Johnson's admission orders. He asked what medications she was taking. She could not remember all of them but told him that her entire medical record was available on the Internet. She gave him the password, which the physician used to access her online personal health record. There he found her medication list and her medication allergies, which included an aspirin allergy. He canceled the aspirin order he had just written and switched it to clopidogrel, signing, "a potential adverse drug event avoided, thanks to patient's PHR."

Nation notices PHRs

The idea of individuals keeping paper copies of their personal health records to facilitate access to health care services is not new. We have all provided or used a personal immunization history, travel history or prenatal history form. In a July 2004 Harris Interactive online poll of 2,242 U.S. adults, 42 percent of the respondents said they kept

personal medical records. Of those who kept records, the vast majority, 86 percent, did so on paper.[1]

While the number of patients currently using electronic PHRs may be small, the experiences patients and doctors had last year after Hurricanes Katrina and Rita might have greatly accelerated their use. The risks of keeping health information on paper were fully exposed when hundreds of thousands of evacuees sought care in new medical communities across the country. The evacuees lacked even the most basic personal health information, such as their medications and dosages. Most of their paper records were destroyed in the muck of hurricane-caused flooding, and many medical practices and hospitals were shut down for weeks, perhaps forever. Out of necessity, a program called KatrinaHealth was created to rapidly develop electronic health records for those displaced by the hurricane. (For more on this program, go to http://www.katrinahealth.org.) In addition, the AAFP has collaborated with the city of New Orleans and Intel, among others, to provide digital PHRs to every New Orleans resident who wants one, and to transfer these to medical practices and hospitals in the displaced residents' current location for follow-up care.

Since the launch of KatrinaHealth, more health care organizations have begun to think about PHRs as the best way to make personal health information portable, interoperable, secure and respectful of patients' privacy. The Centers for Medicare & Medicaid Services is exploring the creation of a national PHR for Medicare beneficiaries. The Department of Veterans Affairs is undertaking a PHR project as part of My Health*e*Vet (http://www.health-evet.va.gov). In the private sector, the number of commercially available PHR programs stands at more than 60 and continues to rise.

- Personal health records are electronic summaries of a patient's medical record that are often portable and easily accessed by the patient.

- The efforts to aid Gulf Coast hurricane victims in 2005 brought attention to the potential of personal health records.

- The Centers for Medicare & Medicaid Services and the Department of Veterans Affairs both are working on projects involving personal health records.

About the Authors

Dr. Endsley, a family physician, is medical director of system design for the Health Services Advisory Group in Phoenix. Dr. Kibbe is director of the AAFP's Center for Health Information Technology. Dr. Linares is regional vice president and medical director of Anthem National Accounts for WellPoint Inc. in Thousand Oaks, Calif. Karen Colorafi is an electronic health record specialist for the Health Services Advisory Group in Phoenix. Author disclosure: nothing to disclose.

Three visions of a PHR

Personal health records are evolving quickly, so much so that when this article went to press, there was no universally accepted definition of a PHR. However, three approaches to electronic personal health records had emerged:

1. A provider-owned and provider-maintained **digital summary** of clinically relevant health information made available to patients.

There are several variants of this type of PHR, but they share the following traits: The PHR is read-only for the patient, and the provider supplies, controls and maintains the data, which the patient is permitted to see. For example, some health care systems and hospitals now permit patients to see a limited set of information, such as lab test results or radiology interpretations, assembled from their electronic data stores. These are typically made available to the patient from a password-protected Web site. Some commercial electronic health records (EHRs) are starting to offer the same sort of digital summary through patient portals and are calling this a PHR. Not to be left out, some health plans recently started to offer physicians (but not yet patients) Web-based portals for accessing claims data on encounters, prescriptions, lab tests and imaging studies on their members.

2. A patient-owned **software program** that lets individuals enter, organize and retrieve their own health information and that captures the patient's concerns, problems, symptoms, emergency contact information, etc.

This software can reside on a person's computer, analogous to using software such as Quicken to manage personal finances, or the PHR software can be Web-based. In that case, the health data and all of the screens for entering and viewing the data online are maintained by a third-party host, much like banks maintain Web sites with individual information.

The limiting factor in this model of PHR is the laborious nature of data entry; it is time-consuming work for patients to create a database, even when they are the subject.

3. A **portable, interoperable digital file** in which selected, clinically relevant health data can be managed, secured and transferred. Platforms for portable PHRs include smart cards, personal digital assistants, cellular phones and USB-compatible (universal serial bus) devices that can be plugged into almost any computer.

This definition corresponds closely to the ASTM International E2369-05, standard specification for Continuity of Care Record (CCR), which received input from the AAFP and other medical specialty societies with help from EHR and PHR vendors. The main CCR standard elements are listed in the box on the left. They are similar to those endorsed by the PHR advocacy group Connecting for Health.

It's possible that the CCR standard will become the core standard for PHRs. If this happens, it will permit PHRs to be both portable and interoperable (able to exchange data) with office-based EHRs and other health care information systems. Interoperability is so important that 12 medical specialty and national physician associations have urged the federal

MAIN ELEMENTS OF THE CCR STANDARD

The CCR standard's main elements create a snapshot of a patient's health data.

• Personal and demographic information

• Emergency contacts

• Insurance information

• Problem lists

• Medications/allergies

• Immunizations

• Labs and tests

• Hospitalizations/surgeries

• Advanced directive form

• Spiritual affiliation/considerations

• Care plan

Source: ASTM International. ASTM E2369-05, standard specification for Continuity of Care Record (CCR). Available at: http://www.astm.org. Accessed April 6, 2006.

■ There are three definitions of personal health records.

■ One version of personal health records is a provider-owned digital summary that patients can access but cannot change.

■ A second definition is a patient-owned program patients can use to enter and organize their health information.

■ The third version is a portable digital file that can be transferred between computers and that corresponds closely to the Continuity of Care Record standard.

government to ensure that PHRs use accepted standards for both content and structure to promote interoperability. This would also help physicians avoid the hassles and extra work of keying in patient data that would result from multiple proprietary formats for PHRs.[2] Connecting for Health has also recommended that PHRs be made capable of standard-driven connectivity with other information systems and care providers.[3]

Benefits and challenges

The Institute of Medicine's 2001 landmark book, *Crossing the Quality Chasm*, delineated 10 "design rules" for improving care.[4] The success of six of these 10 "rules" depends directly on patients' involvement in their care. A recent reanalysis of the U.S. "ecology of medical care" suggests that although 80 percent of patients are experiencing medical concerns at home, only 30 percent are seeking care.[5] Recognizing the importance of having relevant information available to patients for management of their medical conditions, David Brailer, national coordinator for health information technology in the Department of Health and Human Services, has made personal health records a cornerstone in the national strategy for health information technology.[6]

Personal health records offer a number of potential benefits to patients, their physicians and the health care system.[7] These include:

• **Empowerment of patients.** PHRs let patients verify the information in their medical record and monitor health data about themselves (very useful in chronic disease management). PHRs also provide scheduling reminders for health maintenance services.

• **Improved patient-provider relationships.** PHRs improve communication between patients and clinicians, allow documentation of interactions with patients and convey timely explanations of test results.

• **Increased patient safety.** PHRs provide drug alerts, help identify missed procedures and services, and get important test results to patients rapidly. PHRs also give patients timely access to updated care plans.

• **Improved quality of care.** PHRs enable continuous, comprehensive care with better coordination between patients, physicians and other providers.

• **More efficient delivery of care.** PHRs help avoid duplicative testing and unnecessary services. They provide more efficient communication between patients and physicians (e.g., avoiding congested office phones).

• **Better safeguards on health information privacy.** By giving patients control of access to their records, PHRs offer more selectivity in sharing of personal health information. The PCASSO (patient-centered access to secure systems online) study at the University of California-San Diego suggests that PHRs are more secure than paper records.[8]

• **Bigger cost savings.** Improved documentation brought about by PHRs can decrease malpractice costs. PHRs' ability to reduce duplicative tests and services is a factor here, too. (Of course, there is a cost for setting up a PHR. The price varies widely, based on whether the physician pays for the service or directs patients to subscribe, and whether the system is Web-based or stand-alone.)

Personal health records empower patients by allowing them to monitor their health data.

Personal health records have the potential to improve patient-provider relationships, patient safety and quality of care.

One study suggests that electronic personal health records are more secure than paper records.

PATIENT PARTICIPATION

Here are the 10 "design rules" for improving care from the Institute of Medicine's book *Crossing the Quality Chasm*. More than half (those in bold) are directly dependent on patients' involvement in their care, which personal health records promote.

1. **Care based on continuous healing relationships.**

2. **Customization based on patient needs and values.**

3. **Patient as source of control.**

4. **Shared knowledge and free flow of information.**

5. Evidence-based decision making.

6. Safety as a system property.

7. **The need for transparency.**

8. **Anticipation of needs.**

9. Continuous decrease in waste.

10. Cooperation among clinicians.

While PHRs offer many advantages, they also raise at least two concerns:

• **Privacy.** Most Americans (91 percent) are concerned about the privacy of their health information;[9] however, when developed in the right way, PHRs offer security features that can protect patient privacy. Perhaps because of these features, almost 80 percent of Americans say they are ready to trust their doctor with access to their PHR.[9]

• **Accuracy.** Involving patients not only in viewing and interpreting but also entering their own data raises the issue of data accuracy. Here again, proper development of the PHR can reduce this concern. A 2004 study from Johns Hopkins suggests that use of guided data entry through color coding or criteria-defined radio buttons can improve the accuracy of medication or lab result data entry to near 100 percent.[10]

Getting started with PHRs

If your practice is interested in adding personal health records to the spectrum of services you make available to your patients, there are steps you can take to ease the transition:

Step 1. Assess your patients' interest in PHRs. Two Markle Foundation studies in 2005 found that 60 percent of respondents support the creation of a secure, personal health record, and more than 70 percent would use one or more PHR features. (Sending e-mail to their physicians, tracking immunizations or getting test results were the most-desired features.)[11] To gauge your patients' readiness, consider conducting a brief survey to determine your patients' comfort level with using the Internet, their interest level in various PHR features and their willingness to pay for PHR access.

Step 2: Evaluate your PHR options. Define the functions you will require (e.g., secure messaging, patient education, appoint-

ment scheduling). Do you have, or do you plan to purchase, an EHR? If so, does this EHR provide a Web-based portal for patients to access selected information? Are you looking for a free software application or a PHR service to which the patient would subscribe?

Step 3: Consult myPHR.com. The American Health Information Management Association (AHIMA) is producing standards for PHRs and maintains a Web site (http://www.myphr.com) that provides information on more than 60 PHR products, both commercial and freeware. To find information on specific PHR applications, as well as links and useful patient information, go to the site's PHR resource area (http://www.myphr.com/resources).

Step 4: Select a PHR and prepare your practice. Let your patients know about your new PHR service. Set a start date. If you are purchasing a patient portal for your electronic health record, work with your vendor to ensure that the PHR-EHR interface is fully functional. If you are simply providing information for patients to investigate their PHR options, make a list of both recommendations and PHR resources, such as myPHR.com.

Step 5: Go live. Most PHR systems are Web-based, so there isn't much for you to do from a technological angle. Instead, most of your preparation for going live is promoting the system and training your patients. At the start, you should anticipate spending more time talking to patients about their PHR.

Suited to family medicine

Because family physicians are patient-centric by training and philosophy, they are uniquely able to embrace the personal health record technologies as a redesign of their practices. In fact, the movement toward PHRs is firmly embedded in the New Model of family medi-

■ Two of the concerns about personal health records are patient privacy and data accuracy.

■ Get a sense of your patients' willingness to use personal health records before you commit to them.

■ If your patients show interest in personal health records, you'll need to decide what options you want, select a system and prepare your practice.

cine to the extent that the CCR standard permits widespread sharing and exchange of summary health information between PHRs and EHRs – and between patients and their "personal medical home" – for the purposes of education, quality improvement, enhancement of patient safety and gains in both patient convenience and office efficiency. Even as electronic health records are slowly expanding in the medical community, our patients are being offered their own form of health connectivity that can improve their safety and quality of care. **FPM**

Send comments to **fpmedit@aafp.org.**

1. Harris Interactive. Two in five adults keep personal or family health records and almost everybody thinks this is a good idea. Available at: http://www.harrisinteractive.com/news/newsletters/healthnews/HI_HealthCareNews 2004Vol4_Iss13.pdf. Accessed March 30, 2006.

2. Letter to Department of Health and Human Services Secretary Michael Leavitt; Nov. 10, 2005. Available at: http://www.centerforhit.org/PreBuilt/chit_phrleavittltr.pdf. Accessed March 29, 2006.

3. Markle Foundation. Connecting for Health: working group on policies for electronic information sharing between doctors and patients, final report. Available at: http://www.connectingforhealth.org/resources/wg_eis_final_report_0704.pdf. Accessed April 7, 2006.

4. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academies Press; 2001.

5. Green LA, Fryer GE, Yawn BP, Lanier D, Dovey SM. The ecology of medical care revisited. *New Engl J Med.* 2001;344:2021-2025.

6. Department of Health and Human Services. Strategic framework: the decade of health information technology: delivering consumer-centric and information-rich health care. Available at: http://www.hhs.gov/healthit/frameworkchapters.html. Accessed March 29, 2006.

7. Tang PC, Lansky D. The missing link: bridging the patient-provider health information gap. *Health Aff.* 2005; 24:1290-1295.

8. Masys D, Baker D, Butros A, Cowles KE. Giving patients access to their medical records via the Internet: the PCASSO experience. *J Am Inform Assoc.* 2002;9:181-191.

9. Markle Foundation. Connecting for Health: the personal health working group, final report. Available at: http://www.markle.org/downloadable_assets/final_phwg_report1.pdf. Accessed March 29, 2006.

10. Kim MI, Johnson KB. Patient entry of information: evaluation of user interfaces. *J Med Internet Res.* 2004;6:e13.

11. Markle Foundation. Attitudes of Americans regarding personal health records and nationwide electronic health information exchange. Available at: http://www.markle.org/downloadable_assets/research_release_101105.pdf.

If you already use an electronic health record system, make sure it is fully compatible with your new personal health record system.

When your personal health record system goes live, prepare to spend extra time explaining it to your patients.