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The Promise of Personal Health Records for Quality Improvement

EXECUTIVE SUMMARY

It has become widely accepted that electronic health records (EHRs) hold great promise for promoting quality improvement—both to prompt greater conformance to evidence-based standards for care and to streamline the collection and use of performance data. A variant of this technology—the personal health record (PHR)—has not received as much attention, but offers a host of other, distinct potential avenues for the advancement of healthcare quality. Beyond simply organizing all of a patient's health information in an electronic record, a PHR is a tool that facilitates patient engagement and captures, in a more timely manner, patient and family feedback about their experiences with the care delivery process and outcomes such as functional status and the degree to which patients understand and follow through on their treatment plans. In this respect, the PHR offers a direct line of communication with patients that creates the potential to improve quality of care—both by promoting patient involvement in the care delivery process and by creating a new mechanism for measuring patient experience and outcomes. This Issue Brief describes the many distinct ways PHRs can contribute to quality improvement and discusses the key challenges that need to be addressed to realize this potential.

PHRs Gaining Traction

"Personal health records" may sound to some like yet another healthcare fad, but many leading organizations—including major healthcare systems, providers, health plans, and large employers—are making significant investments in PHRs today, signaling real expected value from this tool down the road. In October 2005, IBM announced it would make available to its U.S. employees a PHR that integrates patient-centered information with data from medical and prescription drug claims, as well as a health risk assessment tool. Other large employers, including computer maker Dell and telecommunications giant Verizon, have rolled out or are considering similar services. And December 2006 saw several announcements about significant PHR efforts:

- A group of five major employers—Applied Materials, BP America, Inc., Intel Corporation, Pitney Bowes, Inc., and Wal-Mart—announced that they are funding an independent nonprofit organization to develop "Dossia," a web-based framework for maintaining lifelong PHRs.
- America's Health Insurance Plans (AHIP) and the Blue Cross and Blue Shield Association announced

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a model of core information and standards that their members will incorporate when developing PHRs to enable the portability of PHR data when consumers change coverage plans.

- The Robert Wood Johnson Foundation announced a $4.1 million program called "Project HealthDesign" that is funding nine multi-disciplinary grant teams who "will work collaboratively to design and test a suite of PHR applications that can be built upon a common platform.

The federal government also is promoting the use of PHRs—through the Department of Veterans Affairs My HealtheVet program, the Department of Defense TRICAREOnline program, and feasibility tests conducted by the Centers for Medicare and Medicaid Services—to determine how to transform their claims data into PHRs for Medicare beneficiaries. In addition, the Office of Personnel Management (OPM) has directed the nearly 280 health plans participating in the Federal Employees Health Benefits Program (FEHBP) to work toward offering enrollees access to PHRs containing data maintained by the plans. As early as 2009, OPM will begin limiting premiums and restricting FEHBP participation for plans that fail to embrace these and other health information technology (HIT) initiatives.

What Is a PHR?

PHRs are different from, but complementary to, EHRs. The primary distinctions between them are the intended audience and who controls the record. A PHR is an electronic record of an individual's health information for which the patient is the primary user and the locus of control for managing and sharing data, while an EHR is a computer-based record of patient health information intended primarily for use by healthcare providers. A fully functional EHR incorporates all provider records of visits, hospitalizations, and other encounters with the healthcare system. A fully functioning PHR incorporates all of a patient's care across settings, including data entered by the patient about care provided at home, and complete personal health information, including insurance and emergency contact information.

The Ideal. Ideally, PHRs would be interconnected with EHRs and other healthcare data sources, with information flowing freely in a single system, incorporating software tools that help patients participate in the management of their own health conditions and communicate with clinicians. Patients would be able to immediately view new test results, diagnoses, or care instructions, and providers could easily see changes in patient symptoms, medication usage, or other information. The PHR would include data entered by patients, providers, payers, pharmacies, and other sources of medical care. It would cover the full healthcare experience, incorporating clinical information (e.g., patient history, problem lists, medications, immunizations, laboratory tests, physician notes); administrative data (e.g., emergency contacts, insurance information, claims data, list of care providers); and tools to help patients better manage their own health, such as diaries to facilitate the tracking of pain, symptoms, and side effects; care instructions and disease management plans; physician-endorsed educational information; electronic messaging with providers; and the ability to schedule appointments, view test results, and renew prescriptions. Such a comprehensive PHR system would allow the record to become truly an individual's lifelong resource of health information, allow for patients to contribute to the collection and measurement of desired outcomes, and maximize opportunities for information technology-supported care management on the part of patients and providers. As part of an interoperable network, PHRs could yield significant benefits **(see box 1)**.

Current Reality. Current PHR products do not yet fully realize this vision; in general, PHRs today fall into

one of three categories: 1) standalone software completely under the patient's control, 2) a patient-oriented overlay to a provider's EHR, and 3) insurer- and employer-sponsored PHRs populated with claims data. Each approach has its strengths and weaknesses.

The **standalone PHR** is fully patient directed and offers interactive tools (e.g., reminders for preventive screening or links to educational content), but relies on data entered by individual patients or family members. The main drawback of current standalone PHRs is that they offer no interconnectivity with healthcare providers. Most standalone PHRs offer a place to enter information and store documents and allow patients to link to educational content or reminder lists specific to their health conditions, but they do not offer a platform for the patient to share information or communicate directly with his or her healthcare providers.

PHRs associated with a particular healthcare system can incorporate information from both patients and providers and may include tools such as online scheduling or prescription renewals, bringing them closer to achieving the potential benefits from interconnectivity. However, tethering the PHR to a single provider's EHR still has its limits; for example, a provider-offered PHR may populate the record only with information maintained in that organization's EHR, offering no data from other providers and payers, and only a few "integrated" PHRs allow patients to enter their own data or share it with their providers. Patients also may lose access to information in the integrated PHR if their relationship with that organization ends.

PHRs offered by an insurance company or an employer draw on data from claims databases, information obtained from pharmacies and laboratories, and patient-entered information—offering a more comprehensive overview of a patient's use of healthcare services. This type of PHR is sometimes linked with a health risk assessment tool, which tailors preventive care information to the individual and refers patients to relevant disease management resources. However, these products are limited because claims data can be both inaccurate and confusing, and, because they are not integrated with healthcare providers' information technology systems, they do not offer the benefits of interconnectivity between patients and providers. In addition, similar to the integrated PHRs discussed above, patients may lose access to their information if their relationship with the insurer or employer ends.

Challenges Ahead

Realizing the vision of PHRs will involve addressing a number of policy and practical challenges. PHR adoption has been slow in part because of limited consumer awareness of the technology and some provider concerns about how PHRs would affect clinical practice—barriers

BOX 1 At a Glance—Potential Benefits of PHRs

Activate patients: PHRs give patients better access to data and educational content that improve their ability to participate in healthcare and that also may encourage healthier behaviors.

- One-fifth of patients who had access to a physician-provided PHR reported acting differently as a result of information in the record.[6]
- By enfranchising patients, PHRs may be particularly beneficial in helping people with the self-management of their chronic disease(s).[7]

Improve patient compliance:

- PHR systems also can provide reminders about tests or appointments, make it easier for patients to get medication refills, and create a more continuous relationship between physicians and patients that facilitates shared decisionmaking.[8]

Increase patient safety:

- By improving communication between physicians and patients, PHRs may reduce outpatient adverse drug events and other errors.[9]
- Populating PHRs with provider-sourced data allows patients to correct mistakes in the doctor's record.[10]
- One recent study found that 70 percent of patients allowed to see their EHRs identified at least one error or omission.[11]
- Online access to PHRs also may aid providers in an emergency situation.[12]

Improve physician practice: A comprehensive PHR containing lifelong health information would give physicians access to a more complete patient history. This would facilitate diagnosis, particularly when integrated with an EHR that includes knowledge and decision support capabilities.

- Physicians could be updated more quickly to changes in their patients' conditions.[13]
- Because administrative functions can be handled in advance, PHRs can make patient visits more productive.[14]

Improve efficiency and reduce costs:

- PHRs can reduce paperwork and shorten turnaround time for tasks such as prescription renewal requests.[15]
- Systems that incorporate physician messaging and similar tools also reduce inbound telephone calls, improving staff productivity and increasing access for all patients.[16]
- Ultimately, better management of chronic disease stemming from the use of PHRs and EHRs may lead to significant cost savings.[17]

that a handful of national organizations have been attempting to address through public awareness campaigns. But four fundamental issues need to be addressed to enable the development and diffusion of the ideal vision of PHRs: 1) how to ensure the privacy and security of health data exchange via PHRs, 2) how to speed the adoption and use of fully functional EHR systems that would provide the base for PHRs, 3) the establishment of standards for PHR/EHR interoperability, and 4) clarification of how the information collected via PHRs can be used to support performance measurement and reporting to drive quality improvement.

Privacy and Security. Much about PHR privacy policy remains undefined, including the laws governing PHR privacy and potential breaches. The Health Insurance Portability and Accountability Act of 1996 (HIPAA), which sets minimum federal standards for the use and disclosure of personal health information, applies to physician practices, hospitals, health plans, and any "agents" performing functions involving personally identifiable health information on behalf of a covered entity. But commercial PHR vendors that offer software directly to consumers—rather than on behalf of a provider organization—are not covered entities and are not required to inform consumers what terms and conditions govern the privacy of their data or abide by the privacy provisions of HIPAA.

A key consumer principle for PHRs is that they are voluntary; and therefore patients should be able to decide who sees their records and what health information is shared with others. Ideally, PHR systems should give patients the power to approve record access; produce an audit trail allowing patients to see who has viewed their information; and notify consumers of security breaches—but this has not been the case to date.

There are a host of practical challenges to ensuring PHR privacy and security. For example, authentication of individual users remains problematic. To date, there are no generally accepted methods or policies for initially proving the identity of an individual in order to issue online credentials or for repeated authentication of that individual's identity within an online environment.

Newly emerging payer- and employer-sponsored PHRs that are populated with claims data are particularly challenging in this regard; indeed, consumers using these products may have little control over secondary uses of their data by the PHR vendor, such as post-marketing surveillance of adverse drug events or targeted marketing.[1] Ideally, consumers would be fully informed up front of the vendor's policy for using their personal information; however, there are currently no clearly identified entities responsible for protecting consumers in the rapidly evolving world of PHRs and related technologies.

In some instances, exceptions to patient control may be desirable. One widely touted potential benefit, for example, is that PHRs can provide access to patient information during an emergency. But who may consent to such access if the patient is not conscious? Some have recommended that privacy policies contain a "break glass in case of fire" override available for such situations—however, this override mechanism should include specific permission levels and time-defined access and audit.[2]

Similarly, giving "proxy" PHR access to a family caregiver, such as a child of elderly parents, may benefit patients by allowing that person to supervise healthcare. In many cases, patients themselves can give consent to such access; however, what happens if they cannot, such as if they are incapacitated by dementia? Proxy access also may help parents of minor children better manage family healthcare decisions, but that benefit must be weighed carefully against the need to protect adolescents' right to privacy where guaranteed under state law.

Promoting Diffusion of EHRs. Ultimately, realizing the promise of PHRs is contingent on the widespread adoption of EHR systems that bring all of a patient's

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clinical information into one system that can then be leveraged, mined, and managed in a PHR. Surveys estimate that only 15 to 30 percent of practices use even a rudimentary EHR at this time.[3] Until such numbers increase, PHRs will not realize their full potential.

Interoperability Standards. The interoperability of PHRs and EHRs—or the ability to seamlessly exchange data with health information systems maintained by physicians, hospitals, payers, pharmacists, and others—is essential to achieve the potential of PHR technology. Current PHR systems are developing independently of one another and may, at best, be interoperable with one or two EHR systems maintained by specific organizations. Many believe that national data standards for information exchange will be critical to optimize PHRs and promote adoption. Standards will ensure that all PHR and EHR systems speak the same "language" and will dictate what type of data are exchanged (e.g., patient information, family history, diagnoses), how those data are packaged and coded, and how data transfers among systems occur.

Use for Performance Measurement and Reporting. In addition to the technical and operational hurdles that need to be cleared to unleash the potential of PHRs, more work is needed to explore the unique and valuable ways PHRs can support performance measurement and reporting to drive quality improvement. PHRs offer three critically important applications in this regard. First, the PHR is well-poised to capture information about care processes provided by the patient or family members and integrate it with information about services provided by professional caregivers. For example, the PHR provides a mechanism for collecting information to gauge patient "activation"—or the degree to which patients have the knowledge, skills, and ability to execute their care plans. Such measures may prove to be important components for future approaches to risk adjustment and for strategies to pair process and outcome measures in order to generate more comprehensive and accurate assessments of system performance.

Second, the PHR, as a patient-centered tool, offers the opportunity to gain greater insight into patient outcomes, because it provides access to information beyond traditional clinical variables that define patient health to encompass a broader definition of "health-related quality of life" that accounts for other factors such as functional status, perceptions of health, quality of life, and patient preferences.[4] In this respect, the PHR can help expand the vision of performance measurement beyond the constraints of the conventional healthcare delivery system—not only to capture a more complete picture of the range of services a patient receives, but also to develop a more complete picture of the multiple, interrelated variables that contribute to patient health and well-being.

Finally, because the PHR provides a direct line of communication with the patient, it offers the opportunity to obtain more timely information about patient experience with the care delivery process and more "real-time" and condition-specific assessments of patients' needs than current retrospective survey instruments can provide. This information would be more actionable for caregivers and promises to strengthen measures of "informed decisionmaking," care coordination, and compliance.

While there is great potential for PHRs to advance quality measurement, a number of operational issues need to be addressed. For example, it will be important to develop standardized approaches to enter and extract data from PHRs that are conducive to performance measurement and respectful of patient privacy. In addition, methods to audit and verify the data will be important before the information is used for reporting or quality improvement initiatives.

Current Efforts to Advance PHRs

There are a variety of public and private sector efforts under way to address these issues and pave the way for the development and adoption of the envisioned PHR. One of the leading entities is the American Health Information Community (AHIC), a 17-member public-private commission established by the Department of Health and Human Services (HHS) in 2005 to provide input and recommendations on the development and adoption of HIT, including state and federal privacy and security policies that affect PHRs.

The federal government also has played a leading role addressing interoperability issues, primarily through the Office of the National Coordinator for Health Information Technology (ONCHIT), an office established within HHS in 2004 to facilitate the development and nationwide implementation of an interoperable HIT infrastructure within the next 10 years. HHS also is working with the states and the National Governors Association to address variations in state-level privacy and security practices and laws that may affect the interoperability of healthcare information technology.[5]

Private sector leaders also have begun to explore interoperability, as a handful of major commercial payers, led by AHIP and the Blue Cross Blue Shield Association, are now asking members to incorporate standard information and use common standards for transmitting patient data from one insurer to the next. This effort could be an important step toward ensuring the portability of personal health data in a PHR environment. The not-for-profit organization, Connecting for Health, has been another important private sector leader in shaping the research and policy agenda surrounding PHRs. The American Health Information Management Association and the National Health Council also have been important in raising awareness of PHRs and framing the debate about how the technology can be leveraged to improve health system performance and facilitate a more patient-centered approach to care.

Conclusion

Many tout the PHR as the "breakthrough" technology of the future, and there is

reason to be optimistic, given its many diverse capabilities. As part of a fully interconnected HIT network, PHRs have the potential to improve health system efficiency and quality, empower patients as equal partners in their own medical care, and open up new possibilities to substantially advance performance measurement. The PHR builds on strong consumer interest in having greater access to and control of personal health information and supports the current model of "consumer-oriented" healthcare that payers, employers, and policymakers continue to advocate as the key to improving quality and driving down healthcare costs. But realizing the potential of PHRs means addressing consumer concerns about the privacy and security of health data exchange; promoting the adoption of EHRs; creating national standards for PHR/EHR interoperability; and clarifying how PHR data can be used for performance measurement and reporting. Public and private sector groups hoping to expand PHR adoption are aware of these hurdles. Their challenge now is to determine what policies and practices will most effectively overcome them and move the widespread use of PHRs closer to becoming a reality. ●

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