Personal Health Records: An Emerging Trend

Just how good PHRs are is still uncertain. What is clear is that a confluence of powerful forces—political, commercial, technological, cultural, and clinical—are coming together to push these patient-controlled, electronic records forward.

“There are all kinds of reasons” for the movement towards these records explains David Lansky, PhD, Senior Director at the Markle Foundation, who has been studying personal health informatics closely for 6 years. Reasons include concerns for economy and efficiency, the fuller use of data to improve patient outcomes, and greater empowerment of patients as health care partners. Lansky notes that “for cancer care, there’s a shift going on so that much of the care that we need, we give to ourselves in our own homes. It’s harder to do self care without information as compared to with it. There’s a hope that PHRs will stimulate a new set of services to improve peoples’ ability to manage their own health at home.” PHRs may confer a wide array of practical advantages to both physicians and consumers, especially in terms of making health data portable.

The PHR field is a “new, unformed market. It’s mostly smoke and mirrors,” says Lansky, noting that the PHR market is so new that nobody is tracking its size yet. While today PHRs seem far from the world of working oncology offices, that situation may change soon. In a very small survey of American Society of Clinical Oncology (ASCO) members working in both major urban centers and in the heartland, hardly anyone had encountered a patient using a PHR (see Members’ Comments).

Defining Terms

Patient-controlled PHRs differ from electronic medical records (EMRs) and from electronic health records (EHRs). An EMR contains the results of encounters between a health care professional and a patient which occur during episodes of patient care. A PHR includes electronic copies of information that patients have received from their providers and may include data they enter themselves. An EHR integrates a person’s multiple, physician-generated EMRs and his patient-generated and -maintained PHR.

This article will survey the subject of PHRs. It will describe the two main types that are being offered currently (portals and nonportals). It will explore the stumbling blocks that remain before PHRs become an everyday part of oncology offices. There are serious sticking points to be overcome before PHRs find wide acceptance.

Two Categories of PHRs

When people discuss PHRs, they are actually discussing one of two kinds of emerging services, explains Lansky. “I

distinguish portals from personal health records. They are different. A portal is like a view into something. They’re typically offered by a large health system or hospital. They will show labs, histories, and so on. People get a partial view of their own data.”

“The other kind of service is not connected to any one provider nor tied into any one system. In theory, these can collect data from anybody and pull it together for the patient to look at,” he says. These new services will either rely on a data hub that accesses and integrates data from many sources or provide that set of connections to numerous sources themselves.

“There’s no general name for the nonportals,” says Lansky. “Two varieties are emerging now.” One type comprises PHR platforms (like Google, Health Vault, and Dossia, discussed later). The other includes personal health applications (programs that use personal data for some purpose).

Interest Growing Across Many Sectors

Organizations involved in promoting PHR usage include arms of the federal government, such as the US Department of Veterans’ Affairs, major universities, and corporations. These include behemoths such as Wal-Mart and AT&T and many high-tech firms. Microsoft began offering consumers a PHR service called Health Vault last fall. “Microsoft was the first to offer a PHR platform that could pull data from multiple sources and allows multiple applications to access and use it,” says Lansky, although other PHR services did exist before Health Vault.

Major insurers including Aetna and Kaiser Permanente and many drug companies are deeply involved. These diverse sorts of organizations are encouraging consumers within their orbit of influence to begin using PHRs, and sometimes are providing consumer incentives.

With support from Children’s Hospital of Boston, a large group of major employers has established a nonprofit consortium named Dossia. Its mission is to provide workers with access to their own, previously inaccessible health data.

Dossia involves more than 5 million eligible employees. The consortium promises that records will be secure, private, and portable, even if the employees change employers, health plans, or doctors. Currently, participation is voluntary.

Appealing in Many Ways

Many consumers relish the idea that PHRs will provide them with a systematic way to possess, access, and share their

medical information. “When people are surveyed about why they want access to their records, one major theme is that they want the information so that they can understand it and share it with relatives and other sources of care,” says Lansky.

Consider the convenience and advantages for both doctors and patients. Clinical personnel might slash the energy devoted to taking a patient’s medical history and tracking down lab results and imaging studies. Accuracy might be increased as a continually updated PHR might yield a richer, more reliable set of facts than a patient can recall.

Edward Ambinder, MD, Clinical Professor of Medicine at the Mount Sinai School of Medicine, says, “For patients, it’s a big problem that each time they see a new provider they have to repeat their medical history. The new doctor always says, ‘Get me the CT scans, x-rays, and lab tests.’ It’s a pain for the doctor, too. It takes tremendous time.”

He envisions PHRs eliminating tons of legwork. That will happen, he says, “if we can convince patients that the data is safe. And if we can set up standards so all the data from all over can be sent to a database that can understand the information and format it for the patient so that it becomes a seamless process for the patient. There’s a long list of ‘ifs’ surrounding these PHRs. Still, I expect that within five to ten years they will be a common component of health care in this country.”

Ambinder cites ASCO’s efforts to help survivors manage key medical data, efforts meant, in part, to address the potential of cancer treatments to have negative health impacts years after their use. For certain cancers, ASCO has put together a chemotherapy treatment plan and a chemotherapy treatment summary for patients who have finished treatment. These reports can form the basis of PHRs.

To consumers, PHRs also promise to allay another overriding concern, purging their records of errors. “Tons of mistakes crop up in medical records. I’ve heard of a person coming in with a record showing that they’d had a surgery that they’d never had. In a recent survey, 80% of the patients questioned want to look for those mistakes,” Lansky says.

The records promise to simplify many health care transactions. “PHRs could be useful when a person is refilling their medications. They may offer a chance to reduce medication errors that might occur around interactions. If a prescriber can look at your current medical list, they can avoid drug interactions. This might be better than just asking you,” says Lansky. PHRs may prove useful in other ways such as scheduling appointments and reviewing lab results.

Mark Gorman, with the National Coalition for Cancer Survivorship says, “One major problem with electronic medical records today is that they do not accommodate the

fragmented nature of cancer care. We all have lots of specialists. With the original vision of EMRs, each specialist keeps their own electronic files. What’s been missing has been a way for any provider who needs access to some piece of information to get it, instead of my internist getting on the phone with the radiologist to discuss the report that was just faxed over. There’s an emerging recognition of a need to pull this stuff together.”

Systems such as the Veterans’ Affairs, Harvard Pilgrim, and Kaiser Permanente represent small pockets in the health care world where this kind of integration is working well. Outside of such self-contained systems there are still serious technical obstacles to the seamless ingathering, structuring, and redistribution of PHR data.

More Possible Advantages: The Computer As an At-Home Nurse

“A new industry is developing around electronic resources and services designed to help patients manage their own chronic illnesses, including cancer, at home,” says Lansky. “There’s a hope that PHRs will stimulate a new set of services that improve peoples’ ability to manage their own health at home. It’s harder to do self-care without the information as compared to with it.”

Efforts have begun to use computers to monitor a patient’s condition while that person is at home and then treat him there remotely, with the computer as the intermediary. “Computers are actually connecting to devices in a patient’s home for purposes such as checking Coumadin levels and monitoring patient conditions such as atrial fibrillation,” says Lansky.

In this realm, a large and storied list of organizations formed the Continua Health Alliance in 2006 to address “skyrocketing healthcare costs by creating an ecosystem of personal telehealth solutions.” Membership includes 133 companies. Among them: Astra Zeneca, General Electric, Intel, Nokia, and St. Jude Medical Center.

The Alliance has devised ways to allow people with chronic diseases to transmit health information to their doctors, by means of communicatively empowered devices, including blood pressure monitors and pulse oximeters. It has also created systems whereby patients receive health information and actual care remotely.

Clear Possible Downsides

“With PHRs, there are risks and complexities involved” for both patients and doctors, warns Lansky. “One set of risks is around privacy and people’s trust that their information will be used appropriately, in ways that they want. As companies like Microsoft and Google get into the game, some people see that as a famous brand. For others they symbolize

[objectionable] corporate behavior. The companies are very conscious of these issues.”

Google now offers a free PHR service called Google Health. When someone posts their health information on Google Health, the program responds by sending them information on health topics it identifies as being relevant.

“Most of the large insurance companies are offering PHRs and there is a fair amount of mistrust” with regard to them, says Lansky. “Employers are offering their workers these things. Will employees feel more or less safe when their employer becomes involved with their personal medical data?”

“The anxiety about this technology is very real,” says Lansky. “The likelihood that people won’t use these services is a real fear.”

Discussing the large insurers and hospitals now offering portal views to patients Lansky says, “It’s complicated about misuse. They are acquiring information about you in a completely legal fashion under the contract that you sign. You gave them permission to access your data to justify payment and they gather lots of it. The plans are collecting more and more data.”

“One thing they can do with all of this information is give the consumer a view of it. They may have other uses though which could be areas of concern,” he says. “Whether or not you have access to that data through a portal or PHR has nothing to do with their collection of it.”

Physicians may eventually find that in some ways PHRs complicate their lives. “There are a lot of expectations that PHR might become THE record that a patient uses when coming to see a new doctor,” says Lansky, “But for specialty clinicians, that raises a lot of questions. How does a specialist know if the PHR is accurate, complete? Does the doctor just ignore it and rely on his usual sources of information?”

Doctors may also face PHR-induced data overload. “A doctor may wonder if he’s going to be inundated with data from patients capturing their blood pressure every five minutes,” Lansky says.

Perspectives From ASCO Members

The dynamic nature of a person’s medical condition and the possibility of patient tinkering with the facts are other significant issues, explains Lawrence M. Shulman, MD, chief medical officer with the Dana Farber Cancer Center. “The PHR isn’t a bad idea but there are problems,” he says. “Let’s say I give you your whole record on a CD. Health is dynamic. That six-month old CD may not be fully accurate today. If I talk to someone else, doctor to doctor, I give him the current story.”

“Another issue is that you can actually go in and make critical alterations to that CD. The record may say you’re on high-doses of oxycontin. Integrity of the records is an issue,” says Shulman. Peter Yu, MD, concurs: “How does one verify the accuracy of information in a PHR? The patient decides what gets in and what does not. What isn’t in the PHR may be just as important in understanding the patient as what is.”

Shulman cites the challenges involved in bringing information from diverse sources together in a seamless, efficient fashion. “Medical records are organized very differently from one practice to another. How can they be translated in such a way that the patient will understand them and other physicians will also understand?”

Imagining how such a blending of apples, oranges, and pears might work, John Cox, MD, foresees a time when “there might be an interface program that will ‘subscribe’ to your health records in many settings and coalesce a copy for you. This might be similar to what I do with Quicken for home finance.”

Shulman notes the further issue that not every patient will want to or have the sophistication to maintain a PHR, if doing so demands effort. “Some cancer patients would work 24/7 on this kind of thing. Others won’t do it.”

Dean H. Gesme, MD, with Minnesota Hematology Oncology is the rare ASCO member to report an encounter with a patient who raised the issue of PHRs. He says, “A couple of patients came in with electronically formatted pieces of paper, created from web sites the patients learned about through an employer or insurer. Both times the records were extremely detailed about which toenail was removed in 1978, how and when. One of the patients had actually received chemotherapy out of state and had most of those records recorded. It was all entered by hand by that individual.”

“Seriously though, cool stuff is happening and it’s obviously where we need to go. But there is a lot of work to be done around standardization. Ultimately the federal government will have to impose standards but under the current administration, there’s a lack of will to do anything about this,” says Gesme.

Stay Tuned. . .

The arrival of PHRs in oncology offices seems inevitable at this point although their impact for good or for disruption remains difficult to gauge. ASCO will continue to observe the trends, attempt to influence the shape of the new developments, and equip members to optimally manage this new and potentially huge form of technology.

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