

# Health Records for the People: Touting the Benefits of the Consumer-based Personal Health Record

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*Consumers who maintain personal records of their health history help bring comprehensive information to the point of care. And they have the potential to be more actively involved in their health.*

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Consider the following scenario. A patient is visiting a cardiologist for the first time. The physician asks the patient what medications he is taking. This is not a simple question, and the patient has trouble recalling all the necessary information: which medications he takes, the dosage for each, how often he takes them, how long he has been taking them, and the prescribing physician for each. He is not entirely sure why he has been prescribed one of them.

The patient is not alone. Most consumers find it difficult to answer at least some of their healthcare providers' questions: "When was your last tetanus shot?" "What is your total cholesterol?" "When was your last mammogram?"

That's because consumers see multiple healthcare providers, and they rely on those providers to keep their health information. Most consumers take little personal ownership of their information. Given that it is often not easy or even possible for providers to exchange patient data in a timely manner, both physician and patient in a given encounter may be unaware of the patient's complete health history. The result can be a rescheduled appointment, delayed treatment, a duplicated test, or compromised care. It can also contribute to a lack of engagement by consumers in their own health.

## Have Record, Will Travel

Now consider a different version of the scenario. Tucked under the patient's arm, ready to be accessed when needed, is a record of care that he has compiled from his visits to other providers. The cardiologist asks the patient what medications he is taking. The patient opens his record and provides the requested information.

Something else is different in this scenario, also. The patient has a better understanding of his health because he has been gathering information during physician visits and documenting it in his own record. The information he gathers leads him to better prepare for his appointments. He asks more questions to further understand what he is told. In short, he is taking more ownership of his health information and his health.

The folder tucked under the patient's arm is his personal health record (PHR). The next patient the cardiologist sees may maintain his PHR on a secure Web site or on his home computer. He may have brought it with him on his PDA. The PHR is new, and the formats vary. But the goal is the same: more information at the point of care, better communication between patient and physician, and greater consumer engagement in healthcare.

## The Consumer-based Record

PHR products are many and multiplying, but formal definitions are few. AHIMA defines the PHR as

an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.<sup>1</sup>

It is important to emphasize that the PHR is maintained by the consumer, not the provider, and that it does not replace any provider's legal medical record. Simply put, the PHR is the patient's compilation of his or her health information from all providers. This model differs from a "tethered" record, sometimes also called a PHR—a subset of data compiled by the provider and offered to the patient, often through the provider's Web site. Such records function as a patient's view into the provider's electronic record. Some providers also offer consumers the ability to build and maintain a PHR through the provider's site. Tethered and untethered models can thus offer similar benefits—the two-way sharing of health data between consumer and provider—but the untethered definition stresses consumer control and the inclusion of information from multiple providers.

PHRs are gaining in popularity with more than patients and physicians. The Office of the National Coordinator for Health Information Technology includes PHRs as part of its strategy for implementing electronic health records and a national health information network. Vendors have introduced a proliferation of PHR products in recent years. The sheer number can cause confusion. For consumers to embrace PHRs, the healthcare industry must provide education on the proper use of a PHR—including security and confidentiality—and the technical standards that facilitate the exchange of PHR information. (For more on HIM's role in public education, see the sidebar below.)

There is plenty of room for consumer education. A Harris Interactive poll in the summer of 2004 found that two in five adults (42 percent) keep personal or family health records. Of those who did not, however, the benefits were clear: 84 percent thought it would be a good idea. Respondents agreed that a PHR would help them provide physicians with useful personal information, aid in recalling what care has been received, give access to information in case of an emergency, and help ensure the proper use of prescription drugs. PHRs are especially helpful for patients with chronic conditions that call for careful monitoring of health information and thorough patient-physician communication.

## **Types of PHRs**

The future of the PHR is electronic. However, neither the provider community nor the consumer is ready for entirely electronic records at this point, and various PHR formats are in use. These can be considered incremental steps toward the end goal of an electronic, universally available record.

Today people create and maintain their PHRs in four common formats: paper, personal computer, Internet, and portable devices.

### **Paper-based**

This is the most common way that people start their PHR. (Among respondents in the 2004 Harris Interactive study who kept PHRs, 86 percent kept them as files in a drawer.) Most people already have started PHRs at home and aren't even aware that they are doing so. Paper-based records include file folders containing copies of explanation of benefits, pharmacy receipts and medical instructions, immunization records, and similar common documents.

To share paper-based information with providers, the patient must carry his or her record (or just the pertinent parts) to every doctor visit. While at the provider's office, it is usually easy for the patient to get photocopies of the visit notes and add them to the folder.

### **PC-based**

Some consumers store health information locally on their personal computers. Consumers can scan documents into their computers or complete electronic medical forms, using PHR-specific or generic software. When visiting providers, consumers download the files onto a memory stick or disc for the provider to view during the visit.

### **Web-based**

Web sites offer the ability to store PHR information in private online accounts. The consumer gives access to providers and others simply by granting them rights to view the information via the Internet. Consumers can send information to be included electronically or fax documents to the service. There is usually a small per-month fee. Because the sites can be accessed

around the clock and from any PC with Internet connectivity, the services provide a great way to access information in an emergency situation or when away from home for long periods.

## Portable devices

The capabilities of portable devices are expanding rapidly. Options include smart cards, PDAs, mobile phones, or USB-compatible memory devices (such as memory sticks) that plug in and exchange data on almost any PC. In most cases, portable devices are used as an add-on feature to desktop- and Web-based methods or as a hybrid PHR solution.

## Choosing the Best Format

Selecting a format is based primarily on the consumer's familiarity with, access to, and comfort with technology. The provider's capability is also a factor. If the provider does not have a PC or Internet access in the examination room, a PHR copied onto a memory stick or accessed via the Web will result in a delay as the physician seeks out a PC with Internet access. The consumer should thus consider both factors before choosing a format. A consumer may choose to keep a paper-based PHR if his or her physician cannot access an electronic one. When the physician's office becomes electronic, the consumer could transition, also.

There are some general trends in preferred format. Half of people age 65 and older say they prefer paper, compared with 20 percent of those younger than 65.<sup>2</sup> Most older consumers were not raised with PCs or the Internet and likely did not use much technology during their careers, so it's understandable that paper is their preferred format. Only 10 percent say they prefer a Web-based record.

Thirty percent of respondents under age 65, however, say they do prefer to keep their PHR online. Web-based services are likely to gain greater favor for several reasons. Older generations are expected to come online in increasing numbers—Americans age 55 and older are predicted to have the highest rates of online adoption over the next two to five years, according to Manhattan Research.<sup>3</sup> Secondly, physicians are increasingly communicating with their patients online. Seven in 10 providers currently offer medical advice online, and just over half allow patients to preregister online.<sup>4</sup> Nearly 90 percent of adults who use the Internet would like to interact with their providers online; more than a third say they would pay for that privilege.<sup>5</sup> The trend toward consumer online health services is clear.

Portable devices or PC-based records appear to be the preferred format for the majority of people under age 65. Forty percent say they would use this type of PHR.

## Ensuring Security of the Record

Ensuring the security of electronic PHRs is an important issue in the minds of consumers. Privacy and security were the highest concerns among all adults in the Harris Interactive study (68 and 66 percent, respectively, considered these "serious concerns" in keeping an online record). That is far greater concern than shown over other issues including errors in the record, out-of-date information, and the possible inability to understand medical information received from the provider.

If consumers are to embrace PHRs, they must first be assured that their information will be secure. When considering PHR products and services with online components, they must know the features that will give them confidence in the security of their information. Because the PHR is not a legal record, the healthcare industry should take the lead in creating industrywide answers for consumers. Individual vendors should inform their customers of what they do to ensure security. HIM professionals can play major roles in educating the public on the benefits of a secure, up-to-date, and accurate PHR. (For more, see "[Public Education](#)" below)

The one constant in a patient's encounters with different healthcare providers is the patient. So it makes sense that the patient help serve as the link to his or her health information. With a well-maintained PHR, patients can help bring more information to the point of care, improve communication with their physicians, and increase their engagement in their own care.

### Public Education

#### HIM Professionals as PHR Advocates

HIM professionals serve the healthcare industry and the public by managing, analyzing, and employing data vital for patient care. They understand how health information is gathered, how it is stored, and how it is used. They understand documentation and its importance in providing quality care. With this expertise, HIM professionals can play a key role in educating consumers and providers about the benefits and correct use of the PHR.

This role—the PHR advocate—will require knowledge in the following topics:

- Health information privacy and security
- General healthcare reimbursement
- Operational workflow process
- Change management
- Health informatics
- PHR data standards
- Interoperability standards
- Healthcare organization and delivery system knowledge<sup>1</sup>

It is expected that a qualified PHR advocate will hold an RHIA or RHIT and have three to five years of healthcare experience.

### **AHIMA's Community Education Campaign**

In an effort to educate consumers on the PHR, AHIMA introduced a public awareness campaign in early 2005. The Community Education Campaign was developed to educate consumers and providers about the PHR and patient rights. The goal is to train HIM professionals in each AHIMA component state association (CSA) so that they may take the message back to their individual states and make presentations to consumer groups in their areas.

Trainees receive a packet that contains a PowerPoint presentation, handouts, audience survey, fliers, and newsletter templates to promote the campaign. The materials help presenters with their presentations and also ensure that consistent information reaches consumers nationwide. Members interested in joining the campaign are encouraged to contact their CSAs.

AHIMA also offers a consumer Web site about PHRs at [www.myPHR.com](http://www.myPHR.com). The site explains health records in general and personal health records in detail. Consumers can find forms that will help them begin their PHRs by organizing their health information and pointing out any gaps in that information. A long list of PHR products is also available on the site.

HIM professionals have always looked at the health record as a whole, while providers view it in pieces. They can clearly see how the PHR will help the provider and consumer in many ways. Now they can help clear up confusion around the PHR and educate the public and providers on the benefits of a consumer record.

### **Note**

1. AHIMA. "The Role of the Personal Health Record in the EHR." *Journal of AHIMA* 76, no. 7 (2005): 64A–D.

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### **Notes**

1. AHIMA. "The Role of the Personal Health Record in the EHR." *Journal of AHIMA* 76, no. 7 (2005): 64A–D.
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5. Harris Interactive. "Two in Five Adults Keep Personal or Family Health Records and Almost Everybody Thinks This Is a Good Idea." *Health Care News* 4, no. 13 (2004). Available online at [www.harrisinteractive.com/news/newsletters\\_healthcare.asp](http://www.harrisinteractive.com/news/newsletters_healthcare.asp).

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