Defining the Personal Health Information Management Role

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As HIM professionals grapple with the transition of provider records from paper to electronic, the consumer-driven personal health record (PHR) can seem to be a distant blip on the radar. However, PHRs are arriving quickly, and they represent a major change in managing health information. PHRs embody the industry's transition from a narrower, provider-centric model to an all encompassing, patient-centric model.

The PHR is seen as the tool to achieve patient-centric care in the Department of Health and Human Services' goal of achieving a national health information network. It is believed that the use of PHRs will result in improved quality and safety and decreased costs in healthcare.

This transition to patient-centric records challenges HIM professionals to realign their thinking about health information management. They must begin to consider their roles and responsibilities in the arena of personal health information management.

The PHR Marketplace

PHRs today are available from a variety of sources and in a variety of formats. There has been no agreed-upon industry standard. However, early definitions did attempt to give shape to the PHR, in particular, addressing issues of record ownership, control, and sources. In 2005 the AHIMA e-HIM Personal Health Record Work Group described a 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.[1]

The definition refers to an electronic record because it is meant to be forward-looking. It is realistic to assume that many people will start their PHRs on paper. Although the technology exists, the sociological and cultural framework to move patients toward greater accountability in their healthcare and in its documentation is in its infancy.

In 2006 the Connecting for Health Personal Health Work Group described seven attributes of an ideal PHR:

1. Each person controls his or her own PHR.
2. PHRs contain information from one's entire lifetime.
3. PHRs contain information from all healthcare providers.
4. PHRs are accessible from any place at anytime.
5. PHRs are private and secure.
6. PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it.
7. PHRs permit easy exchange of information across health care systems.[2]

However, no current PHR includes all of these attributes. As Harry Rhodes wrote one year later, "Many current electronic PHR offerings are just one evolutionary step up from paper medical files."[3] While there are interesting products being offered, many are somewhat limited in value. PHR products are currently found in disparate locations and formats and built upon varying models.

The Connecting for Health Work Group concluded in its report that "the immediate effort to catalyze health care transformation must include a strategy to create a networked environment for PHRs and related technologies that takes advantage of these currently available digital data streams," such as health claims data, pharmacy data, diagnostic images, and lab data. "Providers can gradually form and join networks as their systems increasingly interoperate. In fact, networked connections to PHRs could help accelerate the EHR adoption curve as clinicians see advantages to joining the network."[4] This is exactly what Google, Microsoft, and Revolution Health are banking on in introducing online PHRs.

While their models vary somewhat, each of them will provide technical architecture enabling patients to create and maintain their personal health records and providers to access this information and begin building their own EHRs. These services are currently provided at no cost to patients and providers and with assurances of privacy and security. Major laboratories and pharmacies partner with these services to allow access to health data as requested by the patient.

In April 2008 the National Alliance for Health Information Technology concluded a year-long process to create a consensus-based PHR definition based on literature reviews and public comment. The work resulted from a contract issued by the Office of the National Coordinator for Health Information Technology to reach agreement on definitions for five key health IT terms.

In mid-May the definitions were in draft form, waiting presentation to the American Health Information Community. When this practice brief went to press, the PHR definition described an electronic record wholly managed by the consumer, conforming to nationally recognized standards, and capable of exchanging information with multiple sources.

New PHIM Roles and Responsibilities

PHRs offer HIM professionals a wealth of new roles and responsibilities, whether it be in developing policies and procedures for their use in healthcare, educating consumers on how to use them, or exploring privacy and security requirements. The new role of personal health information management will be boundless as the healthcare industry transitions to a national health information network.

Growing into a New Role

The emergence of the PHR challenges HIM professionals to develop new roles in personal health information management (PHIM). These roles and their responsibilities involve:

Privacy, security, and data integrity. When evaluating a product, HIM professionals might determine who can access the data. How can the organization tell when someone has accessed the data and what they did? Does the product make use of encryption, passwords, audit tracking, and permissions?

When information can be accessed by multiple users, how is data integrity maintained? Can a physician trust the information provided by the patient? Can the patient access and change the physician notes?

Records custodian. What about the suppliers of the PHR? Who are they? Are they a HIPAA covered entity? Are they the custodian of the information? Do they have policies and procedures on access, privacy and security, and health information exchange? What if there is a confidentiality breach? How will they address it? How do they use and protect the data that they store?

Legal health records. Where does the PHR fit with the legal health record? AHIMA's definition of the legal health record does not include the PHR, but each organization must have its own policies that address information provided by the patient. How does the organization address this information if it is used by the physician to make clinical decisions?

Data mining. Many organizations stand to gain from data mining. Who will control mining of PHR data, and how will it be controlled? Will organizations be able to access information for research purposes? Will this information allow organizations unprecedented opportunities for improvements in healthcare? Will it lead to even greater transparency?

Patient advocacy. Is there a role for HIM professionals as patient advocates? Only 1 percent of the population now maintains a PHR, but consumers are beginning to speak out and ask for what is important to them as their role in the healthcare delivery system changes. One consumer representative at the 2008 Healthcare Information and Management Systems Society convention spoke up and stated that consumers want PHRs that allow them access to information that will give them a greater ability to drive down healthcare costs.

The challenge for HIM professionals will be to clearly discern where they fit in this new patient-centric healthcare model. How will this affect health information management?

In the patient-centric healthcare model, patients will demand more information from the healthcare industry. They will begin to ask for more for their dollar. The industry will be driven more by patient choice. New regulations will arise because of this.

Already, HIM professionals are being asked to determine how to apply privacy and security guidelines to information available via PHRs. HIM professionals will need to know where to draw the line between the PHR and the facility or provider healthcare record. That line will become more blurry as the healthcare industry moves to a national health information network. The interoperability of records between providers and patients raises questions about custodianship.

It is only natural to assume that patients may eventually expect services that will help them manage their PHRs. Health data banks and entities that provide the technological architecture on which to build a PHR may benefit from the expertise of HIM professionals.

What new roles and responsibilities will be available for HIM professionals in the management of personal health information? Will there be a need to apply the basic concepts of record management to PHRs? The figure "New PHIM Roles and Responsibilities," above, illustrates the issues where HIM practice could intersect with PHR management.

Gauging the Current State of PHIM

Many questions remain about the management of personal health information. Although it is difficult to answer these questions at this point in time, AHIMA's PHR Practice Council, in conjunction with the Missouri Health Information Management Association (MHIMA), developed and posted a survey to determine the current status of PHIM; identify current processes (or lack thereof) used in PHIM; and determine which of these processes best address the significant issues in PHIM.

The survey was posted on the MHIMA Web site. Members were invited to complete the survey. There were 181 respondents.

Half of the respondents were HIM professionals working in the hospital setting, and 14 percent were from educational institutions. The third largest work setting was the integrated delivery system, 13 percent.

The survey findings indicate that PHRs are becoming an everyday part of health information management. Respondents indicated an increase in the frequency of patient requests for copies of medical records for personal use in the last year. Responses also indicated that patients provide health information from other providers in various formats. The most frequently used format is still paper (66 percent). Forty-two respondents (26 percent) indicated that patients provide compact discs to share their health information. Seventy-one percent reported no difficulty in viewing patient-provided information.

HIM professionals should prepare for the increasing interest in PHRs. Organizations must plan how to store patient-provided PHRs in various media formats. This storage must be secure. It may be appropriate for HIM and IT departments to work together to determine the best methods of viewing patient-provided information and develop policies and procedures to guide staff.

Respondents generally agreed that providers use the information generated by the patient to make decisions about care. Patient-provided information is retained in the facility health record in most cases, but only about half of the respondents indicated that they have developed policies and procedures regarding patient-provided information. An even smaller percentage of respondents indicate that they have developed documentation standards that include information provided by patients. Only eight respondents indicated that they have included PHRs in their organization's risk management plan.

HIM professionals should consult with risk managers to determine if the use of a PHR poses any risks to the facility. They should ensure that PHRs are addressed in organizational policies and procedures, and then determine how to indicate that the information is patient-provided.

Out of 22 respondents who indicated that their facilities have developed a PHR, 17 indicated that they were participants in its development and implementation. Their roles varied greatly. Some acted as consultant, help desk, subject matter expert, privacy officer, and trainer.

Respondents listed many interesting projects, including a pilot to develop a one-hour educational session. During the pilot, information about myPHR.com and the printable PHR forms available on the site were loaded onto a thumb drive and given to HIM employees. The project was extended to the community in early 2008. It is obvious that with their skills and background, HIM professionals play an important role in the development and adoption of PHRs.

The majority of respondents indicated that they have applied HIPAA privacy and security standards to the PHRs that their organizations have developed. While most of those respondents do not consider the PHR to be part of the legal health record, 39 percent reported that their organization does consider it a part of the legal health record. Clearly there are questions about the inclusion of the PHR as part of the provider's legal record.

Some argue that the PHR should not be included because it originated with the patient; others argue that if the information is used by the provider to make healthcare decisions, it should be included in the legal health record. These discussions should continue among HIM professionals.

Survey respondents identified new roles and responsibilities including patient authentication, outside records analyst, and health data coordinator. Others reported verifying appointments scheduled through the PHR, training staff on the use of the PHR, and teaching upcoming HIM professionals about the PHR. It is of interest that these are all practical roles that would be a natural outgrowth of the need to manage the PHR. In time, these roles will expand. Health information managers may want to evaluate current processes to determine if assigning these responsibilities would be helpful to the management of the PHR in their facility.

The information gathered in the survey offers a snapshot of current impacts and practices regarding PHRs. However, comparing the survey results to the goal of empowering patients with all of their health information, as described by the Department of Health and Human Services, reveals considerable gaps.[5]

Action Plan for Promoting PHRs

In response to these gaps, the PHR practice council outlined an action plan to guide HIM professionals in preparation for the anticipated rise in the use of PHRs. HIM professionals have a pivotal role in the evolution of patient-centered care by educating consumers about the importance of establishing and maintaining a PHR for themselves and for those whose care they are directly responsible, such as a child or elderly parent.

HIM professionals can provide individuals with the information they need to better manage their personal health information, and they should actively encourage consumers to maintain a PHR to help improve the quality of care they receive. Who knows better than HIM professionals what protected health information is collected, how it is collected, how and where it is stored, and the laws and requirements determining its access and use? HIM professionals can educate consumers in the following areas:

Authorizations. Consumers often do not understand how to go about obtaining copies of their medical records for their PHRs, and they can be quickly intimidated or overwhelmed by the process. HIM professionals can help by assuring consumers they have a right to access their health information. They can inform consumers that authorization and proper identification are required when requesting information.

HIM professionals should also explain that only the patient may sign the authorization and that a spouse is generally not legally authorized to sign for the patient (unless the spouse is the legal guardian of the patient). If the patient is a minor, additional state laws may regulate release of information, such as age requirements for consent for mental health, drug, alcohol, HIV, AIDS, and developmental disabilities records. HIM professionals should explain that the intent of the law is to protect patients against wrongful disclosure of their private health information.

The Necessary Information. Even though patients have a right to their entire medical records, HIM professionals should advise them that usually they will only need a few dictated reports and test results. Patients rarely need their entire record.

If a patient explains that he or she is creating a PHR, HIM professionals should recommend the pertinent information to include, such as a summary of inpatient and outpatient visits and appropriate test results related to each. It is important that HIM professionals encourage the practice of building and maintaining PHRs. They should develop policies and procedures that facilitate patient access to information. HIM professionals can use these to educate, encourage, and help patients.

Fees. HIM professionals should explain the fee structure of health record copies. Patients should only be charged a reasonable, cost-based fee for the copying of the record and postage. They should not be charged a handling fee, per HIPAA.

To encourage patients to request copies, some facilities set fees that are lower than statutes allow; others may charge a nominal amount for a few key pages. Some facilities provide patients with copies free of charge in an effort to provide better service. If a fee will be charged, HIM professionals should share that information at the time the request is made so the patient is prepared to pay for the copies. To help keep patients' costs to a minimum, HIM professionals should provide only the information that is requested.

Creating the PHR. HIM professionals should assist patients as they create their PHRs. HIM professionals understand the contents of the records and the core information necessary to create an adequate PHR. There are many types of documentation that are usually not needed for a PHR, such as nursing notes and flow charts. Organizations should not make receiving a copy of their record cost prohibitive. HIM professionals should sit with consumers, talk to them, and have patience with them.

While paper-based PHRs are still the most common, HIM professionals should be able to explain to consumers the various methods of establishing and maintaining an electronic PHR, whether software or Internet-based, whether delivered by the provider via a Web portal to an electronic health record, hosted by an employer or insurer via a Web-enabled PHR product, or hosted by another commercial entity. Consumers will be more likely to maintain a PHR if they understand their options, how a PHR can improve the quality of care that they receive, how it can reduce or eliminate duplicate tests, and help them receive faster, safer treatment and care in an emergency.

HIM professionals can help promote PHRs through the additional following steps:

1. Ask their organizations to add the myPHR.com link to its Web site.
2. Share the myPHR.com Web site with their organizations' wellness coordinators.
3. Provide the AHIMA article "Helping People Understand Their Health Records" for a company newsletter. The article is available in the Resources section of the State Leaders and HOD Community of Practice at www.ahima.org.
4. Create and maintain a PHR.
5. Encourage family and friends to create PHRs.
6. Keep current on the topic through the PHR Community of Practice.
7. Help identify consumer groups that would be interested in the AHIMA community education PHR presentation (see sidebar). Each AHIMA component state association has a community education coordinator who arranges PHR presentations.
8. Consider becoming a trained presenter for the PHR campaign.

Whether speaking with one consumer at a time or a group of consumers, HIM professionals are in an ideal position to promote the use and benefits of personal health records.

Getting Involved with AHIMA's PHR Campaign

PHR resources are available to HIM professionals and consumers on the AHIMA Web site www.myPHR.com. Consumers can explore what a PHR is, how it works, how it can benefit them, and what it should include. The site provides a step-by-step guide to creating and maintaining a PHR. It offers free forms and up-to-date health information news. HIM professionals can use the site as an educational tool.

HIM professionals also can help educate consumers by participating in AHIMA's award-winning campaign to educate the public about the use and benefits of PHRs through community-based programs. The campaign trains credentialed HIM professionals to deliver presentations to community groups and organizations, offering valuable information that helps consumers better manage their personal health information. Topics include how to access your medical records, how to start a PHR, and an overview of patient privacy rights. This is a great opportunity for HIM professionals to get involved and expand their role within the field.

Notes

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Prepared By Personal Health Record Practice Council

Jill Burrington-Brown, MS, RHIA, FAHIMA

Deresa Claybrook, RHIT

Marsha Dolan, MBA, RHIA

Colleen Goethals, MS, RHIA

Cynthia D. Kelly, RHIA

LaVonne LaMoureaux, RHIA, CAE

Heidi Shaffer, RHIA

Julie Wolter, MA, RHIA

The information contained in this practice brief reflects the consensus opinion of the the professionals who developed it. It has not been validated through scientific research.

Article citation:
AHIMA Personal Health Record Practice Council. "Defining the Personal Health Information Management Role" *Journal of AHIMA* 79, no.6 (June 2008): 59-63.

Driving the Power of Knowledge