Getting to the Good Information: PHRs and Consumer Health Informatics

by Robert J. Campbell, EdD

Linking PHRs and provider Web sites can connect consumers to relevant and reliable health information online. HIM professionals can help.

Each day more and more consumers are using the Internet to locate Web-based healthcare information. This activity has led to the rise of a new field of study called consumer health informatics (CHI). To structure and focus their information seeking, consumers can benefit from online resources actively managed by their providers. These Web portals can be powerful complements to personal health records (PHRs), helpful communication tools between provider and patient, and great tools for applying the basic principle behind CHI: active participation in one's healthcare.

Using their PHRs as a means of compiling information about their health histories, consumers can begin the task of organizing facts crucial to the care of specific health concerns and the prevention of future health problems. Through this organizational process, healthcare consumers can improve communication with their providers, by sharing the information found in their PHRs with their providers and using the providers' portals to explore resources available on the Web. They can learn more about specific healthcare problems, including treatments and evidence showing that the treatments they choose and the people and facilities providing the treatments are of the highest quality.

This article introduces the reader to how the PHR can be used in conjunction with provider portals to promote CHI. It will also consider special populations who may need assistance in adopting and using electronic PHRs, provider Web portals, and the Web, as well as the role HIM professionals can take in facilitating the field of CHI through the adoption of the PHR and successful application of portals.

Consumer Health Informatics

With the growth of the Internet, healthcare consumers have access to unlimited amounts of medical information. For the first time in medical history, savvy consumers have the potential to become experts regarding illnesses or maladies from which they suffer. This has led to the rise of CHI, the "branch of medical informatics that analyzes consumers' needs for information; studies and implements methods for making information accessible to consumers; and models and integrates consumers' preferences into medical information systems."[1]

The core philosophy that pervades CHI is the belief that to receive and maintain better healthcare, individuals must assume a greater role in their own care. The combination of the PHR and the provider portal has great potential as a CHI tool. A robust portal that serves as an active, two-way channel between consumer and provider can help organize and present targeted health information to the consumer as well as deliver the consumer's personal health history to the provider.

Linking to Relevant, Reliable Information

A PHR can be defined as an "electronic, universally available, lifelong resource of health information needed by individuals to make health decisions…"[2] At a general level, the PHR and the provider portal can contain categories of information such as allergies and drug sensitivities, conditions, family history, hospitalizations, surgeries, medications, immunizations, and clinical tests. When evaluating or developing a PHR, the key feature to consider is interoperability.

Interoperability, in the sense that the portal can establish links between data from the PHR to the provider, other information sources, and tools. For example, a portal capable of pointing the consumer to online health resources might operate in the following way. Within the portal, under the category "Health Conditions," individuals with selected problems such as cardiovascular disease, diabetes, and cancer could be linked to educational and disease management programs as well as interactive tutorials, sponsored by government agencies and medical societies. Moreover, for each identified health condition, the portal could link individuals to a set of reliable government and education Web sites (such as Medlineplus and Oncolink) to learn more about their medical conditions and possible treatments.

Under a category such as "Medications," individuals prescribed specific drugs could be linked directly to FDA warnings and recalls along with information on proper use, adverse reactions, and contraindications.

Finally, under the category "Family History," the PHR could provide a record of illnesses suffered by an individual's paternal and maternal family members. Some of these illnesses, such as breast and colon cancers, along with aneurysms, require individuals to be aware of preventive measures that protect against these and other predisposed family illnesses. Many individuals do not keep track of family illnesses and furthermore, do not engage in preventive behaviors. The PHR can aid individuals by tracking family illnesses and creating links to preventive service guidelines. A provider program can use this information to alert an individual when they need to schedule a preventive test (see below).

Boosting Online Communication

To allow individuals more flexibility in communicating with their doctors and other healthcare professionals, provider portals can allow for secure clinician patient e-mail and online consultation services. Physicians can provide more information, request that the individual schedule an office visit, or provide the individual with a set of links to reliable healthcare Web sites.

Other tools to improve communication include a prescription refill service, active reminders of upcoming appointments, scheduled tests, and medication times. Such programs can also offer patients the capability to create graphs and reports that document a healthcare concern. Individuals with diabetes, for example, can create graphs showing the fluctuation of their blood glucose levels over the course of a day, week, or month. The graphs can be shared with providers, who will be in a better position to determine how proper diet and medication can be used to control an individual's blood glucose.

Keeping It Accessible for Everyone

Fox and Fallows report that more than 93 million adults currently look for health information on the Internet.[3] Of that 93 million, roughly 5 million adults age 65 and older have used the Internet to access healthcare information. Even as that discrepancy continues to decrease, a large gap exists between seniors who frequently use the Internet to find healthcare information and those who do not. Initial studies suggest the majority of senior users are highly educated white females, with high economic standing, who own personal computers connected to the Internet.[4] Elderly males and elderly members of ethnic minority groups lag behind in using the Internet to locate healthcare information. In 2003 only 11 percent of African Americans aged 65 and older reported using the Internet for any purpose.[5]

Providing seniors with the ability to create their own PHRs and use the Internet as a health information resource is important for a number of reasons:

- Individuals age 65 and older account for more than 40 percent of medical expenditures in the US.[6]
- Treatment for seniors with conditions such as dementia, mobility disorders, pressure ulcers, urinary incontinence, and end-of-life care fall short of recommended guidelines.[7]
- Seniors live with the greatest risk of succumbing to disability or suffering from a chronic illness.
- Disparities exist in the quality of care delivered to ethnic minority patients, who are more susceptible to cardiovascular disease and cancer.[8]

Another important consideration is that a person who succumbs to an illness is more likely to become passive and fail to participate actively in his or her own healthcare. Such individuals require assistance. Research shows that a "sick patient is not simply a well person with a disease, but someone who is qualitatively different: physically, socially, emotionally, and cognitively."[9] As a person becomes ill, he or she may need help managing a healthcare problem and keeping his or her PHR up to date.

For example, children, friends, and relatives perform online research for older adults too sick to investigate their own health problems. Individuals too sick to manage their health histories will need help keeping their PHRs current. Young children, too, require assistance.

As use of PHRs and provider portals continues to grow, it will be important to take into consideration the needs of various user groups and provide them with the skills to create and maintain their PHRs and become Web-savvy healthcare consumers. HIM professionals can play a major role in helping healthcare consumers, vendors, and providers work together to make health information more accessible and easier to use for the healthcare consumer.

The HIM Role: Advocacy, Design, and Education

HIM professionals can play a role in consumer health informatics at the consumer, provider, and vendor levels.

At the consumer level, HIM professionals can take on the role of consumer healthcare advocates (patient information coordinators), who educate consumers on the role they can play in their own health. One means to this end is the creation and implementation of community-based programs that introduce health consumers to the various ways they can access Web-based health information.[10] These programs can be as elementary as teaching individuals how to use a computer to access basic health information online, teaching individuals how to sign up for healthcare benefits over the Internet, and showing individuals how to create their own electronic PHRs using the information contained in their paper-based medical record. These programs can be held at community centers, public libraries, hospitals, and physician practices.

At the provider level, HIM professionals can take on many roles. When providers offer patients access to personal health data such as lab results through a portal, HIM professionals, in the role of patient information coordinators, can train patients to create and maintain their own PHRs. In acquisition and implementation, HIM professionals can work with IT staff and CIOs to make sure that technologies integrate with the providers' overall health information storage and retrieval solutions. HIM professionals can also work to ensure interoperability of systems. For example, when a patient refill is approved, is it automatically sent to the individual's pharmacy of choice? Are the changes reflected in both the provider's electronic record system and the patient's view of that record through the portal?

HIM professionals can also take part in usability studies. In addition to ensuring that implementation of these new technologies takes into account how physicians and other healthcare professionals perform their jobs, HIM professionals can help ensure that system design reflects how consumers use these technologies to store health information. Is the technology easy for the provider and consumer to use and navigate? HIM professionals must be concerned with the interface and screen design. Furthermore, they must remember that what works for someone age 20 to 55 will not necessarily work for someone age 65 and older. If these new technologies do not make it easier to store, view, and manipulate information, then both providers and consumers will be less likely to adopt them.

At the vendor level, HIM professionals can concern themselves with the design and implementation of PHR and portal products that will benefit both the provider and the healthcare consumer. This includes creating interoperable products that also allow organizations and individual physician practices enough flexibility to tailor the product to meet the needs of their end users.

With the aid of the Internet and their PHRs, consumers can locate information on a specific problem, investigate the treatments available to cure the problem, and find evidence that these treatments work. PHRs and provider-managed Web sites can be combined to direct consumers to reliable online sources. HIM professionals can accept the challenge of designing and implementing these technologies and educating consumers in their proper use.

Notes

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