Health Records Get Personal: A Technology Outlook for Consumer Access to Personal Health Information

by Beth Friedman, RHIT

From banking to travel, consumers manage a variety of personal records online. Now providers are experimenting with several ways to give consumers more control over their health records.

Every day consumers log on to the Internet to access bank accounts, stock portfolios, and travel itineraries. Their records are secure and easy to access. Banks, brokers, and airlines do more than just offer information online, they encourage consumers to manage their records and perform basic transactions. The Internet is serving as the catalyst for online access to virtually everything.

So why not health records? Both consumers and healthcare organizations can benefit when consumers have greater access to their health information. Greater consumer access can lead to fewer calls and requests for information, freer patient-to-caregiver and caregiver-to-caregiver communication, and higher levels of patient satisfaction because of the increased control of accounts. The movement has begun, with some providers granting patients limited access to their records through several Web-based models. HIM professionals have a role to play in helping consumers understand and manage their records and in ensuring that the information remains secure and confidential.

The Shift to Consumer-oriented Healthcare

The personal health record (PHR) is commonly defined as an Internet-based system (or combination of systems) that allows consumers to store, access, and coordinate their health information. The PHR may contain test results, allergies, medical history, e-mail communication between patient and provider, living will, healthcare proxy information, and information from pharmacies and insurance companies.[1]

Some providers are already offering elements of the PHR. Patients can now renew prescriptions, schedule appointments, and consult with clinicians via the Web. Among the country's "most wired" hospitals in a 2002 survey, 90 percent provided such online services for their patients.[2]

Several leading healthcare organizations are making great strides, notably the Veterans Administration with My HealtheVet, Cleveland Clinic Family Health Centers, and Geisinger Health System.[3,4,5] Many patient financial services departments have developed tools that allow patients to manage their accounts, shop for healthcare coverage, and communicate with providers on the Internet.

Consumer-oriented models are being promoted elsewhere in healthcare. The Healthcare Financial Management Association's Patient Friendly Billing initiative seeks to make statements, explanations of benefits, and other billing information understandable and easily accessible. Consumer-driven health plans give patients the responsibility for designing their own healthcare coverage package. Such programs are one of the top 10 trends in healthcare today, according to the Gartner Group.[6] In a 2002 survey of 300 companies that provide benefits, 57 percent reported that they were planning to increase "consumerism" within the next year.[7]

Extending the concept behind these examples to HIM, a world of opportunities unfolds. The first step is the ability to store, view, and access records via the Internet. Once these systems are in place and consumers are educated, the opportunities for HIM abound. For instance, HIM could:

- Establish virtual record rooms where patients can view, update, and print their records

- Create a self-service release of information process wherein the patient grants access to other clinicians, payors, and providers by printing parts of the record or granting online access through passwords and authentication
- Train HIM professionals to serve as online patient record educators, answering questions and helping patients control access to their records

Technology Options and the HIM Professional

Hospitals are already experimenting with a wide variety of Internet technologies that will support the PHR. Four basic technologies are evolving: Web-based document management, secure access to hospital in-house systems (including the CPR), patient portals, and online health information Web sites.

Web-based Document Management

Similar to traditional, in-house document management systems, patient records in Web-based systems are electronically collected, indexed, and stored by the provider. The records are then stored in a vendor's host image repository where they can be easily accessed by consumers via the Web.

To access their records, patients log in via password to a restricted section of the hospital's Web site. There they view the actual images created by the provider. This can be the entire record or a subset specifically for patient access. In addition to tight password and authentication tools, extensive audit logs should be in place to account for all record activities.

HIM professionals are vital to the success of Web-based document management systems used for patient access. They can help define what documents within the record are available online, and they can help determine the specific transactions available (e.g., if patients can print records). In addition, HIM professionals will have an important role to play in consumer education. They can educate consumers on the content of the record and on how to keep their online records confidential.

HIM professionals can also help consumers decide which caregivers should be given access to their online health information. For example, a patient undergoing an orthopedic procedure at a specialty hospital may want to give his or her primary care physician a copy of the chart. While viewing the record, the patient could easily grant others viewing rights to that record. HIM professionals could offer online help with this transaction.

Secure Intranet Access to Hospital Systems

Another option is to give patients access to existing hospital systems. Authorized remote access to systems is already being granted to clinicians and other healthcare workers via virtual private networks, secure socket layers, and other tools. Organizations can extend this access to patients. In fact, this is how many of the patient-friendly billing solutions are being delivered.

Hospitals that provide patients with the ability to schedule their own appointments do so by granting them access to the organization's scheduling system. They give patients access only to the module within the scheduling system created specifically for this purpose.

Geisinger Health System offers this type of secure Internet access, for example. Using one module within the organization's clinical information system, patients can access their medical information, e-mail their physicians, request appointments, and renew prescriptions.

Again, the role of the HIM professional is to help determine what information can be accessed and by whom. HIM professionals should also ensure that all record transactions are incorporated into the legal medical record.

Patient Portals

Portal technology is making great strides in many industries, including healthcare. A portal is a single point of personalized access through which to find, organize, and access content.[8]

Portals consist of several systems that work together to pull and present information based on user preferences. Portals find information relative to the user and bring it together into one view. While healthcare is still in the first generation of adoption, many provider organizations have achieved success with patient portals.

St. Joseph Health System, for instance, a 15-hospital system in three southwestern states, has implemented a physician portal called Physician Connect.[9] Physicians can access results, reports, trending, and radiology images through this single portal. In addition, they have access to knowledge resources, trusted health content, office practice tools, and electronic signature. The next step is to create the patient portal to this information.

The University of Texas M.D. Anderson Cancer Center introduced a patient portal called MyMDA in March 2002.[10] Each patient's portal is customized according to diagnosis and treatment. Once on the site, the patient can view and change appointments, request prescription refills, check billing statements, maintain a daily journal, or download personalized education materials. The portal also includes secure messaging between patients and caregivers.

The organization, however, does not allow patients to view their medical records. The concern is that a patient may see a poor lab result online before the caregiver has had time to interpret the results and counsel the patient. As with the other personal health record technologies, patient portals require input from HIM professionals to ascertain what information is available, at what time, and by whom.

Online Health Information Web Sites

Finally, health information Web sites have begun to increase in popularity. Also called personal health record software, this technology allows the patient to create his or her record online. Information is stored by a hosting company and can be accessed at any time. Patients can also grant access to their records to care providers as needed.

While the majority of patients likely will prefer to have access to their hospital and physician records, some will want to build their own. These sites are designed for consumers who want to have complete ownership of their health information.

Consumers using WebMD can enter vaccination, doctor visit, and health history. This information is stored online and easily accessed by the patient or designated caregivers regardless of location. The company also offers interactive self-assessments, risk analysis for specific medical conditions, and peer comparisons of cholesterol, blood sugar, and blood pressure levels. Unlike hospital-sponsored PHRs, WebMD and other information Web sites charge a small fee. HIM professionals can assist patients as they create their own records in such systems, and they can help vendors design the programs.

Keeping Personal Records Private

Underlying all efforts to expand consumerism in healthcare is the need to maintain privacy of protected health information (PHI). This is both an ethical and practical matter. While 63 percent of consumers surveyed say that having their complete medical history stored electronically would be very valuable, 58 percent were concerned about the privacy of their records.[11]

HIM professionals can help ensure privacy in three ways: by understanding the technology features of the specific PHR program; by contributing to and monitoring compliance with PHR policies and procedures; and by helping educate consumers on the use, maintenance, and redisclosure of their own health information.

Security technology must ensure that the person viewing the information is authorized to do so. It must also protect against unauthorized access both externally and internally. Data must be physically protected and backed up to prevent loss in the event of a disaster.

The hardest piece of the security program to control is the human element. HIM professionals must participate in the development of policies and procedures that help secure PHI. Through strict procedures, monitoring, and education, healthcare workers and business associates can form a cohesive privacy team.

Finally, individual patients must be educated on how to protect their own information. Regardless of the technology used, it will be the consumer's responsibility to keep PHI secure. Today patients keep photocopies of their records at home in a drawer; tomorrow this same information will be stored online. In both cases, it is the patient's responsibility to ensure privacy.

HIM professionals can help by educating the consumer on use and redisclosure of their information. AHIMA's Web site myPHR.com has useful guidance. Additional sites and resources will become available as the PHR concept becomes mainstream.

With Change Comes Risk

Increasing consumer access to medical records is a cause for grave concern among some care providers and health information professionals. Whether the concern focuses on threats to privacy or the misinterpretation of information, issues can be addressed by taking healthcare consumerism one step at a time.

An organization may choose to first give patients the ability to schedule appointments online. Once everyone is comfortable with the first step, a second area can be pursued, such as secure messaging or accessing test results. With each step, it is imperative that HIM professionals help evaluate the technology, develop policies and procedures, and educate both staff and consumers.

Organizations should consider operating health information hotlines to help patients interpret the information contained in their health record. Similar to nursing call centers, hotlines can help patients understand the documents contained within their records and the abbreviations and definitions used throughout the charts. Whether they are nurses or HIM professionals, health information assistants will serve a valuable role in minimizing the risk of consumer misinterpretation.

How organizations deliver health information to the patient will be determined by many factors, such as IT budgets and existing systems. No matter the technology, HIM professionals should help their organizations review and select systems, educate consumers, ensure privacy, and determine which documents are available, when, and to whom.

There will always be a percentage of patients who have no interest in viewing or accessing their information online. For these patients, HIM professionals will continue to provide a valuable service by producing photocopies as needed. Whether paper, hybrid, or totally digital, the record must be capable of being reproduced and delivered manually to this segment.

However, the share of "off-line" patients can be expected to decline, and wired patients will continue to grow exponentially. There will come a time in the not too distant future when health records will become more personal as online PHRs become the norm.

Notes

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