Role of the Personal Health Record in the EHR - Retired

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Health information technology will be integral to the US transformation to a safer, more efficient, consumer-driven healthcare system, and the personal health record (PHR) will be a valuable asset to individuals and families, enabling them to integrate and manage their healthcare information through secure, standardized tools. It is imperative that patients, healthcare providers, and payers work together to develop a PHR model. Establishing a common data set is a vital starting point.

Background

In September 2002 the Markle Foundation established Connecting for Health, a public-private collaborative whose purpose is to "bring greater visibility and coordination to the many government, provider and industry efforts to speed up the adoption of electronically connected health information systems."[1] Phase 1 of the project included a recommendation to engage the American public in this endeavor, with a more specific objective of developing personal health records.[2]

Phase 2 of the collaborative project included the formation of the working group on policies for electronic information sharing between doctors and patients. The working group reported several findings, including:

- PHR development should be accelerated.
- PHRs will help increase consumer health awareness, activation, and safety.
- There is no single pathway to a universal PHR.
- A common data set is a vital starting point.[3]

AHIMA Initiatives

In 1996 AHIMA's Board of Directors charted the future course of the association and health information practice. As part of the Vision 2006 project, several task forces were established to clarify future roles and skills.[4] One identified role was the patient information coordinator, a precursor to the role HIM may assume with the PHR. The duties of this role include:

- Ensuring the timely transfer of patient information among healthcare providers
- Showing patients how to manage their personal health histories
- Showing patients how to access computer-based information resources

Clearly, the time has come for HIM to take up this role and help lead the PHR effort.

MyPHR.com

In October 2003 AHIMA launched myPHR (www.myPHR.com), a guide to understanding and managing personal health information for the general public. The site defines a health record, provides instructions on accessing health information and compiling and keeping a personal health record, and explains privacy rights. The site has tapped into public interest in PHRs, with 5,500 visitors in an average month and reaching as high as 9,000 visits in other months.

Consumer Education

In March 2005 AHIMA produced a public education presentation kit titled "Your Personal Health Information: How to Access, Manage, and Protect It." The kit provides HIM leaders with complete materials for an hour-long presentation to the general public. It includes a video, a PowerPoint presentation, a handout, and fliers for advertising the event.

E-HIM PHR Work Group Charter

AHIMA recently convened an e-HIM™ work group to focus on the PHR. The group studied emerging activity occurring around the PHR. From this research, the work group formulated a definition of the PHR, including its attributes. The work group also recommended the minimum common data elements to be included in a PHR, emerging HIM roles, and consumer education and tools to promote the PHR. Finally, the work group performed an environmental scan of the current industry activity within the United States, including the various products currently available to consumers. Descriptions of this work follow.

Definition of the PHR

The personal health record (PHR) is 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.

Attributes of the PHR

The work group organized PHR attributes into six categories: ownership; function; format and content; privacy, access, and control; maintenance and security; and interoperability. A complete description of attributes is available in appendix A.

Types of PHRs

The future PHR is an electronic application, as noted in the preceding definition. However, at this point in time most individuals maintain their PHRs in one of the following formats.

Paper-based. These are the files that most of us have around our homes in folders filled with information from our doctors, insurance companies, pharmacies, and hospitals. Some have created PHR forms and have developed lists of emergency contacts, drug sensitivities, doctors, immunizations, and medications either in written form or on personal computers.

PC-based. Consumers also store health information on personal computers, typing or scanning information into generic software or specific applications such as Personal Health Record (www.capmed.com) and Health-Minder Health Information Manager (www.health-minder.com). Desktop-based solutions in general lack the ability to easily exchange information between consumers and healthcare providers (e.g., they do not provide direct Internet access). Healthcare providers do not have direct access to the information contained in the desktop PHR nor the ability to update that information.

Web-based. Other services allow consumers to maintain their information in private online accounts, which they access by logging in with a unique user name and password. Web-based platforms do not require software other than a Web browser. They may include secure e-mail, document sharing, and video-conferencing for home consultations.

In most cases, Web-based solutions provide around-the-clock access to a person's medical information from any Internet-connected device. For that reason these solutions serve as excellent information sources in an emergency. Consumers or their caregivers have the option to fax information directly into the PHR repository. Examples of this type of PHR are My Personal MD (www.personalmd.com) and HealthTracer (www.healthtracer.com). A more comprehensive list is described in appendix E: "Personal Health Record Products in the Marketplace,".

Hybrid desktop/Web-based. The typical hybrid solution allows individuals to maintain their PHRs on their personal computers and provides an upload facility to a secure Web server. The Web server provides around-the-clock access to the information. The access is primarily read-only, with the update capability restricted to the individual's personal computer. In most cases individuals are allowed to upload all or part of their medical information as they desire. An example of this type of PHR is "SynChart" (www.synchart.com).

Portable devices. "The capabilities of portable devices are expanding rapidly and may lead to a whole new generation of PHR applications," notes Connecting for Health.[5] Consumers currently have the ability to store their health information on smart cards, personal digital assistants, mobile phones, and memory devices that plug into personal computers.

In most cases, portable devices are used as an add-on feature to a desktop-, Web-, or hybrid-based PHR application. For example, CapMed offers a proprietary "Personal HealthKey" device that fits on a keychain. Information is downloaded to the device, which when connected to a PC's universal serial bus port automatically launches a program contained in the device and displays the individual's medical information.

Minimum Common Data Elements

A standardized PHR must include common data elements in order to ensure its interoperability among different care settings and different providers. Suggested categories of common data elements include:

- Personal demographic information
- General medical information
- Allergies and drug sensitivities
- Conditions
- Hospitalizations
- Surgeries
- Medications
- Immunizations
- Clinical tests
- Pregnancy history

"Common Data Elements in a PHR," appendix B, lists the complete, patient-supplied minimum common data set developed by the work group.

Emerging PHR Roles and Responsibilities

The work group also projected the direction of the HIM profession with the PHR. See Appendix C: "Emerging HIM Roles and Responsibilities with the PHR,".

Consumer Education

The group outlined an approach for professionals to follow when designing PHR educational presentations. The educational presentations must be customized based on:

- The target group or audience (physicians, consumers, providers, payers)
- The most important needs or barriers for each target group or audience
- The most effective way to reach each target group or audience

Preparing the approach is necessary to capture the specific issues within each community of interest—physicians will have concerns that are separate from community support groups such as diabetes or Alzheimer's groups, for example. Presentation examples can be found in appendix D, "Models for Community Education."

Environmental Scan

The work group completed an environmental scan of PHR products on the market. Though current as of the publication date, the list will likely be obsolete within a short period of time as new products are developed. The myPHR Web site (www.myPHR.com) maintains a current listing of not-for-profit products.

The work group's list presents products alphabetically first by individual use (i.e., products available to individuals for their own use), then by those available to individuals as part of a corporate or enterprise system. The list also indicates whether the product is free or for puchase and whether it is Internet-based or for use on a personal computer or device. The list, "Personal Health Record Products in the Marketplace," appears as appendix E in the online version.

As the US moves toward a more consumer-driven healthcare system, the advantages of the patient-controlled health record become more central to the goals of reducing the costs of healthcare and providing a safer system. It is imperative that

patients, healthcare providers, and payers work together to develop a model for personal health records that will serve to achieve these goals.

Notes

1. Connecting for Health. “Connecting Americans to their Healthcare: Final Report” (2004): 13. Available online at www.connectingforhealth.org/resources/wg_eis_final_report_07 04.pdf.
2. Connecting for Health. “Achieving Electronic Connectivity in Healthcare: A Preliminary Roadmap from the Nation’s Public and Private-Sector Healthcare Leaders” (2004). Available online at www.connectingforhealth.org/resources/cfh_aech_roadmap_072004.pdf
3. Connecting for Health. “Connecting Americans to their Healthcare.”
4. AHIMA. “Evolving HIM Careers: Seven Roles for the Future.” 1999. p. v. Available online in the FORE Library: HIM Body of Knowledge at www.ahima.org.
5. Connecting for Health. “Connecting Americans to their Healthcare.”

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