PHRs a Work in Progress: Industry Offers a Wealth of Models, but Standards and Education Still Needed

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by Dan Rode, MBA, FHFMA

The concept of the personal health record (PHR) has been around since the National Committee on Vital and Health Statistics identified a "personal health dimension" in its 2001 report "Information for Health: A Strategy for Building the National Health Information Infrastructure." Interest in PHRs has accelerated, and the past year has brought a number of major developments.

Laying the Groundwork

AHIMA has been involved with various organizations pursuing PHR principles, standards, and models for some time. The association also established a consumer PHR Web site, www.myphr.com, and a Community Education Campaign, which is coordinated and facilitated by various component state associations.

AHIMA also has been very active with Connecting for Health, which has explored PHR models for several years. Its efforts culminated in December 2006 with the report "Connecting Americans to Their Health Care: A Common Framework for Networked Personal Health Information," which lays out policy and technical guides for networked personal health information (available at www.connectingforhealth.org).

The framework introduces the concept of the PHR as an aggregate of consumer data. It also explores networking PHRs into health information exchange networks, which will allow consumers to engage more actively in their healthcare.

These concepts were echoed in work presented in January at the Office of the National Coordinator for Health Information Technology's Third Nationwide Health Information Network forum, which showcased health information exchange prototypes. Several used the PHR as the central axis for the exchange of healthcare information much as the Connecting for Health report suggests. The demonstrations will show whether such concepts can work.

Linking PHRs to EHRs

Another key issue is how the PHR will relate to the standard electronic health record (EHR). The Connecting for Health report and AHIMA's own work with the American Medical Informatics Association (AMIA) suggest that the PHR's value will only be recognized if there is interoperability between PHRs and EHRs. These reports reinforce the need for PHR standards, a task that the standards development organization Health Level Seven has undertaken.

Developing and adopting these standards is absolutely necessary if the healthcare system is to be interoperable and networked. PHR standards will also allow for eventual certification, called for by the American Health Information Community (AHIC) Consumer Empowerment Workgroup in March. The industry expects a Health Level Seven standard by early 2008.

The AHIC Consumer Empowerment Workgroup was formed to "make recommendations to the Community to gain wide spread adoption of a personal health record that is easy-to-use, portable, longitudinal, affordable, and consumer-centered."[1] The group is now addressing this charge, which resulted in the March recommendations calling for eventual voluntary certification of PHRs for interoperability (i.e., standards) and privacy and security specifications.

The recommendations did not pass without controversy. Several dissenters suggested that it was too early for a PHR interoperability standard and that pushing such a standard too soon would affect innovation and development of potential PHR models. AHIMA and AMIA sent a letter to Michael Leavitt, secretary of the Department of Health and Human Services and chair of AHIC, urging his acceptance and approval of the recommendations.

The controversy underscores the fact that there is no one model for the PHR. PHRs come in many shapes and sizes.

Hopping on the PHR Band Wagon

In December America's Health Insurance Plans and the Blue Cross and Blue Shield Association announced their collaboration on a model PHR that is a "private, secure, web-based tool" to be maintained by an insurer and would include a consumer's claim and administrative information.[2]

The announcement reflects PHR development already under way at various large health plans and insurers. These PHRs include not only the claims and administrative data noted in the December announcement, but also information that can be entered by the beneficiary or patient and his or her clinician. These plans are HIPAA entities, and therefore their PHRs are covered by HIPAA for treatment, payment, and operations activities.

Close behind the announcement was another by Intel, Wal-Mart, and several large national employers that joined to form Dossia, a nonprofit organization to provide a framework for electronic PHRs. These companies will offer their employees PHRs to make "the health care system more efficient and effective, eliminating waste and duplication of effort on behalf of consumers and providers."[3] Dossia will determine the exact model, which is reported to follow the Common Framework, and employers are to remain hands-off with regard to holding and accessing the PHRs.

While various employer, health plan, provider, and vendor PHR models have come forth, a separate model was identified in 2006 by the Health Record Banking Alliance (HRBA). HRBA's model calls for individuals, their healthcare providers and plans, and similar entities related to the individual to place personal health information into a bank, similar to the way money is sent to banks by various payers. The original information would be retained by the entity, but under this model the individual would have a collection of data that he or she would control and determine access and release for care and other purposes, such as research. The account holder would have final say on what information is kept, eliminated, or modified.

HRBA members point out that this would be a central consumer-controlled model that could eliminate many of the other models currently under discussion. Currently, there are no real HRBA vendors, but the model is attracting attention.

Selecting a PHR

With so many models in development, what can a consumer, caretaker, or healthcare professional do to ferret out a good PHR? Over time the market will determine some of the winning models, and as standards are approved and the concept of linking PHRs with EHRs and networks is accepted, choosing a model will be easier.

In July 2006 AHIMA and AMIA issued two statements to provide PHR consumers, developers, and policy makers some direction during this interim period. The first statement, "The Value of Personal Health Records," identifies principles that should apply to a PHR and the information that should be accommodated in it. The associations also note concern for the lack of confidentiality and security protections, since not all PHR operators are covered by existing privacy laws.

In the statement the associations suggest that consumers must be protected from the misuse of or discrimination caused by access to their PHR data. AHIMA and AMIA also raise concern with the quality of data contained in some PHRs.

Both associations note that data should be identified by source including the individual, the caretaker, the provider or clinician, and claims since the reliability and integrity of such information may be open to scrutiny. Given the pace of PHR discussion and development, AMIA and AHIMA updated and reissued this statement in February (available at www.ahima.org/dc/positions [web page no longer available; see AHIMA's HIM Body of Knowledge^{TM}]).

The second statement released in July addressed health information confidentiality. In it the two associations raise concerns and identify principles related to access, use, and disclosure of personal health information regardless of the form or model in which it exists and no matter where or with what entity it resides. The concerns raised in the statement are reflected by consumers in recent polls.

Today the call for data that can be delivered in a PHR, EHR, or health information exchange is receiving considerable attention. AHIMA has urged consumers to use PHRs to raise their involvement in their healthcare. While models and standards are under consideration, healthcare professionals have two roles. First, they should ensure that PHR standards, principles, and models meet the goal of making quality personal health information available when and where it is needed-with appropriate confidentiality protections. Secondly, they can educate consumers on the value and limitations of PHRs and inform them of the issues in this evolution to electronic health information system.

Notes

1. US Department of Health and Human Services. "Consumer Empowerment Workgroup." Available online at http://www.hhs.gov/healthit/ahic/consumer .
2. America's Health Insurance Plans. "Industry Leaders Announce Personal Health Record Model; Collaborate with Consumers to Speed Adoption." December 13, 2006. Press release. Available online at http://www.ahip.org/content/pressrelease.aspx?docid=18328
3. US Department of Health and Human Services. "National Committee on Vital and Health Statistics Subcommittee on Privacy and Confidentiality Testimony." January 23, 2007. Available online at http://ncvhs.hhs.gov/070123tr.htm

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