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**Personal Health Records: What's New?**

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**Patty:** The first time we discussed personal health records (PHRs) in this column was on Sept. 14, 2004. I know several national groups have continued working on the challenges of achieving widespread adoption of PHRs. It's time to check in and see how they are progressing.

**Leslie:** Yes, the work continues and the issues that need to be addressed around PHRs are getting more clearly defined by various policy groups, such as the Markle Foundation, the American Health Information Management Association's (AHIMA) PHR Practice Council and the American Health Information Community (AHIC).

**Patty:** Although I have heard of AHIC, I am not that familiar with this group. What is the AHIC?

**Leslie:** AHIC is a federal advisory body established in September 2005 by the Office of the National Coordinator of Health Information Technology (ONCHIT). It was established to make recommendations directly to the Secretary of Health and Human Services (HHS) on how to accelerate the development and adoption of health information technology (HIT).

**Patty:** What is the charge of the AHIC?

**Leslie:** AHIC initially was charged with focusing on four key areas: consumer empowerment, chronic care, biosurveillance and electronic health records (EHRs).

I have been following the work of the Consumer Empowerment (CE) Work Group, which has two charges. The first is a broad charge to make recommendations to AHIC on how to gain widespread adoption of a PHR that is easy to use, portable, longitudinal, affordable and consumer centered. The second is a specific charge to make recommendations to AHIC so that within 1 year, a pre-populated, consumer-directed and secure electronic registration summary is available to targeted populations. They are to make additional recommendations to AHIC so that within 1 year a widely available pre-populated medication history linked to the registration summary is deployed.

**Patty:** The CE Work Group certainly has a tall order to fill in a very short period of time.

**Leslie:** They started meeting monthly in January 2006 and submitted a letter report with recommendations to AHIC on May 9. The report highlighted a number of key issues regarding the electronic registration summary with the medication history linked to it. (More information is available on the ONCHIT Web site at [www.hhs.gov/healthinformationtechnology](http://www.hhs.gov/healthinformationtechnology).)

**Patty:** What were some of the most pressing issues?

**Leslie:** The CE Work Group highlighted the need for privacy and security safeguards as well as consumers' control over their own PHRs. The terrible increase in identity theft in recent years has made the American public much more aware and concerned about the dangers of personal information in an electronic format.

Another important issue that they raised is that there is no widely accepted standard definition for the features of a PHR.

**Patty:** It is interesting to me that though we have heard a lot of buzz about the PHR for the past few years, there is still a debate about its definition.

**Leslie:** Good work has been done in that area, just no consensus yet. The AHIMA e-HIM® Task Force on PHRs developed a definition that they published in July 2005. In Dan Rode's recent column, "Advocacy Update: AHIMA Efforts Span Local and National Levels" published in the June 2006 Journal of AHIMA, he stated that, "Several bodies engaged in PHR policy, including the Centers for Medicare and Medicaid Services have cited AHIMA's definition of the PHR." It's a good start.

**Patty:** What is the definition that AHIMA has developed?

**Leslie:** AHIMA defines the PHR as an electronic, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR does not replace the legal record of any provider.

**Patty:** Why do you think there is still debate about the definition?

**Leslie:** I believe it is because there are a lot of stakeholders in the PHR arena, and more discussion is needed to fully explore the PHR concept from all perspectives. Up until now it seems like employers, health plans and technology vendors have been the most active in discussing and developing the PHR. According to the deliberations of the consumer empowerment workgroup, these stakeholders see the value that a PHR would have in encouraging individual involvement in self-care and care management.

**Patty:** What about the providers? Are they engaged?

**Leslie:** I don't know if providers are fully on board with the concept yet. The idea of patients and their families having access to and contributing to their health records is a paradigm shift of major proportions. The concept of PHRs is one component of the movement from a provider-centric system to a consumer-centric system. This movement is about more than just technology, it is a significant culture change. The PHR challenges long-held beliefs and practices and it will take time for all the parties to flush out the pros and cons, the obstacles, and the benefits that make pursuing PHRs worthwhile.

**Patty:** What about consumers? Are they part of the discussion?

**Leslie:** To some extent consumer groups are engaged in, and contributing to policy discussions. Patient advocacy groups are starting to educate the public about the value of PHRs. AHIMA has a Web site totally devoted to educating the public, [www.myphr.com](http://www.myphr.com). It has a wealth of information on it, including easy-to-download forms for consumers to organize their personal health information at home. The site also provides links to more than 40 Web sites where consumers can learn about and acquire the means of keeping an electronic PHR provided by independent technology vendors. I don't know to what extent the public has embraced these resources yet.

**Patty:** One advantage to using an independent PHR vendor is the consumer has complete control over what goes into the record and who gains access to it. It is truly owned and controlled by the consumer. The downside to using an independent PHR vendor is that for the most part, the consumer must gather and enter his own medical history and maintain the PHR by updating it after every encounter or episode of illness.

At this time, there is very little interoperability between the EHRs of providers and the PHR systems. Even when the two systems are compatible, the providers have to agree to transmit the patient's information electronically to the PHR. That is at least a few years away for the majority of consumers and providers.

**Leslie:** You are right Patty. One of the biggest obstacles is that it is a lot of work for consumers to keep their own records, and many people aren't sufficiently motivated to do so. We still need a great deal of education and outreach to the public and to the provider community. The public needs to learn what a PHR is and how to use it to participate actively in their care, and not all providers are convinced that the PHR is a viable tool for engaging patients and their families in the care process. Also, if consumers alone must maintain their PHRs electronically, only people who are comfortable using computers will be able to participate. That leaves out a pretty significant portion of the public.

**Patty:** What about the alternatives to consumers maintaining their own PHRs? For example, the health plan we use at Care Communications Inc. provides a Web site with a PHR that anybody in the plan can use to maintain a PHR. And, hasn't there been talk of insurers downloading claims data to the members PHR? Wouldn't that make it easier for consumers?

**Leslie:** Yes, populating PHRs with claims data is being discussed, but it too has its drawbacks. In the consumer empowerment group's letter report to AHIC, it was noted that "claims data do not include current health status or health history, because such data represent singular events and lag behind the actual encounters with the health care system."

Here is the challenge: The report stated that "in many discussion groups and forums, interest in PHRs (including medication history) is based on the ability to: 1) secure information consistently from all providers, 2) make available medical information to all providers consistently (common source for the same data), 3) track medications (prescriptions, over-the-counter medicines and supplements), 4) track diagnoses, conditions, test results, hospitalizations, comprehensive treatments and enrollment in clinical trials, and 5) give providers, family members or other caregivers emergency access to health information."

**Patty:** I think it is important to note that this is not the only federal effort related to making personal health information available in an emergency. As a result of the White House's report, The Federal Response to Hurricane Katrina: Lessons Learned, on May 23, 2006, HHS issued a Request for Information: Voluntary Storage of Personal Data in Preparation for Emergencies. To improve emergency preparedness, response and recovery efforts, HHS has invited public comment on the availability or feasibility of private sector services through which individuals could voluntarily submit their personal information for storage, so that they, family members or other designated individuals could access the information in an emergency. They are looking for creative ideas on the establishment of voluntary nationwide services that can best offer these capabilities.

**Leslie:** What an incredible opportunity we have in this country to advance the use of health information in the very best service of our citizens! The true value of medical records and health information has never been a particularly hot topic for the main stream media. Clearly that is changing. Concerns about security of personal information juxtaposed with the drama of hurricane victims whose medical records and prescription information were unavailable during the terrible tragedy now make for compelling headlines.

**Patty:** I believe we have at hand the ultimate “learning moment”; an opportunity to educate the public on the importance of personal health information, and to demonstrate in real time the need for individuals to take responsibility for obtaining and managing their own health information.

**Leslie:** Excellent point Patty. It is a good time for HIM professionals to combine their professional expertise with their own experience as consumers, and get involved at the local or national level with professional and community groups dedicated to increasing the public’s awareness of the value of PHRs. This is an issue that impacts our whole society, and it is one that all HIM professionals can champion.

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