

## PHRs Are Gaining Momentum

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**Leslie:** At long last the personal health record (PHR) is getting the attention it needs in the consumer press. I have seen articles about PHRs recently in the Chicago Tribune, U.S. News and World Report, Prevention Magazine and AARP The Magazine, to name just a few.

**Patty:** It is even on Wikipedia! (See [http://en.wikipedia.org/wiki/Personal\\_health\\_record#Definition](http://en.wikipedia.org/wiki/Personal_health_record#Definition))

**Leslie:** In the letter to the editor posted on [www.ChicagoTribune.com](http://www.ChicagoTribune.com), Dec. 19, 2007, Linda L. Kloss, CEO of the American Health Information Management Association (AHIMA), commented on the importance of PHRs and called for consumers to take responsibility for building and maintaining a PHR. She stated that "the best starting place for consumers to improve personal health care is by building and maintaining a personal health record or PHR."

**Patty:** The increased coverage of PHRs is due in part to a new campaign launched by AHIMA this past fall to increase the consumer's awareness. You can learn more about AHIMA's PHR resources at [www.myphr.com](http://www.myphr.com). The important message for our readers is that every HIM professional, regardless of where they work or what their job title, has a professional responsibility to be a consumer health information advocate!

**Leslie:** I recently had an interesting conversation about this with Julie Wolter, MA, RHIA. Julie is assistant professor in the department of health informatics and information Management at Saint Louis University, and president of the Missouri Health Information Management Association. She is also co-chair of the AHIMA PHR Practice Council and a long-time advocate of the PHR. She has a real passion for this topic and has agreed to let our readers listen in on our conversation.

**Julie:** Thank you for giving me the opportunity to talk about my favorite subject. I do have a passion for seeing every consumer establish a PHR.

**Leslie:** So tell me Julie, what do think about the flurry of recent articles in the consumer press?

**Julie:** It's about time! The PHR has really started to take off in the last year and a half. The impetus is coming from many disparate groups jumping in to encourage consumers to establish a PHR. Not only are health care providers, insurance companies, and the federal government getting behind this concept, private commercial enterprises are jumping on the bandwagon to develop the tools necessary for consumers to efficiently manage their information. With large corporations such as Microsoft, Revolution Health, and Intuit entering the marketplace, I am sure we will see even more media attention.

**Leslie:** What do you tell people who ask you what is a PHR?

**Julie:** I tell people that it is a way to understand what is happening to you when you have encounters with the health care system; it is a chance for you to keep track of your own health care.

**Leslie:** How do people respond to that?

**Julie:** The usual response is “my doctor keeps track of my health information.” So I have to deliver the bad news about the reality of the fragmented health care system. I tell them, “You have to take responsibility for making sure all of your important personal health information is available to your health care provider.” They are skeptical that they can actually do that. When I tell people that they can access their own health records, they usually say, “really”?

**Leslie:** Do they believe you?

**Julie:** Those people who are in crisis believe me. Individuals with a number of health problems, or who are responsible for helping a relative who has serious health issues, get it right away.

**Leslie:** Do you advocate that they start an electronic PHR as soon as possible?

**Julie:** The PHR is a new idea for most consumers. We would all like the PHR to be electronic, but I think we need to take baby steps first, so I tell people that they can keep their record in either an electronic or a paper format. I tell them it doesn't matter how you keep the information as long as you know what is important and that you bring it with you to your doctor's office.

I encourage people to begin by asking their providers for copies of medication lists, laboratory reports and discharge summaries and keeping them in a paper file. This is one area that HIM professionals could begin to create change in their facilities that would make it easier for patients to get their information. For example, several copies of discharge summaries are routinely sent to the physicians involved in a patient's case. I think we should begin to advocate for creating one more copy and sending it to the patient as well.

**Leslie:** In today's always-connected society, I would think most people would prefer to use their personal computers, or other personal devices, to track all their personal information.

**Julie:** Many people do prefer to use computers. They are the ones who already do their banking online and are frustrated by all the paper they receive in the form of medical bills and explanation of benefits (EOBs). These people want the same convenience from the health care system that they have in other areas of their lives.

**Leslie:** But I bet they don't want to have to start entering information into a PHR system.

**Julie:** Right! So until their providers are sending them their information electronically, or at least making their electronic records available to patients, the electronic PHR as we know it today is a less than an ideal solution. Furthermore, even when individual providers have a patient portal, the lack of interoperability among providers is still a problem. In fact, over time, we run the risk of having multiple PHRs just as we have multiple medical records across providers now.

A complete PHR should have information not only from medical care providers, but from dentists, podiatrists, chiropractors, pharmacies, etc. Several models are emerging to accomplish this. For example, one concept being explored is a health record banking model. It is a model in which all providers would contribute to a data base maintained by a paid third party, a health record bank. The patient's “health record bank account” would receive the patient's important information from every provider that the patient authorized to send information to the account. The patient could also add information, and the patient would control access to her record in the health record bank.

**Leslie:** The Arkle Foundation has explored three different electronic models that provide patients with ownership and control over their health information. Visit [www.connectingforhealth.org/resources/final\\_phwg\\_report1.pdf](http://www.connectingforhealth.org/resources/final_phwg_report1.pdf).

**Julie:** Right now, and for the foreseeable future, the only way to get all of one's information into one database is through a patient controlled PHR. And for most people, that is still a paper record kept in a file folder at home.

**Leslie:** If I understand your concern then, while we wait for better electronic tools, we need to educate consumers about the value of gathering and maintaining personal health information in any format—paper, electronic or a mix of the two.

**Julie:** Absolutely! Also, consumer health information education is much more than just how to organize all the information. I think that HIM professionals should take on the role of educating consumers about how the PHR can become a useful tool for managing their own health care, communicating with their various health care providers and for managing the costs associated with their health care.

**Leslie:** Traditionally HIM professionals have not been involved in patient education. That would be a new role for them in most organizations.

**Julie:** Yes it would, but everyday there are golden opportunities to teach consumers and their families that interact with our health care systems. For example, when a consumer picks up their medical records, the receptionist could provide them with a fact sheet, or a simple brochure, on maintaining their own PHRs at home. Simple guidelines within the brochure would help to get them started. The brochure would also include key pieces of information that they should always ask for before and after a visit or hospitalization. HIM professionals can also encourage consumers to keep their personal health information current and provide tips on how to best do that. That would be a great place to start.

**Leslie:** What about teaching them about protecting their information?

**Julie:** Yes, along with teaching consumers about their rights to their own information, we should be teaching them about the importance of protecting their information, just as they protect their other personal information.

**Leslie:** We discussed medical identity theft in last month's column. How can people protect themselves from that?

**Julie:** First we have to make people aware of medical identity theft and that it is a growing problem. Aside from the usual advice about personal identity theft—to immediately report any lost or stolen credit cards, social security numbers, passports, etc., patients or family members need to review each EOB they receive and follow up when they don't understand something or don't even know why they are getting one.

I was once concerned about my mother possibly being a victim of medical identity theft when she got an EOB that I wasn't expecting from the hospital. I tracked it down for her and learned that she had been to a satellite clinic of the hospital and that the EOB was for an outpatient visit that I didn't know about. It took time to figure it out, but it was the responsible thing to do. HIM professionals are exactly the right people to be educating people about their responsibility to protect themselves and their loved ones.

**Leslie:** You have helped us understand better the reality of PHRs today. Do you have a PHR?

**Julie:** Yes, I do. It is my tool. It is not my doctor's tool. It allows me to know myself and my parents and my children better.

**Leslie:** What format do you use?

**Julie:** It's in paper, in a binder. That's what works for me today. I take it with me whenever I go to see a doctor or the hospital. When talking with the doctor, I take it out and add my notes. Sometimes the doctor will ask me what I am doing. I show it to him and get the chance to stress the importance of writing things down immediately so I don't forget. I tell him I expect he will do the same.

**Leslie:** Julie, we thank you for sharing your ideas about and experiences with the PHR. You have inspired me to get more serious about organizing my own PHR and you have given us all food for thought.

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