

Renewing Interest in the PHR: HIM Should Encourage Patients to Embrace PHRs, Consumer Engagement

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By Lisa A. Eramo

Consumers may have been slow to adopt personal health records (PHR) in the past, but experts say this may soon change with the government's increased focus on consumer engagement.

"The role of the patient is so different now in terms of being an active rather than passive member of the healthcare team," says Julie Wolter, MA, RHIA, FAHIMA, program director of health sciences at St. Louis University in St. Louis, MO. "The consumer needs to prepare him or herself for the healthcare encounter. The PHR is one of those tools that can help them be more engaged."

An engaged and informed consumer is presumably a healthier consumer, says Don Asmonga, MBA, CAE, senior director of government relations at AHIMA. "When you have a better understanding of the care you're receiving, you should have a better idea of what might make you better and how you can maintain your health," he says.

As consumers become more engaged in their own healthcare, the quality and caliber of care provided to those consumers will also increase—or at least, that's the theory, Asmonga says. Providers will strive for higher quality scores and metrics so that they are more appealing to this savvy generation of healthcare shoppers. Healthcare costs may also decrease, he adds. Now with federal programs like the "meaningful use" EHR Incentive Program making it easier for patients to download and transmit their health information, and physicians implementing patient portals that offer direct electronic access to health records, PHRs seem poised to have a resurgence. AHIMA has taken notice, launching a revamp of its myPHR.com website along with an advocacy campaign to inform consumers of their rights to health information and ways they can use it to become engaged in their healthcare. But even PHR advocates say it may be a challenge to get people to adopt a PHR.

□ How HIM Can Help Engage Health Consumers

Consumers are now in the spotlight as part of the solution when discussing healthcare reform and a reduction of healthcare costs. "The consumer is going to have this primary role in healthcare," Dolan says. "They are going to have power that they didn't even know they had. We have to help train the consumer to make the best use of that power."

There are several ways that HIM professionals can become more involved in the consumer engagement movement, including:

- Talk with consumers about the importance of their own health information. "HIM professionals have that expertise and ability," Asmonga says. "We want our members to be more proactive on that front."
- It's important to help consumers understand their new role—that it's ok and completely appropriate to ask for copies of one's record and converse with providers about that information, Wolter says.
- "If there is a health fair that your facility is promoting, be there to talk about health information in general terms—the value it has and why consumers need to be using it," says Dolan, who plans to speak about mobile health apps, personal health information, and other issues at her own local health fair this year.
- Provide resources. The Consumer Engagement Practice Council has released a consumer guide for understanding the medical health record, available at www.myphr.com/healthliteracy/myphr.pdf. A primer on mobile health apps is also available at http://myphr.com/HealthLiteracy/MX7644_myPHRbrochure.pdf.
- Educate consumers about choosing reliable and secure technology. This includes reading privacy policies, securing tablets or smartphones, and erasing data. "We want people to be aware that there's still a lot of

theft going on out there in terms of getting people's health information and using it," Dolan says.

- Educate physicians. Ask them to provide copies of medical information to patients and to explain the importance of tracking one's own health information.

Giving Consumers What They Want

Although the regulatory environment may be ripe for the adoption of PHRs, it remains somewhat unclear whether consumers actually see the value in PHRs—or even in their own health information. “I think the million dollar question is ‘How do we enhance consumer engagement?’” says Asmonga, who is leading an effort to revamp AHIMA's [myPHR.com](https://myphr.com) website and working in tandem with AHIMA's Consumer Engagement Practice Council to revive the association's consumer engagement efforts.

Part of AHIMA's strategy is to engage consumers to focus more broadly on personal health information rather than PHRs specifically. “When you're talking about a personal health record, you're talking about a product. Personal health information is bigger and more global,” Asmonga says. “One of the organization's strategic goals is to ensure that consumers have the ability to access their health information where and when they need it, including anywhere in the world.”

The effort will focus on raising consumer awareness and understanding of PHRs as well as other technologies that can help to monitor and track information, such as mobile health applications, patient portals, and more, says Marsha Dolan, MBA, RHIA, FAHIMA, coordinator of the health informatics and information management program at Missouri Western State University in St. Joseph, MO.

The goal is simply to get consumers more involved, says Wolter, who serves on AHIMA's Consumer Engagement Practice Council. Using one's own health information could be as simple as compiling records in a paper folder, she says. “Paper isn't a bad way to start, but with time, we all need to be web-based and interoperable,” Wolter says. “But it's all about the baby steps.”

There won't be a one-size-fits-all solution in terms of getting consumers on board, says Dolan, co-chair of the Consumer Engagement Practice Council. “We're trying to give consumers a lot of options and then let them decide what will work best for them,” she says. To help consumers engage in their healthcare and health information, the Department of Health and Human Services' website [HealthIT.gov](https://www.healthit.gov) has published a list of PHR and consumer engagement projects and products at www.healthit.gov/patients-families/maintain-your-medical-record. These include [myPHR.com](https://myphr.com), the Blue Button initiative, Microsoft HealthVault, and many more potential solutions.

PHRs are appealing to some consumers who want to participate in their own healthcare and have better access to information that is being shared and exchanged between providers. Deborah Kohn, MPH, RHIA, FACHE, CPHIMS, principal at Dak Systems Consulting in San Mateo, CA, agrees that while PHRs can help individuals and their providers manage care, HIEs are best at exchanging information. “At this time, PHRs may be a solution for retaining information but definitely not exchanging it,” says Kohn, who has maintained a paper-based PHR for more than three decades. Kohn hasn't used an electronic PHR because she says she hasn't found one that fits her needs and also because PHRs aren't interoperable. “If I had to show my PHR information to a provider who was not associated with that PHR, I'd have no recourse but to print it to paper and hand it to him or her,” she says. Using flash drives or burning the information to CDs also are not good options because providers' computers often do not have compatible viewers, she adds.

PHRs do play an important role for caregivers, says Wolter, who used a paper-based PHR in a binder to manage the care of her mother. She says she brought the PHR binder to monthly care team meetings at her mother's nursing home. “I'd jot notes down while everyone was talking,” she says, adding that the PHR always included the most up-to-date information.

Wolter is also in the process of creating a paper-based children's PHR as a gift for her niece who is having a baby. She says there is tremendous value in creating a compilation of one's health information, particularly in the absence of nationwide interoperability.

PHRs' Future Role Evolving

The PHR—regardless of whether it's paper or electronic—will likely continue to be a repository of personal health information, but its role beyond that remains unclear, Dolan says. "It will be something that the individual uses to help monitor his or her own health," she says. "Whether the PHR actually fits into the patient portal or HIE is something that I don't think we've totally figured out."

Dolan says she views PHRs and patient portals as stepping stones to true interoperability through HIEs. She currently uses a PHR as well as a patient portal through her insurer, both of which she must maintain separately. She also carries a paper-based emergency PHR with her at all times that lists her providers, medications, and chronic conditions. "I was injured several years ago and couldn't even remember what medication I was taking," she recalls. "But I did remember where that piece of paper was. A friend pulled that information out and was able to give it to the emergency personnel."

Industry experts debate the significance of PHRs and portals—particularly whether they will eventually, gradually get phased out as true interoperability becomes a reality, or whether they're a long-term panacea for consumer engagement, Dolan says.

Until this question is answered, one point remains clear: Physicians appreciate the promise of efficiency that PHRs and patient portals provide. Many physician groups are embracing use of patient portals, especially the ability to securely communicate with patients via e-mail, Dolan says. Ease of use and types of documents received, however, vary among portal and EHR vendors, providing opportunities for HIM professionals to intervene and assist. HIM professionals can also help with patient inquiries sent via portals and similar technology, she adds.

AHIMA Takes the Lead on PHRs

In addition to broadening the scope of [myPHR.com](https://myphr.com) to include general information about how to actively participate in one's own health, AHIMA also plans to rename the site to better reflect this broader message. Focus groups including consumers, HIM professionals, and others will help guide the site's evolution based on what will resonate most with the general population. "We want patients to come to the website for all healthcare consumer issues that they feel are important," Wolter says.

The new website will also include more video and blogs in an attempt to be more interactive and consumer friendly, Asmonga says. "A lot of people are visual learners. We want to add elements where people can click and watch rather than click and read," he says. "I think the blogs provide an outlet for consumers to potentially ask questions and make some points and share stories. It would also allow HIM professionals and consumer experts to provide expertise."

Consumers will have access to a more robust glossary of health terms on the new site. What the site won't do is endorse a particular vendor or technology, Asmonga says. "We have our criteria that we recommend to individuals. We're really not going to point to one or two PHRs and say that they're the best," he adds.

Focus groups as well as consumer and AHIMA member surveys will help the association build the new website around what consumers want and need. AHIMA also hopes to reach out to other partner organizations, such as physician groups, AARP, and the Office of the National Coordinator for Health Information Technology (ONC) for their input, Asmonga says. "The ONC is really focusing on consumer engagement. We're going to need to work more closely with them," he says.

Challenges in Promoting PHRs

Asmonga said valuable information on PHR use and promotion may be gleaned by talking to representatives from Google about why the Internet giant decided to terminate its PHR product, Google Health, in January. In a blog post, Google states:

...We've observed that Google Health is not having the broad impact that we hoped it would. There has been adoption among certain groups of users like tech-savvy patients and their caregivers, and more recently fitness and wellness enthusiasts. But we haven't found a way to translate that limited usage into widespread adoption in the daily health routines of millions of people.

The closure of Google Health was seen by some in the industry as a strike against PHRs. Translating the value proposition of PHRs and other similar technologies to the average consumer will likely be the most challenging aspect of consumer engagement, Asmonga says. "We need to find out what that is," Asmonga says. "The other thing we need to determine is whether consumers even find their health information important, and if they do, why."

Overcoming privacy and security barriers may also present a challenge, Dolan says. Lack of consumer participation in Google Health could have been partially due to consumer fears about Google's ability to track and access information. "I wonder whether people were worried about this and then didn't participate," she says.

She says the new myPHR.com website will highlight privacy and security tips more prominently for easier consumer access. AHIMA is also taking a closer look at health literacy—how to convey information to consumers without overwhelming them.

PHRs for the Well, Too

AHIMA's consumer engagement campaign, set to launch once the new myPHR.com website is live during the first quarter of 2014, will focus on marketing the site, particularly to the population that's most difficult to engage—those who are healthy.

"We want to look at potentially finding a celebrity who can latch onto our cause and promote it," Asmonga says. "That would be outstanding for the site." AHIMA will also explore the feasibility of launching commercials that physicians can play in their waiting areas similar to an AHIMA myPHR.com commercial that was shown on American Airlines flights during April.

The Consumer Engagement Practice Council plans to compile documentation specifically for HIM professionals so they can teach consumers about the importance of health information. "Our education is two-fold—one for the HIM professional, and one for the consumer," Dolan says.

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