But What Does the Public Think?: For Consumers to Adopt PHRs, They Need Reasons That Hit Home

by John Morrissey

The industry knows why PHRs are good for the public. And the public knows, too. But are the reasons the same?

HIM professionals know medical records inside and out. It's second nature for them to know how such records influence and direct the care of patients and how lack of thoroughness or completeness can compromise care quality. But patients, and consumers generally, do not have the benefit of this understanding. In fact, many may have little idea why their records are important to them, because they really haven't thought much about it.

Given this, the case for personal health records (PHRs) can be a hard one to make among the general public. Without an appreciation of their medical records' importance in the delivery of care, it can be difficult for consumers to see the value of access to their medical history and latest medical results.

Thus it's important for the healthcare industry to appreciate what the public thinks about health records before setting out to encourage them to create and maintain a particular type of record.

But how can you gauge consumer opinion when consumers might not have opinions? First consumers have to see the value of PHRs on their own turf, and that requires the healthcare industry to see the healthcare world from the consumer's point of view, not from its own.

Mind's Eye of the Consumer

A conclave of healthcare industry experts sought to nail down that PHR value proposition in a day-long idea exchange conducted by the National Alliance for Health Information Technology. Rather than descend into the details of what a PHR should contain and how it should work, the 20-member discussion group stepped back and used its collective experience in dealing directly with the public to adopt a consumer mindset. The group sought what was most important to everyday consumers who deal with family doctors, pull together the documentation of past medical encounters, and address the tasks of managing their health and that of their family.

Aided at the outset by a focus group of five consumers, the group defined what was most important to Americans:

> Being more in control of your healthcare. Having information when you need it. Not having to sit in a waiting room every time you need to bring up any little thing with a medical provider. Not being forever inconvenienced (filling out the same forms, telling doctors what they should already know about you). Learning how to stay well from those who should be able to counsel you. Not getting the rush from the nurse and doctor; being able to talk your situation out, and learning valuable things about your health that you wouldn't otherwise think to ask about.

From this summary came a pitch for an electronic record, covering both the personal and provider-based models. The objective was to sell the electronic record as a new offering, to make it something desirable, relevant, and sensible to the typical head of a household. The pitch went like this:

> It will give you information at your fingertips, and the same information will be coordinated among providers so you don't have to worry about getting it from place to place. You never have to fill out another form. It gives you more access to your medical information, so you can play a more prominent role in your healthcare. You can be more proactive, take preventive measures, and be reinforced by the feedback you get. You can be more

independent, more in control. That provides some peace of mind: you don't have to worry as much about medical issues, so there's less stress, better quality of life. You get a better doctor's visit because he or she knows more about you going into the session. Having information on all family members helps better manage the health of loved ones.

Quality of Care or a More Fulfilling Experience?

When focus group members were asked to give their impressions of an electronic health record (EHR), their responses largely described a PHR—something available to them online in a secure way, comprising comprehensive information about personal health and history. One participant envisioned an instrument for consumers to become better advocates for their care, including benchmarks to hit and prompts for regular maintenance—comparable to an "oil-change reminder." Another imagined a "health spreadsheet" for making observations and calculating steps to take about personal health.

All saw an online record as a way to get a closer connection to their doctors, who often don't know enough about them. Thorough information, mutually held and freely exchanged, would facilitate interaction with their physicians and lead to more fluid communication. But the consumers on the panel also saw an opportunity for independence from providers through an online PHR, a chance for them to become more aware of their medical conditions and more likely to act on them. An older woman married to a recent retiree said, "The trend is for people to take care of themselves. Although I want to be taken care of, I don't trust anybody to make decisions about what's going on with me but me. And I think the next generation of people coming up are going to be more independent."

From a technical standpoint, however, the consumers seemed to think their data would magically appear in their record for their use. They seemed oblivious to the complexity of getting it there via what the healthcare field knows as an EHR. An unsettling reality emerged: Even better-informed consumers are not well-versed on the role of medical records in general and the benefits of electronic records in particular.

The panelists' views of EHRs were very different from that of the healthcare industry. They weren't plugged into the raging debate about errors, patient safety, and the need to create an infrastructure for complete, accurate, accessible, and secure electronic personal health information. From this standpoint it was evident that the EHR and its companion, the PHR, were not about quality of care but about a more fulfilling healthcare experience.

But that's OK. Focusing on consumers' desires for convenience, portability of information, and increased dialogue with their doctors advances the attractiveness of a PHR and can pull consumers into the marketplace with demands that their doctors and providers work to make such benefits available. That could be a key force to turn the tide on PHRs, because the attitudes of physicians and other healthcare professionals are as important as those of consumers in generating the necessary momentum.

Giving the Personal Record a Chance

Consider the positive experience of Patricia McGinley, a dental hygienist from suburban Cleveland who makes good use of an online link to her internist's practice at a satellite office of the Cleveland Clinic. She credits the encouragement of Dr. Robert Juhasz with introducing her to a benefit she wouldn't have tried otherwise. During a regular check-up, Juhasz gave her the information and said she should sign up. "I looked at him and said, 'Yeah, right.' In my mind I'm thinking, 'This is going to be a hassle, I'm not technological, I don't want to deal with this.' But he's a good friend, and I respect him a lot, so I thought, 'OK, I'm going to give this a try—if for nothing else to kind of appease him.'"

Her skepticism faded soon afterward when she got an e-mail from the Cleveland Clinic informing her that the results of her blood work were in and instructing her to click on a link, which took her directly to the sign-in page for the health system's patient portal. Once in, she saw results of her tests for high cholesterol, a condition she had just been diagnosed with. And not just results but helpful comparisons with normal ranges.

"It couldn't be easier," McGinley said. "I was totally thinking, 'I'm going to hate this.' So for me to be convinced, I was pretty impressed." In addition, McGinley now gets results within a week on blood work for a longstanding iron-deficiency anemia condition, results that used to be mailed months after the test date or dictated personally by Juhasz—while she balanced a phone on her shoulder and tried to scribble down the information.

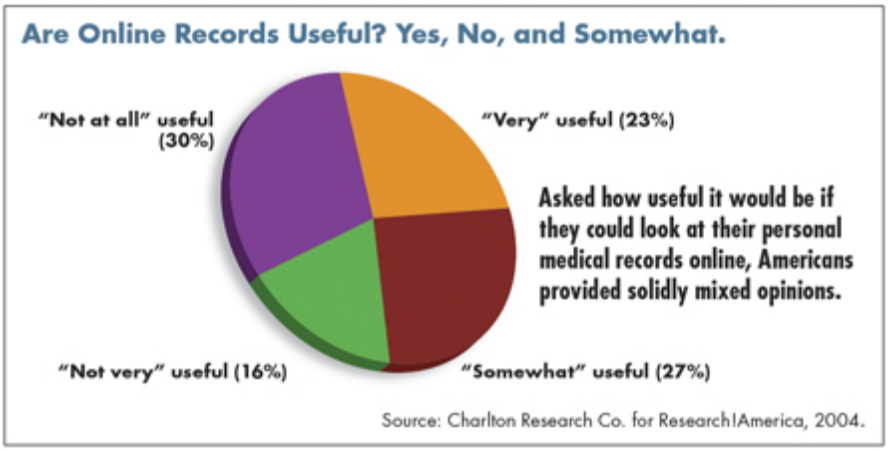
But as she talked with her friends and family, McGinley didn't find anyone else who was using the service. "Part of that problem is—and I've talked to my physician about this—it really comes down to whether the physician's going to take the initiative with the patient and say, 'You really ought to try this.' A lot of physicians view this as just one more hassle, one more thing they have to do." Doctors have first impressions similar to her own, McGinley concluded. "Once you try it, it's great. But it's like anything else in life: 'Jeez, I don't need anything else on my plate. Just don't bother me right now.'"

Unless consumers become well aware of what PHRs can do for them and take their cases to providers, adoption will rely on the efforts of personal physicians. "Doctors are the absolute key to this. I've learned in focus groups that a patient will do whatever their doctor tells them to do," said A.J. Melaragno, assistant vice president of interactive marketing at Evanston Northwestern Healthcare in Evanston, IL, which has developed a PHR that capitalizes on the rollout of an EHR system to its three hospitals and associated medical offices last year. "The physician steers the ship."

About 6,000 patients of 150 primary-care physicians had signed up for Evanston Northwestern Healthcare's PHR by August 1, 2005. This was up from 1,200 patients of 90 physicians at the end of 2004, said Melaragno. He was hoping for 10,000 patients by the end of 2005, though he said the slowness of the prerequisite buy-in from physicians might make the health system miss that target. That slow buy-in is understandable, though—the service changes aspects of office operations, including online scheduling, which requires physicians to cede some control of their practices. "Physicians have to be comfortable. You can't shove it down their throat," said Melaragno. When doctors see that the PHR reduces phone traffic, that office staff don't have to retype messages and contributed information from patients, and that tests and other data automatically become part of the record, the odds of getting their cooperation improve, he said.

Meanwhile, patients participating in the PHR are out in the community talking about it, driving physicians to inquire about the particulars of the initiative, Melaragno added. "We're getting calls from patients asking which physicians are offering this," he said. Patients also are wondering why they're being left out: "There was a lady whose husband and son had access but she didn't. The first question she had was why." In most cases the inquirer's doctor was either outside of the provider network or among the doctors on staff who did not offer the service.

McGinley said her experience is an example of benefit for patient and physician, especially the way a PHR enables quick and accurate communication with her doctor. "And you can look at this stuff at your convenience. I remember he called me once [before the days of the PHR]. I had blood work done in December, and at the end of March, on my birthday, he happened to call me. This was three months later. This wasn't the best day or time to be calling. I wanted to say, 'Gee, Bob, I'm in the middle of my birthday dinner,' but I couldn't hang up on him. I mean the poor man finally found time to give me a call. But it's just so much better when you can look at it at midnight when you've got 10 minutes to sit and look at it rather than at dinner."



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