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The Challenge and the Promise of Personal Health Records: The Consumer's View

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Leslie: The personal health record (PHR) continues to stay in the news as public and private initiatives strive to develop ways that will enable consumers to have more involvement in managing their personal health information. Almost everyday I see a new article on developments in this area. If you enter PHRs into the Google™ search engine you will get 216,000 matches, and that number continues to grow. However, while activity in this area is high on the agenda of the federal and state governments, health care insurers, PHR vendors and some providers, I see little evidence that a desire to have a PHR is a high priority for the majority of consumers and providers.

Patty: A recent survey of 2,000 general consumers by Health Industry Insights™, an IDC company, indicated 83 percent of the 1,095 respondents had never used a PHR in either paper or electronic form. When asked why they had not used a PHR, 52 percent of 909 respondents said that they had never heard of a PHR, 10 percent saw no value, another 10 percent did not trust the security of the currently available Internet-based sites, 4 percent did not want a written record of sensitive personal health information, and 3 percent did not want to spend the time to initially input and update their information.

Leslie: But there is hope for a change. I saw that survey too. Only 8 percent of 909 respondents said that they will never use a PHR and 10 percent do plan to use it within the next 2 years. However, the majority, 82 percent, were uncertain.

Patty: So the jury is still out on whether consumers will embrace the PHR. Clearly, a large scale educational effort is needed to help consumers understand the value of a PHR and to help them learn about the various PHR options that are and will soon be available to them.

Leslie: In our June 19, 2006 Hands-on Help column, "Personal Health Records: What's New?" (accessible at <http://www.health-information.advanceweb.com>), we discussed that some of the consumer advocacy groups are engaged in advancing PHRs, but I think we need to learn more about the consumer's perspective on PHRs from a health care consumer advocate.

Patty: Let's introduce our readers to Lenore Janecek, founder and president of SAVE THE PATIENTSM, a not-for-profit organization with a mission to educate and empower patients and the public to make effective and informed health care decisions through objective resources. Established in 2001 in Chicago, SAVE THE PATIENT provides information to people of all ages, cultures and socio-economic backgrounds. Lenore is also a nationally known health care expert and author. She has been the governor's appointed consumer representative on the Illinois Health Care Cost Containment Council and has served on the Illinois Health Care Reform Task Force. We caught up with Lenore recently to talk with her about the consumer's view of PHRs.

Leslie: Hi Lenore. Thank you for agreeing to talk with us today about the PHR. First, would you please tell our

readers why you founded SAVE THE PATIENT?

Lenore: I was given an erroneous diagnosis of cancer and underwent unnecessary surgery from which I suffered serious complications and many years of illness. Without going into all of the details, I began to suspect that something was wrong when I decided to seek a consultation with an oncologist, and I was unable to get my medical records. The hospital claimed to have lost them. After several additional attempts on my own to get the records, even going in person with a written request, I hired an attorney and went to court to seek relief to get my records. The hospital suddenly found and produced them, and I became aware of some of the facts of my case. A long drawn out legal case ensued and 4 years later the hospital finally admitted the error.

During the time that I was going through this nightmarish experience, I tried to find an organization that could help me, but I couldn't find one. I thought if I, a knowledgeable member of the health care community, could feel so lost, how would people not as familiar with health care resources fare in a similar situation? So I started SAVE THE PATIENT to be the voice of the people, to represent the people's health care interests here and in other countries, without partisanship or special interests behind it.

Patty: Your experience with trying to obtain your medical record is one our readers will surely find shocking. A fundamental part of being an HIM professional is being an advocate for patients' rights regarding their medical records. The HIM professionals that I know are passionate about protecting those rights. How terrible for you to have had to go through such an experience, and how terrific of you to put your time, money and energy now into preventing others from having such an experience.

Leslie: How does SAVE THE PATIENT accomplish its mission to educate and empower patients and the public to make effective and informed health care decisions through objective resources?

Lenore: We are engaged in several initiatives. Our first and most prominent success in helping patients improve their ability to communicate with their care providers was to design and distribute widely a Health Caring Card™. It is a very basic PHR in a paper form that can be folded and neatly kept in one's wallet.

Patty: I have seen these wallet-sized paper PHRs and wondered how well they worked. I have also recently seen high-tech smart cards that look like credit cards that can be kept in a wallet.

Lenore: Well the wallet-sized paper PHRs don't carry as much information as a smart card, but it is pretty amazing how much critical information can be formatted to fit on the folding cards. Your readers can see them and download them for free at our Web site, www.savethepatient.org. In addition to important medical information that is on the card, such as diagnoses, allergies and current medications, we also include instructions on how to prepare for a doctor's visit, the patient's rights during the visit, and a list of appropriate questions to ask.

Leslie: I know you are committed to the underserved population, many of whom do not have ready access to computers. How do you distribute the cards?

Lenore: Primarily, we distribute them at health fairs and through hospitals, clinics and physicians offices, as well as through our Web site. We have also translated the cards into several languages, including Spanish, Polish and Chinese, to better serve those communities. A Japanese translation has just been completed and will be available soon. We are currently working on projects to translate the cards into several Indian dialects.

Leslie: How many Health Caring Cards do you think you have distributed already?

Lenore: Approximately 10,000, not counting the cards downloaded from the Web site.

Patty: Given your success with the Health Caring Cards, can you give us some insights regarding the results of the consumer survey about PHRs that we discussed earlier in this column? Do you believe that the public is uninterested in having a PHR?

Lenore: I do not think that the public is uninterested. Most people outside of the health care industry are unaware of the value and the need for maintaining their own health records. They assume that their providers have what they need, when they need it.

Leslie: That is a wrong assumption in a fragmented health care system, serving a highly mobile society.

Patty: I think a lot of education is needed to get consumers engaged in maintaining their health information in a format that is readily accessible in the event of an emergency, when moving to a new community or when seeing a new provider. What are your thoughts on educational efforts?

Lenore: I agree that education is critical. However, there are other reasons that consumers are not ready for PHRs. For one thing, fear about the security of information is probably the biggest concern that I have heard voiced about electronic health information databases and online access to health records. People read on almost a daily basis about the increase in identity theft and about the serious breaches of security that have occurred with personal information in large databases. It is no wonder that people are reluctant to allow more of their personal information to be exposed to those dangers. You will have to prove to them that their personal information will be safe to keep and access online.

Leslie: Of course to be realistic, there are risks. There are important benefits too, and I believe the benefits far outweigh the risks. For me, having my personal medical information available to emergency medical teams who might need it to save my life in the event of an accident or an illness while I am traveling overrides these other concerns. For example, people who experienced the loss of their medical information during the aftermath of Katrina would surely have benefited from having electronic health records backed up on secure servers. Those victims that had prescriptions in pharmacy systems were certainly better off than those who did not.

Patty: Privacy and security are important issues that dedicated individuals are working on constantly at all levels of the health care industry, from policy makers in the federal government, to national standards setting organizations, to information technology (IT) vendors, to HIM and IT professionals in individual provider organizations. Most health care professionals would agree that electronic records are even safer than paper records. They are harder to access without authorization, they are less likely to become lost and they are legible, another potentially life-saving factor.

Lenore: I agree with both of you. Now it is up to all of us to the two of you, your HIM colleagues, provider organizations, care-givers and the community leaders with whom I work, to help more people learn about the real benefits and risks of PHRs, so that they can make informed decisions.

Leslie: How does your organization get the word out?

Lenore: We have several ways of communicating to the public. We have a monthly 25-minute live interactive talk show, "Community Health Hotline" on The Chicago Access Network (CAN-TV). We reach about one million viewers each month. We publish information and provide links to credible resources on our Web site, which is accessible to people everywhere. We are currently piloting an education curriculum that will be available for community groups to use as an adjunct to distributing the Health Caring Cards. To join in advancing an

electronic PHR, we are currently seeking funding to develop our FlashHealth™ program.

Leslie: Can you tell us a little about your vision for that program if it gets funded?

Lenore: Our vision is to bring technology to underserved populations by providing patients in our communities with a PHR stored on flash drive key chains, so they can carry their most important medical record information with them. While the technical details of our program won't be fully developed until we get funded, we are optimistic that the technology needed will be available. We know that the PHR standards are in development and that interoperability, which is a key requirement for PHRs, is also in the works, but standards work takes time.

In the meantime, we don't want the underserved communities to be left behind. We want to be working now to educate people about PHRs and to prepare them to be able to take advantage of the technology as it becomes available. Many people that we serve do not have a computer, but if they can walk into a doctor's office with their FlashHealth key chain and ask their physician to download their medical information from their flash drive, they too can reap the benefits of PHRs. If, through our program, we can help patients actually input their medical histories that will be even better. We will work toward collaborating with providers and others who will share our vision to make it a reality.

Patty: Lenore, your organization has an impressive list of accomplishments and goals. What advice do you have for our readers, the HIM professionals who are committed to working with patients and their families, to learn about and to create state-of-the-art PHRs?

Lenore: Be involved in your community. Take every opportunity to explain to people in clear, non-jargon, lay language what a medical record is and why it is important to their safety and well-being and that of their families. Collaborate through your employer, or volunteer your time to work with consumer organizations like SAVE THE PATIENT. We need the expertise of HIM professionals to help us move the public from a lack of awareness about PHRs to a new sense of responsibility for their health information, and from fear of unauthorized disclosure to enthusiasm for the potential of engaging more actively in their health care decisions, because they will have access to the same information about their health as do their health care providers.

Leslie: Thank you Lenore for a most stimulating discussion about the challenge and the promise of PHRs from a consumer's perspective, and good luck with creating the FlashHealth program.

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