



Last **W**ords

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Call Me When You Have What I Want

I still vividly remember one of my earliest attempts to sell Internet access to a large corporate account in 1992. I was excitedly extolling the virtues of email, Usenet news groups and file transfer when the sales prospect interrupted me and told me that what he really wanted to be able to do was search the Internet to find the information that he wanted. “Search the Internet?” I exclaimed. “The Internet doesn’t work that way.” (It was 1992, after all). “Well, call me when it does because that’s what I want”, the prospect replied and abruptly ended the conversation.

I learned an important lesson that day. As much as I am a geek (remember, I have more computers than people in my house), I came to realize that most people view their computer as simply a means to an end, not an end unto itself. This realization has driven an intense, lifelong interest in the end-user perspective of IT systems.

For the past six months I have wanted an opportunity to speak with a patient who had used some form of IT in the delivery of their care. Fortunately, with help from Claudette DeLernado at Grand River Hospital, I recently had the opportunity to speak with Allison Armstrong. Allison is a breast cancer patient and an early user of “My CARE Source”, a patient portal operated by Grand River Hospital.

Allison offers a unique perspective on what I call “Personal eHealth” applications. Having survived Hodgkin’s disease as a teenager, Allison can compare what it was like to battle cancer with and without the help of a computer-based tool such as My CARE Source.

During her first bout with cancer, the only information that she received from the health system was a “little green pamphlet”. To find out more about her disease, Allison had few options other than go the library to do her own research or try to find other teenage Hodgkin’s disease patients with whom to speak, a difficult task in her home town of Sault Sainte Marie, Ontario.

When she was diagnosed with breast cancer in 2003, Allison agreed to participate in the pilot program for My CARE Source. She believes that this web based application offers a level of support that she only dreamed possible during her first bout with cancer. When Allison finds herself awake in the early hours of the morning, worried, with questions to which she has no immediate answers or has a question about the many medications that she is taking, she can go on-line quickly get the answers she needs.

Although Allison did not use the phrase “Personal Health Record” (PHR) during our conversation, she did offer a perspective echoed by many PHR supporters. Allison emphatically stated several times during our conversation that she felt very strongly that “they [her medical records] are my records and I feel that I should be able to have immediate access to them when I want.” Further, she asserted that she should be able to offer access to these records to whoever might be involved in any aspect of her care.

Just as I tried to force my view on how the Internet worked with a sales prospect some 15 years ago, so too are many eHealth leaders failing to take into consideration how healthcare consumers want to access their personal health information. While I am an ardent supporter of Infoway’s electronic health record vision, I do not believe that personal health records are merely an extension of the electronic health record as many eHealth leaders are suggesting. Rather, I contend that they are similar to and of equal importance to other point of care systems such as electronic medical record systems.

What is your perspective on personal health records? E-mail me at mmartineau@branhamgroup.com to share your views.

P.S. The sales prospect to whom I referred earlier in this article is now a CIO at a Canadian healthcare organization. ●