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IS THE PHR JUST A TOOL FOR THE WEALTHY AND HEALTHY?

By Neil Seeman

Is the PHR like the "executive physical"? Some have suggested that personal health records (PHRs) – a system whereby patients enjoy custodial rights to their secure health data anytime, anywhere – is a privilege that appeals just to the wealthy, healthy or "worried well."

Where's the Evidence?

From what I can tell, there is very little substance to this argument in the current peer-reviewed literature. Yet I have heard it from those unimpressed by travelling PHR corporate merchants.

One often-cited study, by Weingart and colleagues (2006), found that "younger, healthier patients are most likely to make use of this technology." But that study looked at one portal, PatientSite, used at a Boston teaching hospital (Beth Israel Deaconess) and affiliated community practices. It had a small sample size, and the authors acknowledged that "results may not be generalizable to other portals or health care systems, practices, or patients." Most important: patients were eligible to enrol in PatientSite only if one of their physicians had enrolled, and recruitment efforts had focused on primary care doctors.

The Weingart study, important as it was, looked at data from 2000–2004; consumer behaviour, especially among those suffering from chronic illness, has changed since then. And the new model of the PHR is available to anyone, anywhere, whether or not his or her physician is enrolled.

A Tool for the Rich?

The notion that only the wealthy will benefit from PHRs can be easily dismissed; the same argument was made against the telephone, the television and the toaster, yet all these innovations are now taken for granted by the middle class and all but the very poorest among us. PHRs through Google or Microsoft HealthVault are free to anyone, and at least 75% of Canadians have Web access from home. I predict (although it is hazardous to make predictions in healthcare) that in five years, the percentage of Canadian homes without regular PHR engagement will be lower than 2% (about the same proportion of homes without a television).

Just as Wikipedia re-invented the encyclopaedia and the Web decimated newspaper ad revenues, the ubiquitous PHR will re-invent our relationship with the health system. Keep in mind that Facebook, now the third-most popular website in Canada, was in its infancy five years ago; change occurs rapidly in the world of Web-based consumer engagement. In a recent paper in *Healthcare Quarterly*, Kevin Leonard and colleagues (2008) make the analogy to automated teller machines (ATMs). Most of us can remember a time when there were no ATMs, when all transactions required long teller queues. And now, as former US House Speaker Newt Gingrich once pointed out at an OHA keynote address, who among us – be honest – has not fidgeted while waiting in a two-minute ATM line? Banking expectations have radically changed, for the rich and poor alike.

Just for the Healthy?

Let us deal more seriously with another argument: the idea that the PHR – as proselytized by Google Health, Microsoft HealthVault, Revolution Health and more than 200 smaller competitors – is a gimmick so that the already healthy can maintain their health. After all, PHRs do not keep people away from emergency rooms or from acute care when they're really sick.

We heard this argument against Health Savings Accounts (HSAs). The two arguments, however (and the supporting data), are different. HSAs, according to their most partisan defenders, reconnect the patient and the provider with the true cost of care. And patients thereby start to make wiser decisions – or so the argument goes. We gain insights like: “Whoa, we have increased our use of generic medications, we should shop around for the best deals.” Or, “Maybe an MRI costs a little bit more at this hospital versus that hospital.” And so, according to this theory, we start to use the health system more strategically, perhaps through a high-deductible, catastrophic plan, the deductible being a cash account that accrues interest-free.

Yet the HSA is hardly a panacea. If crafted unwisely, it potentially creates more burden for providers and payers, and can lead to increased spending on wealthy consumers to the detriment of the poor. Although this is a very different issue from that of PHRs, it is instructive. In the case of the PHR, there is every reason to assume that the highest-intensity users of PHRs will be those suffering from chronic disease – a swath of society that transcends socio-economic class.

Research has shown that chronic disease communities thrive exceptionally well on social networking sites. Remarkably, these communities, on sites such as Facebook and MySpace, are more active than celebrity or sports communities (Seeman 2008a). Bottom line: the healthy (and their providers) go to Google for generic health information; the poor, the rich, the middle class – those with chronic disease – seek out, on a daily basis, more niche-oriented Web communities, like diabetesmine.com. The same phenomenon will occur with the PHR.

My own more recent research has shown that the “stickiest” health-related blogs cater to niche, chronic illness populations (Seeman 2008b). The users, chronic illness sufferers, will serve as free ambassadors and champions for tools like Microsoft HealthVault and other PHR platforms, building their own specialized add-on applications, which will then position them to blog about their own PHR experience. A Whatcom County, Washington, consortium that developed a PHR as part of a Robert Wood Johnson Foundation project implemented in 2002 found that chronically ill patients became a kind of PHR sales force, enlisting friends and family to join (Sprague, Lisa. 2006).

There is no reason (other than anti-corporate animus) to suggest that poor people have a lesser understanding of their chronic health conditions than do the wealthy or middle class, or that they have a harder time communicating their issues to a PHR. (PHRs can offer multi-lingual, real-time translation, though admittedly, the technology needs to improve.) Conversely, the people most likely to flock to PHRs are historically underserved and stigmatized populations who now make greater use of online communities than do others. This includes the mentally ill (including young men who are unaccustomed to talking about their mental illness) and populations who are physically dislocated, such as Aboriginal peoples. In a survey by the Markle Foundation (2005), people who perceived themselves as healthy were less likely than all other groups to use a PHR. As one PHR entrepreneur advised me, “The problem with the PHR is that the healthy ignore them, so that many marketing schemes look to make them appealing to disease-specific clusters of patients.”

The Real Role of PHRs

Keep in mind that the PHR is not intended to solve poverty, a multi-factorial problem, or other more systemic drivers of chronic illness. It is meant to improve consumers’ understanding of health issues; to give them more access to and autonomy over their health; to support more timely, appropriate preventive services; to support home monitoring for chronic diseases; to support the continuum of care; to avoid duplicate testing; to increase access to providers via e-visits; and to reduce adverse drug interactions and allergic reactions.

There are several corporate-sponsored reports, laced with bold assumptions, showing that PHRs could save billions of dollars annually in the United States. These numbers need to be approached with scepticism, especially since the benefits (across providers, patients and payers) are dispersed and as yet unknown. There are still important questions to explore about how the PHR revolution will integrate with the interoperable electronic health record and with hospital-based electronic medical records. In truth, there is, to date, only a small body of evidence to verify the financial and, more importantly, the quality benefits of the PHR.

John Snow and the PHR

As many have noted, engagement requires more than usability. The platform applications, whether via Google or Microsoft or other tools, must provide sustained value. But my instinct is that the PHR is akin to John Snow and the water pump. During the cholera outbreak in 1854 in London, Dr. Snow analyzed the geography of water supply and mortality patterns in Soho and found a disproportionate number of cholera cases within a few blocks of a single water pump on Broad Street. At his behest, the pump was removed. This action has been hailed as one of the first public health interventions of the modern era. Although Snow's microscopic examination of a sample of the Broad Street pump water was not conclusive, his studies of the *pattern* of disease were convincing enough to persuade the local council to disable the pump. The same can be said about PHRs. The evidence is hardly conclusive, but we do know that consumers are keen to engage with the Web and share secure personal health information that they own. The burden of proof against the PHR should lie with those who challenge consumers' good judgment.

A related side note: In a future column, I look forward to tackling another myth about the PHR: that it threatens privacy rights. Lawyers, not consumers, are saying this. Consider this statement by Nicolas Terry (2008): "personal health records are dangerously flawed adjuncts to or substitutes for provider-centric records, and while lacking many of the touted quality or cost-reduction benefits of oft-criticized electronic health records they pose substantially higher levels of risk regarding security, privacy, and confidentiality." Sure, identity theft and privacy risks are always legitimate concerns, and there is a role for government to play in ensuring the security of electronic personal health information. But law should be in the service of innovation that matters to chronic disease sufferers throughout the world.

(To be continued…)

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