

Responses to Additional Web Conference Questions
A National Web Conference on Personal Health Records: An Overview
Agency for Healthcare Research and Quality (AHRQ)
March 5, 2008

Q: What is the legal status of personal health record (PHR) information used in a clinical encounter?
What does a clinician need to do/document with PHR information used to substantiate their decision?
How is this different from a clinical decision made from electronic health record (EHR) information?

A: At BIDMC, we consider the communications to a physician from the PHR to be part of the legal record. We do not consider the remainder of the PHR, such as patient added clinical information, to be part of the legal record and do not require our clinicians to review it.

Q: How many PHRs exist today? [What is the] Estimated number of users today?

A: Dozens of PHRs exist today. For an overview, see my January 2008 article in JAMIA.

http://www.ncbi.nlm.nih.gov/pubmed/17947615?ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

A: We have a database of about 200 PHR products but I would guess there are double that. No way to estimate number of users reliably – Kaiser alone estimates about 2 million users of their portal. Ballpark might be 2-4 million portal users, perhaps a million “true” PHR users.

Q: Has PatientSite encountered a measurable amount of trouble with malware mining data once it's on the patient's home computers?

A: We have not had any security issues with PatientSite because we have implemented web-page meta tags preventing the data from being cached or saved to home computers i.e Expires, No-Cache, and Pragma-Privacy tags which cause all browsers to immediately delete the data.

Q: I would like to ask Dr. Halamka how BI Deaconess gets feedback from patients about whether the PatientSite is meeting their needs.

A: We have patient focus groups and have always involved patients in our steering committees. There will be a paper published in Annals of Internal Medicine shortly describing patient feedback.

Q: How do patient requests (refills etc) integrate into an EHRlike Logician or E-clinical?

A: The patient requests to refill meds go directly into our home built EHR medication renewal queue, following the same workflow as existing phone call refills initiated in the clinician's office by administrative staff.

Q: I am struggling with the difference between PHR's and Health Record Banking concept. Can you describe the differences?

A: Per the Health Record Banking Alliance statement of principles <http://www.healthbanking.org/docs/HRBAPrinciplesMay07.pdf> it appears Health Banks and the new commercial PHRs like Google's are similar. In an overview provided by Bill Yasnoff <http://williamyasnoff.com/?m=200606>, he suggests that consumers should pay for health banking services. At this point commercial PHRs are free.

A: Generally, health record bank (HRB) is not an application –it is a repository. In its early framing, it was THE repository for your health data and all providers would send a copy of all data to it, but that has been modified in recent years to be one of many repositories and, in fact, for there to be competing HRBs. HRB is really a policy concept, not a technical or service concept.

Q: Today, a patient has a legal right to request access to his/her medical records. These are typically provided in paper form. This request is made directly to the organization(s) providing the care, e.g. doctor's practice, clinic, hospital, etc. Why is it that in an electronic exchange scenario the patient should be required to go through an intermediary (e.g. Google, HealthVault)? Why would it be "unwise" for a patient to download a continuity of care document (CCD) to his/her computer from a site like PatientSite directly to his/her hard disk? What is the patient benefit to introduce the intermediary?

A: At BIDMC, we enable access via PatientSite, Google, Health Vault or Dossia. The patient can choose. It is just fine to use PatientSite. However, we do not yet have automated CCD export built into PatientSite.

A: The current intermediaries are not asking you to “go through” them – they are actually relying on the patient to make the information request of the provider but then direct that the data be sent to the intermediary hosting service. The intermediary companies have found that they are not credible or have the technology to go directly to the data holders on the consumers' behalf. The patient benefit for using an intermediary is both technical and logistical – there is no software tool today that would allow a patient to integrate diverse and complex information from many sources into a coherent system and “story” on their home desktop and there is no easy way to allow a third-party – a family member, doctor, or information service – to access their home computer and the personal information on it.

Q: How will adverse events be monitored if Google, for example, cannot "mine" their data?

A: Google has no plans to monitor adverse events to my knowledge. Adverse event reporting is done via hospital information systems and EHRs rather than PHRs at this time.

A: Google is not yet proposing to function in a surveillance role but they have talked about asking their users to allow their data to be shared for research or analytic purposes at some future time.

Q: Are there current efforts to apply and/or evaluate the effectiveness of PHRs among transient and homeless populations?

A: We have engineered PatientSite to be available from libraries, internet cafes, or public kiosks. We recognize there is a digital divide but try to make the PHR accessible to as many people as possible.