Supplementary Submission to The Senate Community Affairs Committee

Enquiry on Personally Controlled Electronic Health Records (Consequential Amendments) Bill 2011 and the Personally Controlled Electronic Health Records Bill 2011.

Submissions due January 12, 2012.

Supplementary Submission On PCEHR Design From Dr David G More:

The following, highly germane, material came to hand in the last day or so.

I have summarised it in the following way with relevant links provided.

Methods of Access to Patient Information Held By Clinicians Are Changing In Major Ways.

The following very interesting report appeared very late last year.

Patients, doctors at odds about sharing medical notes

December 20, 2011 | Bernie Monegain, Editor

BOSTON – Patients are overwhelmingly interested in exploring the notes doctors write about them after an office visit, but doctors worry about the impact of such transparency on their patients and on their own workflow, a Beth Israel Deaconess Medical Center (BIDMC) study suggests.

In a study published in the Dec. 20 issue of the Annals of Internal Medicine, patient and doctor attitudes were surveyed extensively prior to the launch of the OpenNotes trial in which patients at BIDMC, Geisinger Health System of Danville, Pa., and Harborview Medical Center in Seattle were offered online access to their doctors' notes written after office visits. Such notes have long been primarily within the doctors' domain, even though patients have the legal right to obtain them.

"Doctors were divided in many of their expectations, and the issues we highlight have important consequences for both their work life and quality of care," writes lead author Jan Walker, a nurse with an MBA, who works at BIDMC's Division of General Medicine and Primary Care.

While many of the more than 100 primary care doctors who volunteered to participate in this experiment predicted possible health benefits from allowing patients to read their notes, the majority of those who declined participation were doubtful about positive impacts. And among the 173 doctors completing surveys, the majority expressed concerns about confusing or worrying patients with the content. Doctors also anticipated they would write their notes less candidly and that responding to patient questions might be exceedingly time-consuming.

In contrast to the doctors surveyed, the nearly 38,000 patients who completed the baseline survey were almost uniformly optimistic about OpenNotes, and few anticipated being confused or worried.

"The enthusiasm of patients exceeded our expectations," wrote Walker. "Most of them were overwhelmingly positive about the prospect of reading visit notes, regardless of demographic or health characteristics."

More here:

http://www.healthcareitnews.com/news/patients-doctors-odds-about-sharing-medical-notes

Here is the Abstract from the Annals of Internal Medicine:

Patient Interest in Sharing Personal Health Record Information

A Web-Based Survey

1. Donna M. Zulman, MD, MS;
2. Kim M. Nazi, MA;
3. Carolyn L. Turvey, PhD, MS;
4. Todd H. Wagner, PhD;
5. Susan S. Woods, MD, MPH; and
6. Larry C. An, MD

Abstract

Background: Electronic personal health record (PHR) systems are proliferating but largely have not realized their potential for enhancing communication among patients and their network of care providers.

Objective: To explore preferences about sharing electronic health information among users of the U.S. Department of Veterans Affairs (VA) PHR system, My Healthe*e*Vet.

Design: Web-based survey of a convenience sample.

Setting: My Health*e*Vet Web site from 7 July through 4 October 2010.

Participants: 18 471 users of My Health*e*Vet.

Measurements: Interest in shared PHR access and preferences about who would receive access, the information that would be shared, and the activities that users would delegate.

Results: Survey respondents were predominantly men (92%) and aged 50 to 64 years (51%) or 65 years or older (39%); approximately 39% reported poor or fair health status. Almost 4 of 5 respondents (79%) were interested in sharing access to their PHR with someone outside of their health system (62% with a spouse or partner, 23% with a child, 15% with another family member, and 25% with a non-VA health care provider). Among those who selected a family member other than a spouse or partner, 47% lived apart from the specified person. Preferences about degree of access varied on the basis of the type of information being shared, the type of activity being performed, and the respondent's relationship with the selected person.

Limitations: The survey completion rate was 40.8%. Results might not be generalizable to all My Health*e*Vet users.

Conclusion: In a large survey of PHR users in the VA system, most respondents were interested in sharing access to their electronic health information with caregivers and non-VA providers. Existing and evolving PHR systems should explore secure mechanisms for shared PHR access to improve information exchange among patients and the multiple persons involved in their health care.

Primary Funding Source: Veterans Health Administration and The Robert Wood Johnson Foundation Clinical Scholars Program.

The full paper is linked from here (.pdf is free):

http://www.annals.org/content/155/12/805.abstract

There is also an editorial found here:

http://www.annals.org/content/155/12/853.extract

Again the .pdf of the full text is free.

The writers of the editorial have some experience in their own organisation over a number of years doing a similar thing with generally very positive results.

It is important to note the large number questions raised by the editorial. Issues of access, interpretation, understanding and use are all open. They also make it clear that this is at the beginning of a long journey.

This type of information access is, of course, the direction I have been pushing for a good while now, with the provider providing access for their patients to their records. It is worth remembering a number of GP Practices in the UK are doing very similar things.

This trend has also been made quite clear by an article appearing in E-Health Insider on Nanuary 10, 2012.

Future Forum calls for access plan

10 January 2012   Rebecca Todd

The NHS Future Forum has said the government needs to develop a plan to deliver on its commitment to give patients access to their online records by 2015.

The forum's summary report – second phase was due to be released onto the Department of Health website at midnight.

Hints of what it contained led to a flurry of media interest in the issue of patient records access in the days before Christmas.

NHS Future Forum chairman Professor Steve Field says in the report that citizens should be equal partners in their care, rather than passive consumers, and that a key part of this is patient ownership of their data.

The government has already made a number of commitments to giving patients access to records and other data.

It's 'Information Revolution' consultation on a new NHS information strategy said patient access to records should start with GP records and then extend to hospital and other medical records.

In his Autumn Statement, Chancellor George Osborne said that all patients should have access to their online GP records by the end of this Parliament – 2015.

The NHS Future Forum supports that commitment and says the information strategy must clearly set out how this will be achieved, "recognising that there is both a financial and time burden to GP practices and by providing meaningful help and support to them."

Professor Field says the Royal College of General Practitioners, in partnership with the British Medical Association, NHS Commissioning Board and relevant patient organisations, should be invited by the Department of Health to "develop a plan that delivers the roll-out of access to patient records by 2015."

"Switching on patient access alone is not enough, and potentially detrimental if appropriate support structures are not in place for patients so that they understand and know how to use the information," he says.

"The planned rollout of patient access to electronic records by the government must acknowledge this and ensure that a support structure is in place, including a proper consent process."

More here:

http://www.ehi.co.uk/news/primary-care/7442/future-forum-calls-for-access-plan

So what we are seeing is a move in the US and UK to provision of access to provider records directly in consultation with that provider and with direct interaction with the consumer

This is just not what the planned PCEHR will enable and will mean the patient cannot build a direct relationship with the EHR managed, curated and delivered by their provider and be supported by them.

I think this is a major directional change and has the possibility to improve clinician / patient engagement and the quality of care. Only time and further experience will tell.

The PCEHR does not provide the consumer / clinician engagement possibilities we see with the approaches outlined above.

----- End Submission.

David G More 11/01/2012