The Role of Tethered Electronic Personal Health Records on the Canadian Health Infoway

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Abstract
The challenge for the tethered Personal Health Record (PHR) is to remain viable as an architecture in the Web/Health 2.0 worlds with its emphasis on social media and interactivity. The analysis will be mostly within the context of the Canadian Health Infoway architecture, which is essentially a standards-based and interoperable blueprint for health information exchange. Examples of tethered systems in Canada will be illustrated. The discussion will argue the merits of a tethered PHR architecture as a more secure, private, and trusted way to maintain the integrity of the medical record.

Keywords: Personal Health Record, Electronic Medical Records, HL7, Electronic Health Records, Consumer Health Informatics, Systems Architecture

1.0 Introduction
In Canada, the Personal Health Record (PHR) has received an environment literature scan as well as had systematic review and clinical trial testing, using one of the PHR systems to be discussed in this paper. If physicians help determine PHR adoption by implementing EMRs, as the environmental literature scan showed, are physicians also looking for PHR systems when they do procurement and selection? In the United States there have been surveys on public and consumer attitudes towards PHR. Health Information Technology trade shows and conferences seem to have new PHR products every year. Increasingly, a feeling of inevitability for the PHR is being shared by family physicians, as well as computer technology inventors and innovators, as a recent study of Ontario family physicians' perspectives on PHRs' discovered.

Web 2.0, social media, and mobile smartphones are making collaboration, openness, and social computing more ubiquitous. Even so, the traditional relationship of trust between physician and patient can still be seen in a “tethered” PHR system. The typical data configuration is a record that is not stored on a nationalized, centralized, or cloud system, but is backed up on the physicians’ or institutions’ own computer servers. This enhances the benefit of trust in the value of the privacy and security of the medical record. “Trust comes when the personal health record has the endorsement of the physician and is designed to interface seamlessly with care delivery, as when output is shared and the personal health record refers patients back to their physician for assistance or helps them prepare for upcoming office visits.”

As software engineering developments increasingly make interoperable PHR more technically feasible, questions about the clinical and business model for them remain wide open. The question is, what will be the role of the “tethered” PHR on the Canada Health Infoway in the future? Infoway is a model architecture of shared standards for interoperability. One of those shared standards is HL7 and there is currently a working group for PHR by the HL7 organization. So, will it be the end of the line for tethered PHR in Canada?

This paper will examine how tethered PHR in Canada are currently operating and discuss their architectural features using several sample cases from Ontario; the Mydoctor.ca Health Portal, MyChart/Telus Health Space, and MyOSCAR.

2.0 Defining Tethered PHR Systems
Starting as an innovative approach for physicians to share information with patients, Electronic Personal Health Records (ePHR) were only accessible through the Electronic Health Record (EHR) system of the clinical care institution or the Electronic Medical Record (EMR) of the physician. This was made through various implementations and developments by early adopters of web portals, so that a limited view of the health record, with relevant information for the patient, was made available. This was eventually called a “tethered” PHR system, because it was so closely connected to the clinical expert and the master patient record. Other system developments offered ways to make PHR systems more integrated and controllable by patients, eventually creating a sub-class called the personally controlled health record. For the purposes of this paper, it is assumed that “tethered PHR” are all electronic.

There are a variety of definitions of tethered PHR systems from the literature, but the most useful one is by Daglish and Archer. They define three basic types of PHR from which all the rest can be distinguished; tethered, integrated, and standalone. These are broken down into a table summary of systems architecture attributes which is useful
because tethered architectures appear to be blending into integrated models, especially as more features are being added to them.9

In terms of interoperability, few PHRs use HL7 or “meta health data”.10 The Canada Health Infoway architecture does not model PHRs, appearing to only make a case for a “patient centric, life-long longitudinal record of clinical data” in the EHR, suggesting perhaps that there is either no entrance point or interoperable model for them, or they are considered to be the under the same category as EHRs.6 If it is the latter, a case for the interoperable PHR can be made that is based on accessing electronic health information through the proposed Health Information Access Layer (HIAL) architecture. 6

Even though tethered PHR follow more closely with the traditional physician-patient relationship, there is generally a movement towards greater social media interaction, online patient forums, mobile smartphone “apps”, and internet searching for health information. A Canadian study of physician-patient perceptions of the PHR indicates that many physicians are concerned about losing the face-to-face interaction.4 Many PHR systems have secure messaging systems and there is a trend towards more physician-patient “texting”, but that can also be construed as being in line with the tethered PHR model architecture. If physicians can find a way to work texting into their billing process, no doubt many might be more willing to use that. In that model, physicians really need to know when they need to see a patient face-to-face, and when they don’t.

It is worth noting that the tethered architecture functions not only with the very large EHR systems, but also with the much smaller physician clinics. The Beth Israel Deaconess Medical Center will cease to provide Google Health interconnectivity for their patients because Google Health will be retired by January 2012. 10 This suggests that it is not the end of the line for the tethered PHR, because the “most successful PHRs at large health systems” deploy this architecture in conjunction with other interconnectivity access points. What could and perhaps should be discussed, is the extent to which the tethered PHR is defined by the EMR/EHR to which it is tethered. This is an important point to take note of because it applies to such things as selection and procurement, as well as certification, especially because tethered PHRs in particular are often highly proprietary in regards to the EMR/EHR system to which they are bound.

3.0 Push and Pull Factors for PHRs

One answer to the criticism of lack of clinical evidence for EHRs is to keep PHRs tethered as closely as possible to the clinical source, or at least to think twice before spending vast sums of money on national clinical architectures. But according to the tethered PHR architecture, higher adoption rates of EMRs are also needed to be made by physicians, and more of them need to see the clinical utility of “prescribing” them to their patients: “We found that because primary care physicians play a key role in patient health, PHRs are likely to be linked to physician electronic medical record systems, so PHR adoption is dependent on growth in electronic medical record adoption.” 1

There are push and pull factors in the development of PHR in Canada. These factors can be examined in terms of the software "technology push", that is the natural evolution and perceived benefit of the technology, plus the pull factors of the professional medical and patient/consumer communities. Gunter and Terry defined push and pull factors, which can be applied to the development of the pan-Canadian Infoway architecture.11 Daglish and Archer have also written about the push and pull of PHI in relation to centralized repositories,9 as well as defining Push and Pull Models for “integrated PHR” systems architecture. The Pull Model uses data from a central source, and data is pulled from multiple primary sources. The Push Model uses a central sources as well, but it is receiving data that is pushed from multiple primary sources.9 Since the Canada Health Infoway architecture has standards for interoperability in their national electronic medical record architecture, data will be able to be pulled or pushed to or from databases along a Health Information Access Layer (HIAL). Public Health agencies will be able to pull information from EHRs, or PHRs or at least from those where patients have consented for their use. Physicians as well have a duty to push data to Public Health.

Currently the model to access PHI through the nationalized service is being implemented in the United Kingdom and Australia. A “web-based, distributed personal longitudinal record”11 is where the individual would have a home health information repository, perhaps tethered through a family physician practice, to which all records or interactions with the health care systems can be transferred through interoperability standards. There are still real problems with that prospect, as outlined by Gunter and Terry, among them being the question of where the most up to date or master record is located.11

4.0 Pushing Data to the Tethered PHR

In the United States there is a burgeoning idea that Healthcare institutions should push records to the
individual PHR holder, or the “electronic medical home chosen by the patient”. Presumably the patient would also need to take more control over the management of their health information in order to push it to a medical home. The “electronic medical home” on the other hand, might necessitate having a national, or federated database, from which patient data could be accessed anywhere.

The programming idea to push data to the PHR as the ultimate medical home is based on REST, SOAP or SMTP. These were originally proposals made by the Nationwide Health Information Network (NHIN) Direct Project. Each patient would have a Health URL or email enabling an easy transport of health information exchange to the correct location. One way to think about this innovation is to think how wide open information communication technology really became when the SMTP protocol was created, so that someone who had an AOL email URL was actually able to send an email to someone who had a CompuServe email URL instead of to just another AOL user. Imagine if people with gmail accounts could not email friends who used hotmail! Physicians can now send healthcare information to their patients' PHR like sending a very secure email, and vice versa. The technical feasibility of doing this is of course tempered by the willingness of physicians and patients to be data transporters, but no doubt software usability designs with point of click interfaces can be created to help facilitate the trafficking in PHI to and from PHRs. Working off the nationalized grid and pushing healthcare information onto the cloud and giving more control of the PHI to patients is also a form of decentralization, as well as convenience, starting to be adopted in the United Kingdom, by those frustrated by the national architecture. Something like the Project Direct “Health Internet” URL could open interconnectivity everywhere, and not just in the UK.

As I have had a Google Health account since 2008, I was able to export my profile fairly easily. I am technically savvy enough so I understand file extensions and options for exporting such as zip, CSV, PDF, XML, HTML. I was also given the option to export my profile to Microsoft Healthvault which was as easy as logging in with a Microsoft Live ID. However, the stumbling block was that since I was outside a mostly US proprietary geographic area, I required an identity code from a healthcare provider before I could create my account. That is kind of a “tethered” idea for a standalone system. I was therefore unable to transfer my Google Health profile right away to Healthvault. However, Microsoft Healthvault recently added a Direct Project interface so that I was able to use a Direct Project URL email to send my Google Health profile directly to Microsoft Healthvault. I am all set to have my healthcare providers send copies of my health information to Healthvault through my @direct.healthvault.com Direct Project email.

Health information uses the “push and pull” model of a distributed Service Oriented Architecture (SOA) that is potentially fully automated to register and transport health care data events WHEN they happen. Why create a nationalized PHR system for ten million people, the majority of whom might never use it? Not everyone will need a PHR until such a point in their lives when having access to the information becomes critical. Then a person will want to have something that is accessible, transferable, convenient, usable, secure, etc. The tethered and decentralized model is supported by physicians who wish to “prescribe” a PHR to a patient based on their belief in the clinical utility of such a support system.

5.1 MyOSCAR

Architecture: Based on the open source Indivo project (MIT/Harvard) content management system. Can be accessed by a physician through hypertext link on an EMR system like OSCAR if consent is given by the patient. Patient must be part of the practice of the physician in order to have a MyOSCAR account. Patient logins to an internet based interface. MyOSCAR was developed using Open Source tools (Linux, Tomcat, MySQL, PostgreSQL, Plone, Python)

Tethered Features: Patients can send secure messages to their personal physician, and receive responses. There is an ability to book appointments and manage prescriptions and renewals. It is being used in clinical trials, i.e. MyBP and MyMeds because physician data in the EMR can be compared readily to patient self-reported data, as an example.

Integration: There is OSCAR – MyOSCAR integration though they run on different servers, by way of an “integration engine”. .

Interoperability: It is tethered to the OSCAR EMR which supports HL7 file transfers, and is based on Indivo which was designed for interoperability, but it doesn’t have interoperable features.

5.2 TELUS Personal Health Record and MyChart

Architecture: Originally MyChart was a tethered portal for Sunnybrook Hospital patients in Toronto. TELUS purchased MyChart and launched their own for-profit PHR product which is built on Microsoft Healthvault, but is hosted on Canadian servers, renamed as “Health Space”. Windows operating
system, as the System Developer Kit is an .exe or Windows executable file). 17

Tethered Features: In TELUS Health Space, a primary care physician can choose which module of the EMR the patient can have a view, such as medications, blood pressure, prescriptions, or all of the modules, simply by clicking a button inside the EMR record of the patient and selecting from those options. A patient can use it as a stand-alone system. Only Sunnybrook Hospital patients have a MyChart account, but they can grant access to personal physicians, others in the circle of care, or even family members. Includes secure messaging (as secure as a bank's) to prescription refills, lab test results, personalized diary, and links to personalized health information. 18 Tethered to Sunnybrook Hospital at first, patients, can continue to use it, for free, throughout the continuity of care.

Integration: Health Space can integrate with many other EMR systems and is not platform specific, for example, Healthscreen, which is an Ontario EMR, KinLogix Medical (Quebec), Wolf Medical Systems. (Alberta, British Columbia) 17 Also integrates to other devices like smartphones, for example, the “bant app” for diabetes tracking on the Apple iPhone. 17

Interoperability: There is greater promise of interoperability as more integrated features are added. TELUS Health Space has Canada Health Infoway “Consumer Health Platform certification” which means it has passed criteria for interoperable databases that contain personal health information for the consumer health platform. 19

5.3 MyDoctor Health Portal

Architecture: Is a proprietary product since 2008 of MD Physician Services, a software company owned by the Canadian Medical Association. It is the number one EMR system, in terms of market share as per OntarioMD certification. 20 Typically, the mydoctor PHR is tethered to the Practice Solutions EMR. Can be “prescribed” to the patient by the physician or staff who sends an email invitation to enroll them. May have an annual fee, i.e., online interactions as uninsured services. Can be used to manage consultation requests. Not much information on the architecture is available online. 20

Tethered Features: Patients record chronic condition readings from home, viewable by physicians. Access to a health library, handouts, health metrics, a PHR (medical history, allergies, medications, lab results), secure messaging

Integration: In future the Health Portal will be better integrated to the Practice Solutions EMR with better access level views for the patient.

Interoperability: The Practice Solutions EMR supports HL7 data transfers to hospitals so there is the potential to open a view of that data to the mydoctor PHR. 21

6.0 Discussion

Only MyOSCAR is more or less publicly available as it is an open source system. The system architecture for MyOSCAR can be traced to the Indivo architecture developed by the Harvard-MIT Children’s Hospital Informatics. 15 MyOSCAR maintains the open source standard very strongly and is a very tethered system. The TELUS Health Space system, though packaged and promoted like a consumer product, still remains essentially a standalone PHR system, in spite of it’s EMR integration and tethered patient views. It is an architecture developed by .NET but remains the basic Healthvault version. Mydoctor tends to preserve the stronger tethered architecture with a proprietary software system, while MyOSCAR developed more of the personally controlled subset of the tethered PHR.

If you build a PHR system on XML, do you automatically loose it as a tethered system? The physician-patient relationship can be built on a shared data model of the EMR-PHR, and the tethered nature of the data integrity can be maintained even if there is a potential for data sharing, integration and interoperability because of something like the XML platform. This is what Eysenbach means by “at minimum an XML download”. 22 The silo or island of information does not have a lot of potential meaning or utility in an integrated data world, but it still maintains a great deal of security, privacy, and trust. If the patient needs to move to a different place or their interaction with the health care system becomes really complicated, a PHR system would be of some value. An XML-based tethered PHR would be flexible, even capable of receiving or sending PHI through distributed web services. For the consumer who wishes to change personal physicians, there is a greater possibility of transferring medical records to a different EMR/PHR system if records can be exported or exchanged through XML messaging or download.

The Canada Health Infoway architecture promotes the use of standards nationally, but there is nothing in the architecture for a national PHR integrated system. The province of Alberta has an initiative for a backbone PHR system which has technical capacity for tethered PHR. 23 Countries like the United Kingdom and Australia are following models for national systems, which use centralized and integrated approaches, but Canada appears to be only
moving to use the integrated approach, but not a national system.  

There is an argument that PHRs should be “tethered” because the alternative can lead to commercialism.  

This view is supported by the literature that maintains “the ‘integrated PHR’, that is an extension of physicians’ electronic health records (EHRs), will go further in facilitating the type of physician-patient relationship that will improve health and healthcare, at a lower cost.”  

Part of the atmosphere of distrust around commercial PHRs in the United States is that they are not regulated HIPAA compliant entities.  

The regulatory nature of PHRs in Canada is captured in an article by Williams and Weber-Jahnke who maintain that EMRs and PHRs might have to be certified in Canada as class 2 medical devices.  

Probably it would be easier, and less expensive, to certify the tethered PHR after the EMR it is tethered to is certified.  

Sharing patient health records in the tethered model need go no further than the physician-patient relationship, as opposed to Web 2.0 and shared internet or cloud spaces. The idea is that many people will want to maintain the trust inherent in their traditional doctor-patient relationship.  

Health care is complex and health information is shared among many different institutions. Using Web 2.0, the cloud, or Software as a Service (SaaS) for storing medical records might seem to contradict the notions of privacy, security, and trust most consumers have, but using Facebook to do that has saved a patient’s life, and perhaps others as well.  

The architecture of using Facebook to store one’s PHR might be a kind of “virtual panopticon”, unless one actually knows how to set the privacy features correctly! Given the legal entitlement of patients to PHI, there is great freedom in how patients will use what rightfully belongs to them. The limitation is how readily available it is. This is indeed in fulfilment of the prediction of Eysenbach that Web 2.0 savvy consumers will push the envelope and demand more than just an institutions-specific “portal” (also called “tethered” PHR) which allows them to view or access their data but not to do anything else with it. Patients 2.0 will demand full control over their data (as a minimum, XML export).  

7.0 Conclusion  

As more physicians implement EMR systems, they will begin to work through whatever liability, usability, economic and clinical issues remain to prescribing or treating patients by way of a PHR interface. Just from a project management success point of view, defined as being on time, within scope, on budget, and to the satisfaction of the client, the best architectural model for the PHR is one that is controlled by the GP and the patient together. As a consequence of the technological pull and push of PHI to the PHR, medical event records will be driven through something like a distributed SOA and web service, the HIAL of the Canada Infoway architecture, or the Direct Project “Health Internet”. PHR systems might even become the ultimate medical record or “home medical repository” for all PHI, as long as they can be tethered and un-tethered to a main clinical point of care, with seamless data integrity. The principle will always be, not the technological nature of “being tethered”, but the gravitas of being closely aligned with an authenticated and trusted medical institution or physician.  

8.0 References:  


Acknowledgements: To Dr. Ann McKibbon, Dr. Norm Archer, the students and staff in the M.Sc. eHealth program at McMaster University.

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