

## Commentary: the patient's memory stick may complement electronic health records

Health information management is hugely complex - possibly more so than any other industry vertical, with large numbers of concepts and high rates of clinical knowledge change. Perhaps more importantly, health is one of the very few industries in which data needs to be actively exchanged between participants. Electronic health records (EHRs) are definitely not simple concepts that are solved by storing information in a relational database for use in a single organisational silo, but require the capture of a breadth of health information in a manner that can be easily stored, retrieved in varying contexts, and searched. Then there is the additional and unique requirement of sharing this same information with a range of healthcare providers, each with a differing focus, requirements, technical tools and term-sets. When you add in some of the other more lateral requirements such as medico-legal accountability, pooling data for public health research, and privacy, consent and authorisation for sharing sensitive health information, it becomes increasingly evident that health data management has no real equivalent existing in other industries.

In order for shareable electronic health records to become ubiquitous, there are numerous building blocks that need to be in place – commencing with appropriate levels of funding, legislative changes, consensus on a range of standards, stakeholder engagement, implementation of massive change management programs etc. Australia's solution is the *HealthConnect* program – a joint Commonwealth and state government initiative – which is gradually identifying the required pieces, and laying them out in a systematic way to solve the e-health system puzzle.

There is no doubt that successful navigation of our health system will be assisted by timely availability of high quality and comprehensive shareable health information at each step of the journey. This will definitely come - but if we rely on the top-down system approach to EHRs it will take a considerable amount of time, money and effort to reach critical mass and provide broad benefits. We will still need motivated healthcare providers seeking active access to that information in order to achieve best outcomes for all in a complex health system, and we will require matching processes and communication mechanisms in place to support the best-practise use of the information and minimise risk.

A common feature observed in nearly all of the existing and ongoing EHR developments is that the major focus is on data capture for the *use of the clinician* and *about the patient*. Most EHR planning revolves around the needs of GPs, hospitals, specialists, software vendors, health organisations and government, so that care can be provided to 'the patient'. Whatever the term you prefer to use - the consumer, individual or patient - is still essentially regarded as a passive participant amongst this flurry of activity.

In the main, current EHRs are actually patient-centric only in the notion that the subject of the health record, and all of the information contained within, is about one single individual. However the record is still primarily clinician-centric – in that all of the data captured, exchanged and stored is primarily to enhance the clinician's ability to make diagnoses and treatment decisions for a given patient. In most cases this record is then owned and managed by clinicians, or hospitals, as custodians on behalf of the patient, in order to maintain the 'integrity' and 'quality' of the EHR.

It is ironic that the bulk of both consumers and healthcare providers seem to believe that while individuals can manage every other part of their lives, their health information is somehow different. Until recently the paternalistic health system that we have inherited perpetuated the roles of 'authoritative' healthcare providers and 'submissive' patients. It is pleasing to see this gradually changing, with more patients taking an active role in their health decision-making.

There is no doubt that consumers are becoming increasingly involved in researching information on the internet about their health and treatment options, with the term “health” being one of the most popular searches on internet sites such as Google.

There is enormous potential to revolutionise the way we deliver healthcare by educating and supporting consumers to be more pro-active, participating in decision-making and managing their health information in an active partnership with healthcare providers. But how do we facilitate a better shared care model of health service delivery, with healthcare consumers and their clinicians working effectively as a team to achieve improved health outcomes?

How many of us keep at least some of our own health records in our home filing cabinets? How many of us know when we were last immunised for tetanus? Can you remember which of your children broke which bone, or do you confuse them? Do you recall what your last cholesterol test results were, or who would have a copy of the report? Is there an unrecognised cumulative trend in your test results, all of which are currently scattered in various clinics and databases around the country?

For a moment, consider the subtle, yet quite distinctly different concept of a truly consumer-centric health record, which would be primarily for the *use of, and about, the individual* - a record that is truly owned and managed by the individual, containing all the breadth and depth of their own personal health and wellbeing information. The concept of a Personal Health Record (PHR) is not new. Paper-based records have been used for many years, especially in the form of shared antenatal records, some chronic disease care projects and the ubiquitous ‘Baby Book’ recording the broad health professional contacts in the first years of life. Other projects utilising smartcard technology have been used to store and carry restricted health summary information with some success, but encountered problems related to cost and limited data storage, plus the pervasive problem of multiple smartcard formats requiring the healthcare providers to have multiple specialised card readers.

Internet-based Personal Health Records have increasing momentum in the USA as any internet search will demonstrate, but are not so prominent in Australia. To my knowledge, the only active online PHR in Australia is a diabetes-specific online health record for Royal Children’s Hospital, Melbourne, being used by over 350 of their patients with diabetes since its launch in July, 2003<sup>1</sup>. It provides the infrastructure for a collaborative model of care, by supporting the teenagers to communicate securely with their clinicians from home; to create and share their own electronic health record with providers; upload clinic summaries from the hospital and home glucose test results to their record; and encourages them to more actively manage their diabetes. Privacy, consent and authorisation models are built into the PHR and managed by the consumer, as they have ownership and control of the health information.

In recent times the USB memory stick has become commonplace and is another alternative as the basis for a PHR - prices have been reducing, and more importantly, there is at least one USB port in every desktop and notebook computer made in the last few years, which makes it potentially easy to share health data stored on a USB stick. The memory sticks now have built-in hardware features such as segmented secure/non-secure areas which might enable easy emergency access to critical data while keeping other health details secure and needing a password to access. Again the US seems to have been quicker off the mark to utilise this technology, for example, with an emergency PHR held on a USB<sup>2</sup> -.

Personal Health Records are now a significant part of the US e-health strategy. In 2004, Dr David Brailer, National Coordinator for Health Information Technology, released the Framework for Strategic Action in which the third of four overarching goals was entitled “Personalize Care” – “We are pursuing three strategies for personalizing health: encouraging the use of PHRs,

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<sup>1</sup> [www.betterdiabetes.com](http://www.betterdiabetes.com)

<sup>2</sup> [www.medicalert.org/E-Health/](http://www.medicalert.org/E-Health/)

enhancing informed consumer choice, and promoting the use of telehealth systems<sup>3</sup>. Unfortunately PHRs have had little traction within Australia to this point.

Within the general population, a PHR will be a disruptive move in the health system, and will be extremely popular with many consumers who have long-term health issues and/or complicated medication regimes. For example, a consumer-held health record on a USB memory stick has the potential to be the first realistic and practical way for an Australian consumer to draw together authoritative sources of their recent health information. This is entirely compatible with the Commonwealth government's *HealthConnect* vision, but offers a bottom-up, consumer driven, faster approach, with the benefit of a simplified privacy and consent model, compared to the current slower and somewhat ponderous top-down implementation. In the longer term, as *HealthConnect* is gradually implemented, a PHR that has already been active, collecting and accumulating current health information, could become a future source of data for provider EHR systems.

Imagine how a consumer-held health record could help individuals...

- ... to collect and collate lifelong health information, to share with authorised healthcare providers at their own discretion, or to make a health summary of critical health information available in emergency situations. It could underpin a more effective shared care model of healthcare delivery that will embrace the broadest range of healthcare providers including the traditional providers such as GPs, hospitals and specialists, but also be inclusive of the ambulance service in an emergency, carers, dentists, pharmacists, allied health providers, naturopaths, and even school teachers on excursions.
- ...who have a chronic health condition. Initial emphasis could be on collecting information that will focus on a condition-related health summary that will augment overall clinical care and communication, and later be extended and enhanced towards a comprehensive shared clinical health record. This approach is initially likely to get high uptake amongst those who want to view and share their personal health information because they believe that it will directly and positively benefit their day to day healthcare. It can be extended via web portals to link the consumer into a condition-specific virtual community, designed to support the individual in maintaining their physical health, provide psychosocial care and advice, connect with others experiencing the same condition, and enhance quality of life. For those who are essentially fit and well, community portals can be focused on health promotion and preventive health and maintenance of wellbeing.
- ...who are on a complex daily medication regime. It would enable them to keep a record of current medications, allergies, adverse reactions, and medications that have been stopped including the reasons for cessation. It could even enable them to print out a medication chart showing which tablets to take at what times, the reasons for taking each one, and a picture to confirm which tablet is which. They could have a chat with the local pharmacist and update their medication list (including OTC medications) and then share it not only with their GP but also their naturopath, dentist, physiotherapist etc.
- ...who were in an emergency situation and unconscious. An online record with emergency access or override, or a USB memory stick with limited emergency access could provide fundamental life-saving information regarding conditions, allergies and current medications for use by the ambulance services or emergency departments.

Data downloads would be the preferred data entry mechanism to enable a quick and simple initial population of an online or USB PHR. The potential sources of data include all electronic systems where important health data is kept for individuals. Initial phases could focus on hospital systems

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<sup>3</sup> [www.hhs.gov/healthit/goals.html#personalize](http://www.hhs.gov/healthit/goals.html#personalize)

for clinical summaries, pharmacy systems for medication data, and organisations such as the Blood Bank for test results, blood pressure measurements and blood group. GP clinical systems could also be an excellent source of information. The capacity for self-entered data into a PHR would be able to enhance the traditional health summary by addition of a broader range of health-related and personal information, making the resulting record much richer and deeper than could be captured in the best kept clinician's record alone.

There are issues around the use of PHRs that need to be promoted for further discussion:

- Privacy and consent models are simplified with use of a PHR. As the health record is controlled by the consumer, it is shared at their discretion and thus their consent is inherently implied.
- There are some people in the community who are not capable of managing their own PHR. This is true - however these are generally people who are frail or disabled and already need assistance from a parent, advocate or carer to simply attend a clinical consultation or to manage other aspects of their lives, such as banking etc. Some would need help, but for most people it will empower them to be more proactive in managing their health and wellbeing.
- PHRs are either more secure or less secure – depending on your point of view! However the benefits of having easily accessible information, in most cases, far surpasses the problems created by having inaccurate or out-of-date data, or no information at all. The old paper clinical records are certainly not a secure.
- Clinicians may not accept data that has been entered by patients. This requires careful consideration as the data source in any shared EHR must be easily identified, whether entry is by a consumer, allied health provider, pharmacist or medical practitioner. All information is valuable in its correct context, and should be kept and stored for that very reason. However in an extreme life-threatening situation, for example, a clinician must understand that they are basing their decision-making on data from a known and/or credible source, and then place appropriate weighting on the data in making their clinical decision.
- Use of a PHR requires a major change in the way both clinicians and consumers think about health information. Motivated individuals – who may have chronic health conditions, multiple complex medications, or conditions that may require emergency intervention – are most likely to be among the first to adopt a PHR. However, it may require quite an extensive education process for some, but as our younger, computer literate generations mature, they will embrace this new way of approaching health care in much the same way that using ATMs or internet banking has now become a routine part of our day-to-day life.
- Development of PHR and EHR systems needs to be undertaken to ensure that data can be exchanged seamlessly from one to another.

A grassroots push by consumers wishing to hold, own and manage their own health information has the potential to make relatively quick, inexpensive and significant changes to the way healthcare is delivered, to support and encourage consumer input to their own health information record, and kick-start electronic health record development in Australia. And eventually when our individual PHRs evolve to amalgamate and integrate with the HealthConnect implementation, we will all be beneficiaries of an integrated and interoperable health system, meeting the needs of all participants in a timely manner, and most importantly enhancing health outcomes, and minimising risk.

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