

Can we have an organic and evolutionary EHR?

In Karen Dearne's article "Compromising confidentiality" in The Weekend Australian on Saturday February 13th she addresses some of the privacy issues and likelihood of uptake of a government sponsored national health record in Australia. Ms Dearne echoes concerns expressed by many about the inappropriate use of national identifier numbers and questions whether current health record approaches are suitable for the new e-Health environment. Her approach is fundamentally conservative, and with good cause. Achieving the sort of health outcomes hoped for through the use of computers has largely eluded even massively funded national programs such as the UK's 'Connecting for Health' and Canada's 'Infoway'. Some have dubbed these the programs as the 'place where the rubber hits the sky'. Perhaps our recent and current governments should be congratulated for not bowing to industry pressure and spending money on major 'top-down' programs of this kind. Imagine if the government took this approach to banking or electronic initiatives in law.

The axiom "Information is power" probably drives much of the scramble for ownership of the new shared electronic health record. Governments around the world want to be recognised for realising the benefits. The promise of this technology includes less healthcare accidents, less repeated steps in care, less investigations, more appropriate treatment, more accountability and so on. There is clearly a perceived commercial opportunity too as telcos, insurance companies, pharmacies and companies like IBM, Microsoft, and Google also want in. But let's consider some of the barriers, because these are considerable.

Electronic health records are collections of information which are designed primarily to provide an historical account of care received, to defend a health professional's actions and to assist a group (sometimes a team) of health professionals to work effectively together. It has been proven that it is safe for the vast majority of people to view their own health records and is also likely to lead to more accurate records. All forms of records, such as legal and banking, benefit from scrutiny in much the same way. Beyond this, the impact of personal access to health records is largely uncharted; there is a lot to learn.

Having our personal information stored somewhere on the internet should make us concerned: it is immediately more available and information can be copied very quickly if unauthorised access is gained. The current rate of electronic fraud in banking may be acceptable (or manageable) for that industry as, on the whole, there is a clear incentive to replace what is stolen and the resources are available. Health care is not as straightforward; information is complex, highly personal and can be used against that person's interests both commercially and politically. Confidentiality is far harder to assess in cyberspace; information can be used without consent and without any recourse. For instance, if you remove your date of birth (e.g. 1965) from Facebook it will not prevent you from getting advertisements like "Are you 45? " What can you say or do?

It is attractive ideologically and politically to ensure people are in control of their own health records but it is not clear exactly what this means. The most sensible idea that arises from this is for people

to give access to care teams rather than individuals. Logically it might be a hospital at times, with access control then being managed within that institution for the information that has been shared. Electronic health records are living things that need to be maintained to be useful and to provide an accurate view of the person's health and health care. Information will become out of date or be proved wrong. Aggregated records may not be consistent. For example, a diagnosis made by a pathologist (e.g. ductal carcinoma in situ) will be different from statements made to patients (e.g. pre-cancerous changes in the breast). A person having a 'fear of having cancer' must be differentiated from one 'having cancer'. Some web-based health records downloaded from clinics in the USA have had entries that expressed the concern of clinicians reinterpreted as meaning the person actually had that condition. This is a cause for concern. Who is going to maintain these records to ensure they are coherent and to help patients achieve maximum benefit? It is certain that those with this duty will need considerable clinical knowledge and skill to do this efficiently and effectively.

For the benefits of electronic health records to be maximised there must be a focus on the ability to share information between authorised health care providers, the patients (clients or consumers) and, where appropriate, their carers or guardians. Ideally this information should be able to be processed by receiving software used in different settings. But it is more complex than that. These days patients are able to measure their own blood pressure or blood sugar using quality devices and good techniques. These measurements are amongst the most useful to assist management and demonstrate that it will be increasingly important that people are able to contribute to their own records.

The negotiations that led to electronic downloading of music and the success of the iPod were arduous and protracted. Likewise, a framework for effective electronic health records will take time and commitment. The electronic health record that will provide real benefit will be a sophisticated technology that supports clinicians and allows others to contribute. But it will not be a free-for-all and if it does not support the health care providers adequately another solution will have to appear. But where to start? Do we need evolution or revolution?

If government and software companies cannot get this off the ground then it is necessary to look elsewhere. Consumers can support this development and it will have to meet their needs, but instigation requires leadership of a different kind. In this case clinical leadership is probably ideal. The reason health records exist, after all, is to help clinicians deliver health care. If clinicians are to lead the e-Health evolution in Australia then general practice is the ideal champion. GPs are paid for by patients and subsidised by the federal government. They can act independently of other stakeholders and the solution can be national.

Connecting general practitioners with each other may be the ideal starting point. GPs have an electronic longitudinal record for many patients already and one that is organised to support preventative care and management of chronic disease. As people move around the country they like to take their records with them, taking them from their previous to their new GP. This is still done largely by printing on paper, photocopying or faxing. The real point is that there is an established need and process for doing this. Thus, the sharing of electronic health records could begin in a way that follows these current norms. Such sharing could then be extended to specialists and hospitals as appropriate ways and means are found. It won't take long. At present this is not possible (although

the Department of Health and Aging has agreed to fund such an initiative in the past) because the power of software companies has prohibited the collaboration required to make it possible. Shared records also require an agreed format for the health record. The *openEHR* specifications (www.openehr.org) were designed specifically for this purpose and can be seen as the MP3 for health information. However, these specifications do not, as yet, have industry backing despite government uptake and interest in countries such as Sweden, Slovakia and Brazil.

What to share? The answer is – it depends. It depends on the need of the recipient and the wishes of the person being referred. If someone is referred to a physiotherapist by a GP it may be quite a limited subset. If an elderly person is transferred from a hospital to an aged care facility there will be key information to share and it is likely to include the last time the person used their bowels. Impacted faeces are no fun for the person or their carers. If a person moves from one general practice to another it will be the entire record. If a person is admitted to hospital it may be all their recent records and a comprehensive summary. If it is a record at a sexual health centre the norm will be for this information to remain on site although some people will understand why certain information may be required elsewhere.

Where to store it? A general practice shared record would allow people to keep their record in a repository where they can access it and where they can provide access to others. This would not require unique identifiers as subscription to a service (like email) provides a means of generating a unique identifier for that service. Some may choose to keep all or part of their EHR on their person with a backup somewhere safe.

A general practice based shared electronic health record would simplify things a great deal and start with key players who are doing this already – the people and their general practitioners. Such an approach would require public funding initially although the billion dollars Ms Dearne mentions seems a little excessive.

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