Submission to Electronic Health Records and Healthcare Identifiers Legislation Discussion June 2015

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Background

I am making this submission as an individual. My comments are the result of my experience as a health services consumer, six years as health industry blogger and 30 years as the owner of small business.

My experience with health services is primarily as a patient with end stage renal failure. I have received two kidney transplants, the first in 1995 donated by my wife (which failed), the other in 2005 from a deceased donor (which lasted for three years). I have been on dialysis, on and off for just over 20 years.

I have written a blog, *BigDandMe, Healthy dialysis techniques for people whose kidneys have let them down* since April 2009. I recently completed an eHealth MOOC offered by the Karolinska Institutet in Sweden (see below for details).

I am excited about the Australian Government's eHealth strategy and implementation. I have high expectations of the improved medical outcomes it can (and will) deliver via a single universal health record to Australians both individually and collectively, and of the economic and national health management benefits at the Big Data macro level.

I first registered for my PCEHR in April 2013. I was disappointed by the clunky usability and especially by the lack of content: it was essentially empty. There is little point commenting on the poor quality of the implementation and promotion. The PCEHR Review of Dec 2013 has provided an excellent summary and roadmap for recovery.

Submission

With regards to the proposed changes set out in the Electronic Health Records and Healthcare Identifiers Legislation Discussion document, I offer the following ideas and responses to the issues and questions raised.

Legislation proposals

I agree with the proposed changes.

Governance

I agree with the proposed changes.

Participation

I agree with the proposed changes and suggest the following access control ideas for consideration.

- Every large scale new use of MyHR "identifying information" should be subject consumer agreement, either via a national online, non-compulsory ballot, or specific referendum.
- Large scale (big data) use of the MyHR data must use de-identified records.

Obligations of parties

I agree with the proposed changes.

Privacy

I agree with the proposed changes and suggest the following MyHR privacy ideas for consideration.

Most countries are setting up or designing an eHealth framework of some kind or other, all for the first time, all for the same very good reasons. However this framework is a genuinely new paradigm: never before so much detail about each and every individual been collected and stored in one place.

But, put simply, MyHR wants every Australian to provide intimate personal details about themselves, right down to their DNA, to in an online System that can be accessed by a range of people and organisations. The first things most people ask is: how can I be sure it is not abused?

Handing over all our health information, our history, warts and all is a big ask; a big chunk of our secret self. Collectively sliced and diced right our health data it could change the nature of our society. We know the benefits it offers: efficiency and financial savings at the macro level and better health outcomes for all ay the micro level.

But in the wrong hands, it could be used to select winners and losers for jobs, promotion, insurance, health services, welfare, or even life itself. Imagine the power it could give a fascist, tyrannical or dictatorial regime. This may not be such a worry in Australia but ask someone living under a dictator or psychopath in the Middle East or North Korea or Jews that survived the Nazis, or any other oppressed peoples, if they think it is OK.

Even in Australia, in the wrong hands and without our approval and appropriate controls, MyHR could quickly, by stealth become: a de facto:

- Australia Card
- Mobile telephone directory
- email address directory
- Proof of identity for opening a bank account, etc.

It is critical that all MyHR stakeholders, especially consumers, can trust that the data is used only by those who are authorised to do so, for reasons specified by the legislative, governance, participation, obligations, reviews and especially privacy protocols set out in the discussion document and the original system design.

Additional Access Controls

Since this national personal health data system is a new organism, we need some new privacy thinking, new laws, checks and balances. These could include:

- Each MyHR should be legally owned by the person it documents both as copyright and as an asset

- Ad hoc access to MyHR information should be only with each individual's express permission. This applies especially to law enforcement and national security agencies currently nibbling away at our human rights
- There should be NO opportunity to bypass the legislated access permissions by government officials or members of parliament (especially by ideologs in minister's clothing)
- Every large scale change of use of MyHR "identifying information" should be subject consumer agreement, either via a national online, non-compulsory ballot, or specific referendum.
- Large scale (big data) use of the MyHR data must use de-identified records.

Encryption

Obviously, MyHR data should be encrypted in transit, but it should also be stored in an encrypted form (like in many cloud-based public data stores) with the private key held by the owner. Access to the record could then be made available via a public/private key combination provided by the owner. This structure would readily support many of the above access control suggestions.

Reviews

I agree with the proposed changes.

Ideas for increasing System Take-up

Most countries are setting up or designing an eHealth framework of some kind or other. They include the usual suspects, like all of Scandinavia, the UK, most of Europe, Hong Kong, Singapore, Australia and New Zealand, and parts of Canada and the US. The rest of the world is also on the job, like Russia, Brazil, India, Pakistan, the Philippines, Mexico, Turkey, Nigeria, Israel, Iran and Saudi Arabia.

The majority of these eHealth frameworks are based on the World Health Organization's 2005 Resolution WHA58.28 establishing National eHealth Strategy for all member countries.

In terms of national eHealth system goals, I rather like Israel's: *To achieve a universal access to health care services leaving no one behind.* Short, sweet and inclusive.

Many countries have started with fairly simple eHealth functions like eAppointments and ePrescriptions because they can be developed relatively quickly as stand-alone projects.

Other countries (including Australia) decided on the big bang: to develop a national eHealth record system and then convince patients, clinicians, hospitals and healthcare services generally to use it. Without exception, this approach has been very expensive and very, very difficult, especially in countries with a mix of public and private healthcare providers like ours; to the point that most have failed on the first try.

The Swedish eHealth system is the most advanced, because they started earlier (a couple of decades ago) so they have the most scar tissue and the most success. And the most functionality. Residents (and users in adjacent countries) can make appointments, order prescriptions and referrals, track visits and treatments, manage vaccination and much more online. It has been taken up enthusiastically and its functionality grows each year.

Compare that with our PCEHR/MyHR: essentially a government service portal containing passive records of our departmental interactions with Medicare, PBS prescription, Child Support, ATO (why I don't know), NDIS, DVA, JobSearch, Centrelink and perhaps others.

Even the future vision, where MyHR will eventually to be populated by updates from primary, secondary and tertiary healthcare services, it will remain an essentially passive record. This will be nice, but hardly an overwhelming drawcard for enthusiastic use by consumers.

Functions that will Promote System Take-Up

To be successful, MyHR should be more than just a passive record; it should be somewhere that people go to for DOING health-related activities. Activities like:

- ePrescriptions. -prescriptions generated in the doctor's electronic prescribing system, and then transmitted through a secure network to the national e-prescription database. While only the prescribing physicians and pharmacy personnel have access to the prescription, I can then have my medication dispensed at any convenient time and pharmacy
- eReferrals: especially for renewals, simply going online and requesting a renewal, which would be emailed to my specialist I'd be happy to pay a small fee for this rather than taking both our time (and paying for a full visit).
- eAppointments for other health care services: my nephrologist, general practitioner or family doctor, clinics/hospitals, nurse practitioner, pharmacist, physiotherapist, psychiatrist, clinical psychologists, occupational therapists , dietitian – the lot
- eVaccination: a system that tracks my vaccination history and reminds me when we need another (currently I am more likely to get a vaccination reminder for my dog!)
- eTransplant: Showing details of my antibodies, potential for transplant, even my place in the mythical transplant queue
- eDonor: if there are any useful bits of me left when I go for the big sleep, the fact that I would donate should be both with me (on my driver's licence) and online somewhere
- eResults: online access to all my test results, blood and body fluid tests, biopsies, ECGs, MRIs, and all other medical imaging, with facilities to email the associated clinician for advice/discussion or to set up an appointment (for a fee)
- eMedications: a list of all my current and past medications, with side effect details, would be useful
- eEmergency: An on-my-person record of personal details, next of kin, ailments, medications, prescriptions, health insurance, and emergency contacts
- eInsurance: Readily available, electronic proof of health insurance
- eDialysis: that provides dialysis performance details after each session, with opportunities for contact with dialysis clinicians for queries and support
- eAppointments for dialysis: being able to set up my treatment times, to swap times and even book times in other dialysis clinics electronically
- expand the service to include the Australian e-mental health service
- eDNA: access to my genetic profile, showing my health risks, inherited conditions, drug risks and general traits. I want to know if I have any vulnerabilities or inherited diseases
- eAppData: where eHealth apps from iTunes and GooglePlay can dock, and store App data.

Many of these are already available in Australia (my family has changed GPs because the new one offers online appointments and test results). Many other countries began their eHealth service with small scale apps, like ePrescriptions, e-appointment s or e-vaccinations, or a national infection prevention and control system. Implementing one or two as part of the eHealth vision to raise its profile and excite and promote its use. When the final vision – secure online access, ideally in timeline and calendar formats, to a patient records about consultations with a GP, clinic, specialist and

hospital stays, transplants, infections, heart problems, etc – is released, it will be a logical outcome of a gradually expanding and eagerly awaited eHealth system.

eHealth MOOC

Sweden's Karolinska Institutet offers a six-week long MOOC called *eHealth – Opportunities and Challenges:* An introduction to the eHealth field featuring practical examples. It is an excellent course, with experts from several countries speaking from experience.

If they have not already, as many Australian Government MyHR staff and contractors as possible should complete the course. It should also be recommended to stakeholders and clinicians, to promote an understanding of the environment and generate interest and take-up when MyHR is finally rolled out.

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