

Queensland Council for Civil Liberties

My Health Record

The time to opt out of the My Health record system expires on 15 November 2018. We urge everyone to consider carefully this issue. You can opt out by going to this link

<https://www.myhealthrecord.gov.au/for-you-your-family/opt-out-my-health-record>

You will need:

- your Medicare Card, or Department of Veteran's Affairs (DVA) card, and
- one of the following forms of Australian identification:
 - your driver licence; or
 - your passport; or
 - your ImmiCard

In our view you should opt out for the following reasons:

Security

If there was ever any doubt in the mind of Australian citizens of just how safe their personal data is in this information age, it was put to rest in 2017 when the coalition's Minister Alan Tudge exposed the personal details of a Centrelink support recipient in Parliament, for no other reason than she had asked on several occasions for the department to tidy up her information in their system after the so-called "Robo debt" debacle wrongly accused her of having a debt to his department.

By the end of the "Robo debt" process over 200,000 Australians had been accused of having a debt to the Department, which was the result of bad information being fed into a bad system which was the result of lowest price quoting for yet another failed IT system, by the federal government.

<https://www.smh.com.au/politics/federal/robodebt-has-harmed-thousands-say-senators-20170621-gwvvgzg.html>

Lack of effectiveness

Many potential benefits have been claimed for the creation of this database. The evidence for those claims is sparse at best.

One of the reasons the database is unlikely to result in significant health benefits is that the My Health Record is a summary system, is not a real health record like the ones your GP and hospital might hold. It is like comparing a bicycle with a 4+4 SUV. Both will get you to the local shops and back for a paper, but the SUV does far more.

Because the record is only a summary clinicians will not be able to rely upon. This is reflected in the survey results showing 76% of doctors think it will not improve patient outcomes -<https://aushealthit.blogspot.com/2018/07/looks-like-adha-has-lot-of-work-to-do.html>

Privacy

The Council opposes the creation of a centralized database or linking of databases to create in effect a centralized database. A centralized database of this nature is a honey pot for fraudsters and for public servants and other government officials.

The potential for misuse of a database combined with a unique identifier is well demonstrated by the tax file number:

“The use of the tax file number provides a recent example of function creep. There is a voluntary quotation principle...by which quoting one’s tax file number is guaranteed to be voluntary. When the tax file numbers first came into effect in 1988, for many people, the only penalty for not quoting it was that for some income, for example a dividend stream, you made an interest free loan for less than a year to the tax office of the difference between the top marginal tax rate and the marginal tax rate you paid (this amounted to nothing for high income earners and not much for most others). Through a range of legislative changes since 1988 it is now the case that some Australians are not able to survive without obtaining and quoting their TFN (for example to obtain unemployment benefits and a number of other interactions with government). The function of the tax file number has moved from a purely taxation related function, as it was initially, to the present situation where it is used to cross-match data relating to government assistance of various sorts.”

The Council’s view is that the government should produce an ehealth model which does not focus on pulling or centralizing all the data into one system, but rather in facilitating local health practitioners to place their records in an electronic system in which they can, with the consent of a patient, share that data with other health practitioners when appropriate.

Professor Ross Anderson of Cambridge wrote in the February 2008 edition of “The Economist” magazine as follows:

“Patient data held at a GP practice may be vulnerable to a security lapse on the premises but the damage will be limited. You could have security or functionality or scale. You could even have any two of these. But you can’t have all three and the government will eventually be forced to admit this. In the meantime billions of pounds are being wasted on gigantic systems

projects that usually won't work and that place citizen's privacy and safety at risk when they do."

The Council endorses the comments of the report of the Joseph Roundtree Reform Trust Limited entitled, *The Database State*. At page 16 when commenting on various electronic health records in the UK the report said:

"Putting everything into one pot not only makes privacy compromises more likely (more users have access to a larger set of data) but also precludes careful consideration of context specific information flows. It also becomes less clear who is the "controller" of the data. Given that the whole data protection system hinges on the duties of the controller and that patients mostly trust their doctors, but distrust ministers and officials, any move to make the Secretary of State that data controller rather than a doctor, undermines both legal protection and trust. There is thus a developing consensus among practitioners that for safety, privacy and system engineering reasons we need to go back from the shared record model to the traditional model of provider specific records plus a messaging framework that will enable data to be passed from one provider to another when this is appropriate."

The proposition is well summarized in recommendation No. 4 of that report at page 43:

"By default sensitive personal information must be kept on local systems and shared only with the subject's consent or for a specific lawful purpose."

Our Canadian colleagues at the British Columbia Civil Liberties Association have pointed to the possibility of making use of the much cheaper open source software system known as "OSCAR".

Summary

The Queensland Council for Civil Liberties believes that citizens should opt out of the "My Health Record" system, and maintain a good relationship, wherever possible, with a single general practitioner. This would obviate the need for an online system to even be built, let alone legislated into the lives of the Australian population.