

Website FAQs:

Why is the government consulting on the secondary use of My Health Record data?

By the end of 2018 all Australians will have a My Health Record unless they choose not to have one. The use of My Health Record data for research, policy and planning purposes can improve the Australian health system by making it more efficient, effective and sustainable.

While legislation is in place to enable the secondary use of My Health Record data, a Framework is required that reflects Australian expectations about how the health information held in the My Health Record system should, or could, be used.

Public consultations on how data in the My Health Record system may be used in future will occur between 5 October to 17 November 2017. This is your chance to have your say.

The release of a Public Consultation Paper on 5 October 2017 marks the start of a consultation process for the government to find out what Australians think the Framework should say.

What is secondary use, and why My Health Record data?

‘Secondary use of data’ is when information is used for a purpose other than that for which it was originally collected. The primary purpose of My Health Record is to assist your doctors and healthcare providers with their clinical decision-making – so your doctors and healthcare providers can all look at the same information about your health. This way, everyone can work together in one secure digital environment to better coordinate your care, even when you can’t speak, like in a medical emergency.

For the purposes of these public consultations, ‘secondary use’ is defined as “using the information in the My Health Record system for purposes other than the provision of direct healthcare to the individual person, which is considered to be the primary use” – for example, to facilitate better research, or to enable better public policy design.

Over 5 million Australians now have a My Health Record. Most doctors and hospitals in Australia are connected to the My Health Record system, which currently holds over 2.75 million clinical records and 12 million prescription and dispense documents. As the volume of information in My Health Record grows and more Australians get a My Health Record, it may become one of Australia’s most comprehensive health data resources.

The Framework will build upon existing privacy laws to enable secondary use of health data for the public good. The use of data solely for commercial and non-health related purposes is considered out of scope.

There are many existing public and government health datasets being used for secondary purposes. It is envisaged that the Framework will address overlap between commercial and health related uses of data. For example, use of data for development of pharmaceuticals could be considered both a health related and commercial purpose.

What arrangements are currently in place?

Currently, data in the My Health Record system is not used for research, policy and planning purposes, although legislation is in place to enable it. Under the *My Health Records Act 2012*, one of the functions of the Australian Digital Health Agency as the system operator for the My Health Record is “to prepare and provide de-identified data for research and public health purposes.” In addition, the legislation states that health information in the My Health Record system may be collected, used and disclosed “for any purpose” with the consent of the healthcare recipient. The *Privacy Act 1988* will also apply to the My Health Record in respect of consumers’ health information. Before My Health Record data can be collected for secondary purposes, a Framework is required that reflects the expectations of all Australians about how the health information held in the system should, or could, be used.

The release of the Consultation Paper marks the start of a consultation process for the government to find out what Australians want the Framework to say. It gives people the opportunity to provide input about who should be able to access My Health Record data, for what purposes and what the oversight arrangements should be.

What are the benefits of secondary use of data?

In the future, the secondary use of My Health Record data is very likely to provide important insights into the effectiveness and safety of medical treatments and clinical care across Australia’s health system.

A good example of evidence-based policy-making as a result of secondary data use occurred in 1989 when Western Australian researchers linked health data from different registries. The researchers determined that the inclusion of folic acid in expectant mothers’ diets prevents neural tube defects in their babies. This finding was followed by education campaigns to encourage women to eat more folate enriched foods or take folate supplements during pregnancy. In 2007, all Australian governments (Commonwealth, State and Territory) agreed to introduce the compulsory enrichment of bread-making flour with folate, which reduces incidents of spina bifida and other neural tube defects in children.

Secondary use of My Health Record data could also occur when new treatments, like new drugs, are offered to Australians for diseases like diabetes or cancer. Identifiable information in My Health Record may be securely linked to quickly locate people who may want to be part of clinical trials.

Researchers involved in clinical trials may also request permission to link My Health Record data to other databases to help investigations into subsequent hospitalisations, diseases and death.

What about privacy and security risks?

My Health Record has operated successfully, securely and at scale for over five years. The system has security similar to that of a bank and is built on proven technology. It has controls in place to detect and mitigate denial of service attacks and hacking attempts.

Typically in Australia, data custodians like the Australian Institute of Health and Welfare and the Australian Bureau of Statistics play a central role in privacy protection and use of

data for monitoring and research. Their duties include undertaking activities to maximise the value of the data they hold, while minimising risks to security and privacy. In 2016, new participation arrangements for My Health Record were trialled in several parts of Australia. Residents in these communities had a My Health Record created for them unless they chose not to have one. As part of these trials, an independent evaluator found that once the majority of participants understood the My Health Record system, they agreed that the benefits of having a record “far outweigh the possibility of risks to privacy, confidentiality and security.”

How can I have my say?

There are a number of different ways you can participate in these consultations. You can:

- Provide a written submission by 17 November 2017,
- Complete the online survey by 17 November 2017,
- Participate in a webinar, to be held at 10.30am AEST on 12 October 2017, participate in the Consumers Health Forum national webinar, to be held at 12:30pm AEST on 16 November 2017 (go to <https://chf.org.au/events/webinar-secondary-use-my-health-record-data> to register for this event),
- Attend a workshop in the city or town closest to you, or if you cannot do this
- Contact HealthConsult directly to provide your views.

The Framework for the secondary use of My Health Record data will be informed by the expectations of the Australian community. This is your chance to tell us:

- When you see a doctor or go to the hospital and information is uploaded to your My Health Record, do you think it should be shared with others (such as researchers). If so, how? If not, why not?
- What processes or guidelines should be in place to allow My Health Record data to be accessed for things like clinical trials and research.
- In addition to existing requirements for management of sensitive personal health data, do you have any other expectations regarding the future management of My Health Record data?

Where can I go to get further information about the public consultations?

Go to myhealthrecorddata.healthconsult.com.au to register your interest and receive updates via email.

Who is leading the consultations?

The Department of Health has engaged HealthConsult Pty Ltd to undertake consultations and develop a Framework which faithfully reflects their findings.