



## Secondary use of My Health Record data: A 'plain English' guide to the Public Consultation Paper

### Purpose of this document

The Australian Government is consulting with the public about how data in the My Health Record system may be used in future. This is your chance to have your say. The Department of Health is leading the public consultation and has prepared this guide to the **Public Consultation Paper – Development of the framework for the secondary use of My Health Record system data** (‘the Consultation Paper’).

### What is My Health Record?

The My Health Record system allows you to share your important health information (like your medical conditions, treatments, allergies, and details about medicines) securely online with registered healthcare providers – from anywhere, at any time. It can include information from Medicare (like the last time you went to see your doctor), prescription data (what medicines you take) and test results (like blood tests or x-ray reports). It can also hold other documents uploaded by your GP (like letters to specialists) and hospitals can upload discharge summaries and follow-up care information.

### What is ‘secondary use’?

‘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 all your doctors and healthcare providers can 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.”

### Why use My Health Record data for secondary purposes?

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 3 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 and 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* also applies to the My Health Record in respect of consumers’ health information, for example, the Australian Privacy Principles Guidelines explicitly states that in order for you to give consent for anything, you must be *adequately informed* beforehand, you must give it *voluntarily*, your consent must be *current and specific*, and you must have the *capacity to understand and communicate* it. *Consent* is defined as “express or implied consent.”

In 2018, all Australians will have a My Health Record created for them unless they choose not to have one. This means that people can exercise a choice to opt out of the My Health Record system. If a person does not opt-out, their consent is implied.

Before My Health Record data can be used for secondary purposes, a Framework is required that incorporates such existing rules. The Framework must reflect 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.

### The folate story

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. Since this measure was introduced there has been a significant (14.4%) overall decrease in the rate of neural tube defects in Australia. The rate of neural tube defects decreased by almost 55% among teenagers and by 74% for Aboriginal and Torres Strait Islander women.

### Other likely benefits

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 with millions of participants for almost 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, agencies that hold and manage data and information, 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. The Framework will be developed with a view to defining a role for a single accountable authority to be responsible for secondary uses of My Health Record data.

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.”

## New participation arrangements in 2018

The Government will make My Health Record participation 'opt-out' by the end of 2018. This means that we will create a My Health Record for you if you don't already have one *unless you tell us not to*. Once you have a My Health Record you can cancel it at any time. Read the **My Health Record [Privacy Policy](#)** for more information.

## Have your say

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:**

- Under what circumstances or conditions do you think your health data should be shared with trusted third parties, like researchers? Why? How?
- 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?

The Government has engaged HealthConsult Pty Ltd to undertake public consultations and develop a Framework which faithfully reflects their findings. Visit [myhealthrecorddata.healthconsult.com.au](https://myhealthrecorddata.healthconsult.com.au) to register your interest and receive updates via email.

## I want to participate in these consultations – what do I do?

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 national 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 the city or town closest to you, or if you cannot do this
- contact HealthConsult directly to provide your views.

### Consultation Paper Quick Guide:

- The history of the My Health Record (including the decision to build an electronic health record system) can be found on **page 1**.
- More information about the laws that apply to My Health Record data can be found on **page 2** and **page 21**.
- The table on **page 5** contains a comprehensive list of the different types of information that can be held in My Health Record.
- Examples of secondary *uses* and *users* of My Health Record data may be found on **page 7** and at **Appendix A**.
- Privacy and security issues are discussed in detail from **page 10**.
- Existing processes for requesting and gaining access to various health data in Australia is discussed in greater detail on **page 11**.
- Issues around anonymisation, de-identification, and data re-identification are discussed in more detail at **page 13**.
- A list of current policy initiatives that are underway to provide guidance around the use of government data is on **page 22**.

Visit [myhealthrecord.gov.au](https://myhealthrecord.gov.au) for more information about My Health Record.