



How secondary use of My Health Record data can improve health outcomes for Australians

What is secondary use of My Health Record data?

The primary purpose of My Health Record is to provide you and your family with safe and efficient care. It's your choice who sees your My Health Record and what's in it. You can choose to share your information with the healthcare providers involved in your care. By allowing your healthcare providers to upload, view and share documents in your My Health Record, they will have a more detailed picture with which to make decisions, diagnose and provide you with treatment.

Making data and information available to approved users is a secondary use of My Health Record data. There are a variety of secondary uses of health information that are described in the My Health Records Act 2012, such as for the purposes of research and public health, law enforcement or System Operator functions.

It's your choice to share your information for public health and research purposes.

How secondary use of My Health Record data for public health and research can improve healthcare

By the end of 2018, most Australians will have a My Health Record, and most GPs, pharmacies, hospitals, diagnostic imaging services and pathology labs will be connected to the system. This means there will be an increasing amount of information available to guide health service planning, policy development and research to further improve Australia's health system.

My Health Record data may be used to offer insight into the effectiveness of the services and treatments being provided to improve health outcomes for patients.

This data will help health researchers and public health experts ensure patients receive evidence-based care and that future health investment is directed at those who need it most.

About the framework to guide the secondary use of My Health Record system data

The Australian Government has developed a framework to guide the secondary use of My Health Record system data for research, policy and planning purposes (the framework). This framework was developed in consultation with consumers, clinicians, medical researchers and industry experts.

You can access the framework on the Department of Health website (www.health.gov.au).

The aim of the framework is to be clear and open about the potential use of your data. The framework includes the following principles:

- ◆ There will be no use of My Health Record data solely for commercial and non-health related purposes.
- ◆ Insurance agencies will not be permitted access to My Health Record system data.
- ◆ Data can't be used to assess eligibility for benefits (e.g. use by Centrelink and/or the ATO to make determinations relating to an individual).
- ◆ High standards are set for protection of people's privacy.
- ◆ Use of identified data will be subject to strict ethics approvals.
- ◆ My Health Record data released for secondary purposes must not be sold.

You can decide if you don't want your My Health Record data to be used for research and public health purposes.



For more information go to:

MyHealthRecord.gov.au
Help line 1800 723 471



Ensuring protection of your data

The Australian Institute of Health and Welfare (AIHW) has been appointed to manage the use of My Health Record data for research and public health purposes, while protecting the privacy and security of that data. The AIHW has a remit to make information and statistics available that can help shape and improve health in Australia through better services and programs.

All applications to AIHW will need to meet strict privacy, assurance and risk mitigation requirements to be considered. They will be reviewed by a governance board with representatives from the AIHW, the Australian Digital Health Agency (as the System Operator), the Aboriginal and Torres Strait Islander Peoples' Advisory Panel, as well as independent experts including representatives from population health, research, health services delivery, technology, data science, data governance and privacy, and consumer advocacy.

When will secondary use of My Health Record data begin?

It is expected that My Health Record data will be used for public health and research purposes from 2020.

Each application for access to My Health Record data will be assessed on its merits by the AIHW's Secondary Use of My Health Record Data Governance Board and will be subject to ethics committee approval on a case by case basis to ensure people's privacy is protected.

Will my personal details ever be released?

It is expected that most applications which are assessed will be for the use of de-identified data. This is where your personal details are removed from the dataset and you cannot be identified.

Applications can be made for the use of identified data for research and public health purposes. However, there will be no release of your identified data unless specific consent from you has been granted. As a result, it is not possible for any identified data application to be approved until functionality within the My Health Record allows an individual to grant specific consent.

It's your choice to share your data

If you are happy for your data to be used for public health and research purposes, you don't need to do anything.

If you don't want your health information shared for public health and research purposes, follow the steps below to withdraw your participation.

1. Log in to your My Health Record through myGov.
2. Navigate to 'Profile & Settings' menu.
3. Select 'Profile'.
4. Scroll down until you see the 'Secondary use of data' section.
5. Click the button that says 'Do not participate'.

If you change your mind, you can choose to share your data again by following the same steps, and choosing 'Participate'.

If you need assistance with any of your privacy and security settings, contact the Help line.



For more information go to:

MyHealthRecord.gov.au | Help line 1800 723 471