CONSUMER FACT SHEET My Health Record

25 June 2018



What is My Health Record?

My Health Record is an online summary of your health information. My Health Record allows your doctors, hospitals and other healthcare providers to view your health information, in accordance with your privacy settings. Under certain circumstances your information may be shared with other government departments. You are also able to access your health information online.

What information can be uploaded to My Health Record?

Healthcare providers such as doctors, health specialists and pharmacists can add clinical documents about your health to your record. These include an overview or summary of your health, allergies, test results (pathology results, blood tests or x-ray reports), prescriptions, information from Medicare and the Pharmaceutical Benefits Scheme (PBS) information stored by the Department of Human Services, Medicare and Repatriation Schedule of Pharmaceutical Benefits (RPBS) information stored by the Department of Veterans' Affairs, organ donation decisions, referral letters to specialists, hospital discharge summaries and follow up care information.

'Primary Uses' of your My Health Record

My Health Record was created for the primary purpose of improving the quality and safety of healthcare, reducing waste and inefficiency and improving health outcomes for individuals. Primary uses of your health record will improve the coordination and quality of healthcare and will reduce the incidence of adverse medical events by ensuring health professionals have the information they need to treat you.

'Secondary Uses' of My Health Record

The Department of Health released a Framework to guide the secondary use of My Health Record data. The framework outlines some possible uses of your health information not outlined in the Primary uses. These uses include clinical trials and research and providing health data to law enforcement authorities in preparation for legal proceedings before any court or tribunal. Individuals may be able to offer or withdraw consent for specific secondary uses of their data except when your data is requested by law enforcement for "public safety" purposes. For all other secondary uses that involves identifiable data, there will be a consent process involved.

Do I have a My Health Record?

By the end of 2018 every Australian that does not actively *opt out* will have a My Health Record account set up by the Australian Digital Health Agency (ADHA). The My Health Record *opt out* period will begin on 16 July and run until 15 October. During this period, you will have the opportunity to prevent a My Health Record being created on your behalf. If you do not *opt out* your My Health Record will be created by uploading the past two years of Medicare and PBS records.

Informed consent and My Health Record

If individuals choose not to *opt out*, consent is provided for all registered healthcare providers to start uploading health data to a My Health Record. This health data is then provided to all healthcare professionals involved in your treatment and care. There is no requirement for a healthcare provider to obtain consent on each occasion prior to uploading clinical information. You can request a healthcare provider does not upload a particular document if you do not want this information on your record. A provider is obliged to follow your request.

Privacy settings and My Health Record

By default, documents in My Health Record are set to general access for healthcare providers. You can change this at any time and set up privacy and security controls. Privacy settings include creating an access or pin code which you can provide to healthcare professionals to access your record. You can "effectively" remove documents from your My Health Record at any time but they will still be available to government and enforcement agencies. You can monitor who has accessed your My Health Record and you can set up automatic notifications. In the event you are not able to make a decision because of an emergency or accident, all privacy settings will be lifted for five days. This means healthcare providers in this emergency setting will have access to hidden or password protected records.

Who can view My Health Record and under what circumstances?

Registered healthcare providers can view your My Health Record. The definition of healthcare provider includes but is not limited to physiotherapists, counsellors, dentists and podiatrists. Third party contractors (ie, IT contractors) who provide services to your health practitioners may also have access to your medical records. These third parties are bound by confidentiality agreements prohibiting the unauthorised use of this information. The ADHA will have access to your My Health Record and have the authority, if requested, to provide your information to law enforcement agencies which includes the Australian Federal Police, Australian Border Force and the Australian Taxation Office if it is deemed 'reasonably necessary' to prevent or investigate a crime. Your My Health Record information can be shared without a subpoena or court order.

What are the benefits to My Health Record?

There are many benefits to My Health Record. For example, all your health information is in one place and if you change doctors, all your test results and medical information are easily accessible to your new doctor. If you are in an accident or you are unable to communicate, your healthcare providers can better coordinate your care and emergency staff can act quickly and confidently access your medical history. Eventually, you will be able to organise medication and prescription repeats online and have them sent to your local pharmacist without the extra cost of a medical appointment.

My Health Record will benefit individuals living with chronic and complex conditions who require coordinated care from multiple healthcare providers, who are at risk of multiple hospitalisations, living with complex mental health conditions and who are highly mobile (for example, fly-in/flyout workers).

What are the risks of My Health Record?

People with or affected by blood borne viruses and sexually transmitted infections or communities where legislative barriers still affect their health, may want to further explore the implications of data sharing around my health records. You may also want to have a conversation with your doctor about what information you consent to being uploaded to your My Health Record.

How can I opt out?

If you decide that you do not want a My Health Record, you will have the opportunity to tell the ADHA at any time between 16 July and 15 October 2018. If you do not have access to a computer or the internet there will be options made available for you to *opt out* offline. AFAO, the National Association of People with HIV Australia (NAPWHA), Scarlet Alliance and the Australian Injecting and Illicit Drug Users League (AIVL) will provide more information on how to *opt out* as it is made available by the ADHA. You can register for updates from the ADHA on how to *opt out* here.

This Consumer Fact Sheet has been developed by AFAO in consultation with:





