

# People living with HIV & My Health Record

Trust in the health system is critical for people living with HIV to remain engaged in our health

## What is My Health Record?

My Health Record is a national electronic summary of health information and health documents of all Australians including people living with HIV (PLHIV) who are eligible for Medicare.

- It can be shared securely online between you and your healthcare providers.
- From 2019, anyone in Australia who was eligible had a My Health Record automatically created for them by the Australian Government.

## What does this mean for PLHIV?

- The **'primary use'** of the My Health Record will benefit some PLHIV. It will improve the coordination and accessibility of your healthcare and ensure everyone has the information they need to treat your health, even in an emergency.
- **'Secondary use'** of the My Health Record is when information is used for a purpose other than that for which it was originally collected. Consent for secondary use is implied unless you cancel your My Health Record or choose not to share your health data for secondary purposes (please see instructions over page).
- Some examples of secondary use include sharing your de-identified (anonymous and can't be traced back to you) information for research and public health purposes, marketing for clinical trials, or passing information on to law enforcement if they have a court order.
- It's your choice to share your information for public health and research purposes. In some cases, an application may be made for your identified data (which includes your personal information). If this happens, you will be contacted directly so you can choose to share your data or not.



## Your My Health Record

Can include your prescriptions, your medical conditions, immunisation history, allergies, blood test results, x-ray reports, information from the Medicare Benefits Scheme (MBS), or Pharmaceutical Benefits Scheme (PBS) items.

It can also hold documents uploaded by your healthcare providers like specialists' referral letters and hospital discharge summaries

## Secondary use of My Health Record

Secondary use of My Health Record data is not permitted for the following:

- Commercial use which includes direct marketing to consumers, assessment of insurance premiums, or employment purposes and/or claims; or
- Non-health related use which includes assessing eligibility for social security benefits (e.g. use by Centrelink and/or the Australian Taxation Office); or
- Remuneration or audit of individual clinicians, or determination of funds allocation for a health service; or
- Criminal and/or national security investigations, except as required by law through a court order (e.g. to investigate the interactions of individuals with the health system as part of assessing their behaviour).

### How to opt out of secondary use of data

When your My Health Record is created you are automatically signed up to share your secondary data. Follow these steps to withdraw:

- Log in to your My Health Record through myGov at [my.gov.au](http://my.gov.au).
- Click on 'Profile & Settings' from the menu at the top of the page.
- Select 'Profile'.
- Scroll down to the bottom of the webpage until you see 'Secondary use of data'.
- Click the 'Do not participate' button.
- If you change your mind, you can choose to share your data again by following the same steps and choosing 'Participate'.

### To cancel your My Health Record

You can cancel your My Health Record at any time. If you cancel your My Health Record or you die, all documents in your My Health Record will be kept in the My Health Record system for a period of 30 years after your death or, if the date of death is unknown, for a period of 130 years after the date of your birth.

- Log in to your My Health Record through myGov at [my.gov.au](http://my.gov.au).
- Click on 'Profile & Settings' from the menu at the top of the page.
- Select 'Profile' and scroll down to the bottom of the webpage.
- Read the information and click on 'Cancel My Health Record'.

If you change your mind and decide you want a My Health Record, you will be able to restore your record by re-registering. Re-registration means you can access your My Health Record, including documents and information included in the record at the time of cancellation. When a record is re-registered, your Provider Access List and document access settings will be the same as at the time of cancellation. All other notification settings and access settings will return to default.

### Managing your privacy settings

If you want to keep your My Health Record, you'll be able to manage your privacy settings, including controlling who can access and view your information, and which documents are available on your record. The following steps will restrict, hide, or remove access to a document:

- Log in to your My Health Record through myGov at [my.gov.au](http://my.gov.au).
- Select the 'Documents' menu.
- Select the type of document (e.g. 'Medicines information', then 'Medicare overview'), and then click on the document you want to restrict, hide, or remove access to.
- Select the 'Manage Access' link, on the right-hand side.
- Select the option you would like (e.g. 'Restricted access', 'Hide Document', or 'Remove document') and then select 'Save'.

Once you remove a document, this is permanent and there is no way to reinstate it in your record. Healthcare providers won't be able to view any documents you have removed from your record, including in an emergency. Healthcare providers can still view restricted or hidden documents in an emergency.

Your My Health Record offers additional privacy control options which allows you to view record access history, invite people to access your record, or set up a record access code to allow you to limit who can access your record.

### Assistance & Support

For PLHIV living with HAND, with limited access to a computer, or would like support with the online processes, Positive Life staff are available to assist you on (02) 9206 2177 or freecall 1800 245 677.

You can also call the My Health Record Helpline on 1800 723 471 for assistance managing or cancelling your My Health Record.

**For more information phone 02 9206 2177 or 1800 245 677 (freecall) or visit [www.positivelife.org.au](http://www.positivelife.org.au)**

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The voice of all people living with HIV

Positive Life NSW