A guide to
My Health Record

What is My Health Record?

My Health Record is an online summary of your health information. You can think of it like a digital filing cabinet that you can access anywhere you have an internet connection.

Your record includes both **information uploaded by healthcare providers involved in your care,** like specialist letters, prescription records, scans and pathology reports, and **information you have entered yourself,** like personal health notes and advance care planning documents.

This guide is here to provide you with information so that you can decide if or how you'll use My Health Record. These are **some of the questions** we hear from our communities about My Health Record:

1. How much control do I have over my information?
2. Why would I want to use My Health Record?
3. What do I need to keep in mind when using My Health Record?
4. How can I configure My Health Record so that it works best for me?

How much control do I have over my information?

Before we jump in, let's address the big issue — LGBTIQ+ communities have valid concerns with health systems.

We have a long and ongoing history of experiencing stigma, discrimination and trauma from within the health system. This can leave us feeling uncomfortable about using digital health tools and worried about having further negative experiences.

You, as the consumer, are in control of your My Health Record.

You can ask your healthcare provider not to upload a document to your record and they must follow your request. When documents are uploaded, you get to choose who can see the information in your record. You can do this by using My Health Record's privacy and access controls.

One important thing to note is that these privacy and access controls apply at the healthcare organisation level rather than to individual healthcare professionals. Healthcare organisations can include GP clinics, pathology collection centres or allied health practices such as a psychology clinic.

This means that if you give a trusted healthcare provider, such as your regular GP, access to your My Health Record, their colleagues in the same practice will also be able to view your record.

Healthcare providers are only allowed to access your My Health Record for the purpose of providing you with healthcare services. There are serious penalties, including fines and potential criminal penalties, if someone accesses your My Health Record for an unauthorised reason.

So, here's a breakdown of the key privacy and access controls and when you might want to use them:

Restricting access to specific documents in your record and using a Limited Document Access Code (LDAC)

What is it?

If there are specific documents you don't want all healthcare professionals to have access to in your My Health Record, you can set them to 'Restricted Access'.

An LDAC is a code that you can set to control which healthcare provider organisations can access documents you choose to restrict in your record. It means that an organisation won't be able to access or view restricted documents unless you give them the code or in a medical emergency. Once the code has been used by a healthcare provider organisation, they will be listed in your provider access list as having 'Restricted Access' to your record.

When could it be useful?

- When you have some documents that you only want to share with select, trusted healthcare provider organisations but you don't want to restrict your entire record.
- If you generally don't see regular healthcare professionals. For example, you might prefer to book appointments with whichever GP practice has the soonest availability rather than going to the same practice every time. In this case, you might want to curate which documents are restricted and which documents every new healthcare provider can view.

You can find out more about restricting document access and setting up an LDAC here:
https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access/restrict-access-to-documents-in-your-record

Record Access Code (RAC)

What is it?

If you want to restrict access to your while My Health Record so only certain healthcare provider organisations can access it, you can set a RAC.

This is a code that you can set to control which organisations can access your whole My Health Record. It means that if you visit a healthcare organisation for the first time, they won't be able to view or access your My Health Record unless you give them the RAC. They can still upload documents without having the code but cannot view your My Health Record.

When could it be useful?

- When you have a lot of documents you want to restrict provider access to.
- When you see the same healthcare providers regularly and aren't concerned about new providers needing frequent access to your information.

You can find out more about restricting access to your entire record here:
https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access/restrict-access-to-your-record

---

Hide a document

What is it?

Hiding a document is pretty much what it says on the box – you can make it appear as if the document doesn't exist to anyone viewing your My Health Record.
Only you will be able to see the document in your record and you can choose to unhide it at any time, so that it becomes visible.

When could it be useful?

- When there are documents that you don't want healthcare providers to see, including in an emergency.

You can find out more about hiding a document here:
https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access/hide-or-remove-documents-from-a-record

Delete a document

What is it?

This option permanently removes a document from your My Health Record. It is no longer available to you or any of your healthcare providers through My Health Record.

It is important to note that the original document still exists, there just isn't a copy in your record anymore. That means the healthcare provider organisation that wrote the original document might still have a copy in their records and so might any other providers that they sent it to.

The only way to get the document back, is to ask the original author to upload it to your My Health Record again.

When could it be useful?

- When a document has been uploaded to your My Health Record that you don't want in there at all anymore.

For example: Alex has visited an endocrinologist to talk about starting Hormone Replacement Therapy. The endocrinologist sends a letter to Alex's referring GP after the appointment and the letter is also uploaded to My Health Record. Alex doesn't want any of their other doctors to see the letter, so they delete it from their My Health Record. Alex's endocrinologist still has the original copy in their records and Alex's GP still has the copy that was sent to them for their records. If Alex changes their mind, they can ask their endocrinologist to upload the letter to My Health Record again.

You can find out more about deleting a document here: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access/hide-or-remove-documents-from-a-record

Cancel your record

What is it?

This option permanently deletes your entire My Health Record, and it cannot be recovered. Deleting your My Health Record doesn't impact any original copies of your health documents kept by the healthcare provider organisation that created them.

You can start a new record if you want but you will need to ask your healthcare provider organisations to upload your documents to your My Health Record again.

When could it be useful?

- If you change your mind about having My Health Record – it is always your choice whether you have a record or not.
- If you didn't realise you had My Health Record to begin with and would rather not have a record.

You can find out more about cancelling your record here: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/profile-and-settings/cancelling-a-record

Key Takeaways

- You, as the consumer, are in control of your My Health Record
- My Health Record has privacy and access controls to help you choose who can see the information in your record
- There are serious penalties, including fines and potential criminal penalties, if someone accesses your My Health Record for an unauthorised reason.

Benefits of My Health Record

There are two main benefits of My Health Record that we want to talk about: agency and coordination. Those are pretty big ideas, so let's break them down.

Agency

By providing you with access to your health information, My Health Record gives you agency over that information. In this context, 'having agency' over your information means you're in control of it and get to make decisions about it. Having agency over your health information means that, because you can see it and decide what to do with it, you have more power to make decisions about your own health. You can think about using My Health Record like curating an art exhibition – you are organising and giving people access to your health information in the way that you want them to experience it.

For people from LGBTIQ+ communities, who historically have experienced stigma, discrimination and trauma from interacting with the medical system, having agency over your health information can give you some control back and help to minimise these negative experiences happening in the future. This can be especially true for people who have experiences of medical trauma and people who have to contend with a lot of medical curiosity. **For example:** an intersex person who has been subjected to medical procedures without their consent or a trans person who is in the process of medically affirming their gender.

The important thing to take away is to use My Health Record in a way that works for **you**. If the way you are currently accessing healthcare works for you and you don't want to change anything, that's okay. If you do choose to use My Health Record,

Benefits of My Health Record

it's important that you regularly check the information that is in there and your privacy and access settings, to make sure that your record works the way you want it to.

Coordination

Coordination means organising things so that they work effectively. My Health Record provides a single platform to store your health information, which makes it easier for you and your healthcare providers to access. You can think of it like a virtual filing cabinet that keeps all your health information in one place. This has some specific benefits for people from LGBTIQ+ communities.

Health care engagement is complex and sometimes uncomfortable. Having your information coordinated can mean you don't have to retell your story, and you can potentially avoid reliving traumatic experiences. It takes the burden off people from LGBTIQ+ communities to keep health

providers up to date on information that can be difficult or uncomfortable to reshare, while making sure that healthcare providers have all the information, they need to provide you with the best care possible.

For example: you can ask your GP to prepare a shared health summary with you that they can upload to your record. Your summary can list information about your medical history including your allergies, any known medical conditions, medical procedures you have had, medications and vaccinations. You can ask your GP to exclude any medical information from your summary – it is up to you what you want shared. Having a shared health summary in your record may mean not having to answer questions about your medical history over and over again.

Using My Health Record also means that your health information moves

Benefits of My Health Record

with you. Considering that healthcare is managed state by state, if you move interstate or if you're travelling and need healthcare, your records stay with you. Even if you just move over to the next suburb and change your healthcare team, My Health Record can make this easier by coordinating your information in one place.

This coordination can also simply mean you are able to access better quality healthcare. There is a level of safety to having your health documents available in one place. It means you don't have to interpret or remember information for your healthcare providers, which is always useful but especially in an emergency. **For example:** having pathology or diagnostic imaging reports available to your health providers can help to avoid unnecessary repeat testing and can be used to compare your past results with current information.

Key takeaways

- My Health Record gives you agency over your health information – this means that because you can see it and decide what to do with it, you have more power to make decisions about your own health
- My Health Record provides a single platform to store your health information, which makes it easier for you and your healthcare providers to access
- This means less retelling your story, your health information moves with you and your health providers can provide higher quality care
- Use My Health Record in a way that works for **you.** If the way you are currently accessing healthcare works for you and you don't want to change anything, that's okay

Things to keep in mind

There are a few things we want you to be aware of if you're thinking about using My Health Record as an LGBTIQ+ person.

1. You might already have a My Health Record without realising it.

Who is this relevant for?
All LGBTIQ+ people.

What does this mean?
Over 21.4 million Australians currently have a My Health Record – that's most people. You might already have some health information in your record available to healthcare providers from previous or recent appointments and tests. You can set up notification to stay aware of information being added to your record or set up privacy and access controls. You can find out more about setting up your access here: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/getting-started/set-up-your-record-online

2. My Health Record works like an information hub or filing system for your health information – this means that you might get access to surprising or unexpected information before you have had a chance to talk to a healthcare provider about it.

Who is this relevant for?
All LGBTIQ+ people.

What does this mean?
All the information in your My Health Record is yours and you have the right to access it. If you are deciding whether to opt in or set up access to your My Health Record for the first time, it's important to be aware that you might have information available to you that you weren't expecting, before being able to discuss it with your healthcare provider.

Things to keep in mind

For example:

- If you get regular or routine sexual health tests and return a positive result, you might see this in your record before having the chance to discuss with your healthcare provider.
- A healthcare provider notes a potential mental health diagnosis they want to explore further in a report. This report is then made available to you through My Health Record before the provider gets a chance to talk with you about it.
- You might see information that describes you in a way that you aren't comfortable with. This might happen when a document is uploaded to your My Health Record from a medical specialist using a computer system that isn't configured to represent information about gender identity accurately. While the doctor knows to refer to you by the correct name and pronouns in person, the report generated by an old computer system doesn't have this capacity and may contain inaccurate information that doesn't affirm who you are.

3. The system can't limit access to your information to only a specific healthcare provider.

Who is this relevant for?
All LGBTIQ+ people.

What does this mean?
Access controls, like a RAC or LDAC, apply at the healthcare organisation level rather than to individual providers. Some examples of healthcare organisations include GP clinics, pathology collection centres or allied health practices such as a psychology clinic. So, if you have a trusted GP and you want to give them access to your record, it isn't possible to restrict access to their colleagues at the same practice.

4. Healthcare providers can override access controls you have set in an emergency.

Who is this relevant for?
All LGBTIQ+ people.

Things to keep in mind

What does this mean?

Access to your health information can be lifesaving in an emergency and is only authorised to lessen or prevent a serious threat to the health and safety of you or others. All uses of the Emergency Access function are recorded and there are serious penalties for misuse.

If there is an emergency, a healthcare provider can use the Emergency Access function to view restricted documents. They will not be able to see any documents you have hidden from your record. You can find out more about Emergency Access, including what counts as an emergency, on the Office of the Australian Information Commissioner website.

5. My Health Record sources your personal details from Medicare.

Who is this relevant for?

Trans and gender diverse people, and intersex people.

What does this mean?

My Health Record displays personal details like your name, date of birth, age and sex. This information is based on how your details are recorded with Medicare and can't be edited within My Health Record.

This might mean that the information displayed in My Health Record does not align with the way you describe yourself. To find out how you can update your details with Medicare, visit https://www.servicesaustralia.gov.au/how-you-update-your-name-date-birth-or-gender-for-medicare?context=60092

Key takeaways

- How you decide to use My Health Record is up to you
- As an LGBTIQ+ person, you might want to think about how you use My Health Record in more depth.

| FAQs

Have a specific question about My Health Record you want answered? You might be able to find it here:

Q1. How is my data managed and used?

There are lots of processes aimed at keeping the information in your record safe and secure. You can find out more by visiting these pages:

- My Health Record system security
- Secondary use of data
- My Health Record privacy policy

Q2. What are some specific examples of documents I might want to restrict or hide in My Health Record?

There are many reasons or situations where you might want to restrict or hide a document. Some examples might include:

Mental Health Treatment Plans: these can contain sensitive information about your mental health and treatment. For many people from LGBTIQ+ communities, accessing mental health care might be directly or indirectly related to your lived experience. You might want to restrict new healthcare provider organisations from accessing this information, especially if your lived experience isn't directly relevant to the reason you are seeking care.

Specialist Reports: these can include detailed information about any diagnoses or treatment plans. For people from LGBTIQ+ communities that access specialists to affirm their gender, these reports might be something you want to limit access to.

FAQs

Medications List: there are some medications that you might not want all healthcare providers to know you're taking because this can reveal other information about you. For example: a person taking PrEP might be presumed to be from LGBTIQ+ communities or a person living with HIV who is taking medication as part of their treatment.

Pathology Results: information from blood test results or other pathology results that might reveal information about you. For example: regular sexual health testing or sexual health tests that show a positive result.

Imaging Reports: reports from X-rays, CT scans or MRIs might contain detailed information about your medical history. For example: you might want to limit access to information about any scans done before gender affirming surgery.

For LGBTIQ+ people with disability: when negotiating supports, such as in the context of NDIS, health information can be misused.

When deciding if you want to restrict or hide a document, it is important weigh up whether having the information you are limiting access to would make a difference in an emergency. Remember – restricted documents are still visible if your My Health Record is accessed in an emergency. Hidden documents are not visible, even if the Emergency Access function is used.

FAQs

Q3. The privacy and access controls sound good in theory; they also sound like a lot of extra work for me and that feels a bit overwhelming. What can I do?

Using a RAC on your entire My Health Record, rather than restricting individual documents, is one way you can make controlling your My Health Record a little simpler.

If you really like the idea of using the LDAC function but it seems like a bit too much upkeep, you can also enlist the help of someone you trust by making them a nominated representative on your record. This could be a chosen family member, close friend or carer who can help you manage your My Health Record.

Q4. Will I know when someone has accessed my record or information?

Yes. Using the Access History page in My Health Record, you can see which healthcare organisations have accessed your record, the time and date of access and the actions they took on your record. This information is available for the last 12 months. You can also set up notifications for certain actions taken on your account.

If you notice any actions in your Access History that worry you, you can call the My Health Record helpline on **1800 723 471** to report your concerns.

Q5. How old does the record go back? If I opt–in now, will I have access to my previous medical information?

If you previously opted out of My Health Record, and you opt back in, the only information that will be available is Medicare data from the previous 2 years. You can choose whether or not to include this information. This might include:

- PBS medications
- Vaccinations you have received

|FAQs

- Organ and/or tissue donation decisions (if you recorded these with the Australian Organ Donor Register)
- Medicare or Veterans' Affairs claims.

Your other medical history or information won't be automatically included in your record.

Q6. Can I upload my own historic health documents to My Health Record?

(Unfortunately) no.

You can add some information to your record, like personal health summaries and advance care planning documents. Other health information needs to be uploaded by your healthcare providers.

Q7. What happens to My Health Record when I die?

When a person dies, their My Health Record registration is cancelled. This means any information in the deceased person's record can't be accessed by any healthcare providers or representatives linked to the record.

Q8. How do I report unauthorised access? What is the process of this?

If you are concerned about something in your access history, or a notification that you have received, call the My Health Record helpline on **1800 723 471.** The helpline is available 24 hours a day, 7 days a week.

FAQs

Q9. Can I access My Health Record when I'm overseas?

Yes! You can access My Health Record anywhere you have an internet connection through MyGov or the My Health App. It is important to remember to use a secure internet connection when doing this.

Q10. What sex and/or gender markers does My Health Record show? Is there a way for me to indicate my chosen name or pronouns?

My Health Record displays personal details, like your name, age and sex. This information is aligned with the information you have registered with Medicare and can't be changed in the My Health Record platform. There is currently no way to indicate your chosen or preferred name or your pronouns within My Health Record.

If the information listed with Medicare is wrong, you can find out how to change it here: https://www.servicesaustralia.gov.au/updating-your-gender-details-with-us?context=64107

Q11. What happens in My Health Record when I affirm my gender or update my Medicare details?

When you change your details with Medicare, this information is automatically updated in My Health Record. It is important to note, **this doesn't mean your healthcare providers are notified**, and your details aren't automatically changed in their systems.

You will still need to tell your healthcare providers that you have affirmed your gender and provide them with the correct information.

| FAQs

Q12. Can my spouse or partner access my information?

Not unless you provide them with access. You can nominate anyone, including your spouse or partner, as a representative on your My Health Record if you want. Nominated representatives can view your record and help you manage it. To find out more information, visit: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/manage-your-record/privacy-and-access/nominated-representatives

Q13. Can I access My Health Record as a young person? Will my parent or parents get access to my information?

You can access My Health Record on your own if you are 14 years or older. You can choose whether to give any parent or guardian access to your record as a nominated representative, but you don't have to.

If you are under 14 years old, your parent or guardian is entirely responsible for managing your My Health Record for you and they are listed as an authorised representative. They will have access to all the information in your record. Once you turn 14, all authorised and nominated representatives are removed from your record. They will no longer have access to your record from then on unless you choose to give them access.

Q14. What happens to My Health Record if I am incarcerated?

Your record remains as normal if you are incarcerated. If you have reduced access to your account, you can still manage your record, or cancel your record entirely, by calling the My Health Record helpline on 1800 723 471.

FAQs

Q15. What can I do if my information is incorrect or something is uploaded that is for someone else?

You can call the My Health Record helpline on **1800 723 471** and choose **option 1**.

Q16. Where can I find more information?

If you want to find out more about My Health Record, you can visit: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record

You can also find out more about using digital health tools for older LGBTI people, rainbow families and LGBTIQ+ people with disability by heading to https://lgbtiqhealth.org.au/digital_health

Was this helpful?

Scan the QR code or head to:

lgbtiqhealth.org.au/