People with disability

There are lots of digital health tools to help you manage your healthcare. This fact sheet is for LGBTIQ+ people with disability, to help you understand digital health tools and your rights.

Your healthcare rights

To start with, let's remember your rights when it comes to all healthcare:

- You control your healthcare choices
- You can choose which digital tools to use
- You have the right to accessible healthcare
- You can ask for help understanding your options
- You can have a support person
- You choose which aspects of yourself to share
- You have the right to affirming, respectful care
- You can change providers if you're not receiving appropriate care

Digital health tools

What are digital health tools?
- **My Health Record** — your online health information
- **my health app** — a mobile app to view your my health record
- **Electronic prescriptions** — digital medical prescriptions
- **Telehealth** — healthcare appointments by phone or video

How digital health tools can help

My Health Record

My Health Record is an online summary of your key health information. You can think of it like a digital filing cabinet that you can access anywhere you have an internet connection. You might feel cautious or sceptical about My Health Record. So here is some information:

- Your record includes information uploaded by your healthcare providers, like specialist letters, prescription records, scans and pathology reports – this means your health information is available in one place.
- It can also include information you have entered yourself, like personal health notes and advance care planning documents.

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- My Health Record gives you a lot of agency and control over what information is included and who can see it. You can control your information by using the privacy and access controls to decide who can see what.
- It can make it easier to share information between your healthcare providers.

my health app

The my health app lets you view important health information that you and your healthcare providers have uploaded to My Health Record and more. Here are some ways it can help:

- Access your health information without a computer (on your phone or tablet)
- Makes it easier to see your health information or show it to someone else
- Keep track of discharge summaries and care planning documents
- Share information with support people when needed
- Manage electronic prescriptions and Active Script List
- Book an appointment with a healthcare provider

Electronic prescriptions

Electronic prescriptions are another option instead of paper prescriptions. Benefits of electronic prescriptions include:

- They can be sent directly to your phone or email
- They can be sent straight to LGBTIQ+ friendly and disability inclusive pharmacies
- They can make it easier to manage multiple medications by allowing you to create a digital list called an Active Script List
- They can make it easier to access and manage repeat prescriptions
- There is no need to carry paper prescriptions, which means you are less likely to lose your scripts and it can make things easier for you if you travel around Australia often

Telehealth

Telehealth lets you have healthcare appointments by phone or video instead of in person. Telehealth can help you to:

- Talk to your GP, specialists, and other healthcare providers at home
- Connect with LGBTIQ+ affirming and disability–aware healthcare providers, even if they are far away

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- Get prescriptions without physically visiting a doctor
- Access healthcare services even when you can't travel or mobility is difficult
- Make choices about how you access healthcare services, such as choosing phone if you're not comfortable with video
- Make it easier to access healthcare services while having a support person with you

Privacy and your rights

My Health Record has many privacy and access controls you can use to make choices about who can see your health information.

What you can control in your health record:

- You can ask your healthcare provider not to upload a document to your record. The provider must follow your request.
- If a healthcare provider uploads a document and you would like it removed, you can ask them to remove it or you can remove it yourself. The healthcare provider who originally uploaded the record may still have a copy on their local computer system

- The following privacy and access controls apply at the healthcare organisation level rather than to individual healthcare providers (for example, we can't restrict access to one GP within a clinic and not another). You can:
  - Restrict access to specific documents in My Health Record using a code
  - Restrict access to the whole My Health Record so only certain healthcare provider organisations can access it
  - Hide a document in your My Health Record
  - Delete a document from your My Health Records
- You can also cancel your My Health Record at any time

The My Health Record Privacy Policy also explains how your information is used by the Australian Digital Health Agency to run the My Health Record system.

You can read the Privacy Policy by yourself or with a support person by clicking this link: https://www.digitalhealth.gov.au/about-us/policies-privacy-and-reporting/privacy-policy#mhr-privacy-policy

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Does My Health Record connect or share information with other government services, such as NDIS or Centrelink?

No! The information in your My Health Record can only be viewed or accessed by an organisation that is providing you with healthcare. This does not include NDIS or Centrelink.

It is important to remember that My Health Record can still play an important part in your application to access supports through the NDIS. When you are applying for the NDIS and asking for supports, you will need to include reports from your healthcare professionals. These documents can be uploaded to your My Health Record, which can make it easy for you to keep track of everything when submitting your NDIS application or getting ready for your planning meeting.

Information in your My Health Record cannot be used to decide if you are eligible for Centrelink benefits.

So while you can use the information in My Health Record to help you manage NDIS or Centrelink services, My Health Record is not connected or shared with them in any way.

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

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

- If there is inaccurate or irrelevant information in your My Health Record, you may want to hide a document when negotiating supports from NDIS. Health information can be misinterpreted or misused, especially in context of getting supporting documentation for NDIS from your healthcare providers. For example:
  - There might be information in your My Health Record that isn't accurate anymore or isn't related to the reason you are seeking NDIS supports.
  - The information in your My Health Record might be worded in a way that doesn't meet NDIS criteria.
  - It is important to note that NDIS cannot access your My Health Record, so the benefit of hiding a document is so your healthcare provider has access to the most accurate documentation.

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- To avoid potential discrimination and harm related to being transgender or gender diverse – for example pre-surgery chest CT scans
- To avoid potential discrimination related to stigmatised experiences, like test results related to sexually transmitted infections or blood borne viruses
- To get a second opinion confidentially

Other important privacy tips:

- Only share what you're comfortable with
- Keep your passwords and access codes private
- Check your My Health Record regularly to review any new information for accuracy
- Know how to remove or hide sensitive information
- Ask for help if you are unsure about privacy settings

Want more detailed information on the privacy and access controls in My Health Record?

CLICK HERE to see our full guide on My Health Record for LGBTIQ+ communities.

Case Studies

Jai's Story

Jai, a queer woman living in regional NSW, manages complex health needs including chronic pain and a psychosocial disability. Living three hours from the nearest major city, she specifically seeks out healthcare workers who are women who can provide affirming care.

Using digital health tools, Jai:

- Accesses specialist appointments via telehealth, reducing the physical and emotional strain of frequent travel and allowing her to choose healthcare providers who understand her needs
- Maintains her My Health Record as a secure central point for her key health information, allowing her chosen specialists to coordinate care effectively
- Uses privacy controls to keep sensitive personal information visible only to specific healthcare providers she trusts
- Coordinates medication management between her rural GP and city-based specialists through shared electronic records

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Digital health tools help Jai access appropriate, affirming healthcare while maintaining control over her personal information and reducing the burden of travel from her regional location.

Ari's Story

Ari, a 34-year-old non-binary person, has multiple healthcare providers for their spinal injury and mental health needs. They get regular physiotherapy and occupational therapy through their disability service provider. Ari is concerned about sharing their mental health information as they're unsure about how LGBTIQ+ affirming they are.

With digital health tools, Ari:

- Uses My Health Record to coordinate care between their chosen GP and mental health provider, through secure uploading and sharing of their health information
- Sets privacy controls in their My Health Record to restrict their mental health records from their disability service provider, while maintaining full access for their GP and psychologist
- Uses telehealth for psychology appointments, saving travel time and money
- Tracks medications prescribed by different providers using electronic prescriptions and the my health app
- Regularly checks the Access History section of their My Health Record to review which healthcare providers have accessed their record

These digital health tools help Ari maintain control over their sensitive information, putting their own health information in their hands and enabling effective care coordination between their trusted healthcare team.

Who can help with digital health tools?

If you want more help with using My Health Record or other digital health tools you can ask:

- Healthcare providers
- Disability support services
- LGBTIQ+ community organisations
- My Health Record Helpline on **1800 723 471**
- Advocacy services

Here is a list of potential questions to ask:

- "Can you show me how to use this?"
- "What happens if something goes wrong?"
- "How do I protect my privacy?"
- "Can I have this information in a different format?"
- "Who can help me understand my rights?"
- "How do I know if someone's been looking at my health information?"
- "Can you show me how My Health Record helps all my doctors work together?"
- "What should I do if I think someone's accessed my records who shouldn't have?"

Was this helpful?

Scan the QR code or head to:
lgbtiqhealth.org.au/digital_health

Remember: you have the right to accessible, respectful healthcare that meets your needs. Digital health tools should make healthcare easier, not harder. If something doesn't feel right, ask for help to find better options