

# NSW Health genetic services and your privacy

## Patient information sheet

MAY 2024

This information is for people who are patients of NSW Health genetics services. It outlines how and why your genetic information is collected, and includes information about how it is stored, your rights and our commitment to privacy.

### Collecting your personal information

NSW Health collects information from you directly when possible. If you are unable to share certain information, the service may collect it from your family or carer.

This information helps determine if you are at risk of genetic conditions. With your help, information may be collected from your family about their medical history.

This information forms part of your extended medical record in a family file. This file includes genetic test results, family information and any other relevant information.

If you are related to another family seen by a NSW genetics service, your record may be added to that family file. This increases the accuracy of the information we have about a particular family.

### Security of your information

Your information is only accessed when you and your family receive genetic counselling.

NSW Health has strict policies for the storage of personal health information. Information collected by NSW Health is kept in a variety of ways, including:

- paper medical record
- electronic medical record
- genetics information system (a password protected database that can only be accessed by NSW Health genetics services staff)
- x-rays, photographs, audio or video recordings (securely stored on password protected local systems).

**NSW Health genetics services are committed to treating your personal and family information contained within your health record in accordance with privacy law.**

### How your information will be used

Your information may be used or shared according to privacy laws in relation to your healthcare, for example:

- other health services, hospitals or medical specialists involved in your care and treatment
- your nominated general practitioner, including information provided with your discharge referral documents

- contacting you at home about follow-up appointments
- sharing with your carer to assist them with your care
- the NSW Ambulance service
- processing pathology tests and x-rays
- contacting you for feedback on the services you have received from us, so we can evaluate and improve our services
- billing and debt recovery
- pastoral care workers, including hospital chaplains, providing spiritual and pastoral care
- students and other staff for training purposes
- other health services and approved third-party organisations
- to help prevent a serious or immediate threat to someone's life, health or welfare
- claims manager or other persons for the purpose of managing a complaint, legal action, or claim brought against the health service or a treating health professional
- for reasons relating to the operation of the NSW Health service and treatment of our patients, including funding, planning, safety, and quality improvement activities.

## Your genetic information may help a family member

The genetic information collected through your consultation may help in caring for some of your genetic family members, as it could be relevant to their health as well.

Please share the results of your consultation with your genetic family, or your genetics health team can contact them with your permission. When possible, they will do that without identifying you.

In rare cases, privacy laws might not let you keep your genetic information private. This happens if a genetic relative's life, health or safety could be at risk.

## Sharing your information

Your NSW Health genetic service may need to share your personal health information for reporting, research or safety reasons. For example, sharing with:

- state and federal government agencies for mandatory reporting (e.g. notifiable diseases, such as cancer and infectious diseases)
- researchers for public interest research
- law enforcement (under privacy law) for serious crimes
- other agencies for the safety, welfare or wellbeing of a child or young person
- a court order or search warrant requires information for evidence.

**Let your NSW Health genetic service know if you do not want them to collect, use or share specific information about you. They will explain any effect this might have on your healthcare.**

## Accessing your health record

You can ask to access your personal information, including your health record, at any time.

Send a written request with identification (such as a driver's license) to the manager of the health service you attended or the Bureau of Health Information service (see contact on [page 3](#)).

There may be a fee for a hard copy, and you should get a response within 28 days.

Sometimes, information is not given; for example, if it invades the privacy of another person or if it puts you or another person at risk.

If you believe there is a mistake in your health information, tell your NSW genetics team and they will correct it or add a note to your record.

## More information

If you have concerns or questions about any of the information in this brochure, speak with your NSW Health genetics team.

If you are concerned about the privacy of your personal information, contact the Health Information office in your local health district or specialty health network. A list of privacy contact officers is available online: <https://www.health.nsw.gov.au/patients/privacy/Pages/privacy-contact.aspx>

NSW Genetic Health Guidelines have been issued by the NSW Privacy Commissioner and are available from: <https://www.ipc.nsw.gov.au/nsw-genetic-health-guidelines>

If you'd like to request a copy of your health information, contact the Bureau of Health Information by email [BHI-eng@health.nsw.gov.au](mailto:BHI-eng@health.nsw.gov.au) or phone **+61 2 9464 4444**.

Visit the Centre for Genetics Education <https://www.genetics.edu.au/SitePages/Home.aspx> and the Genetic Alliance Australia <https://www.geneticalliance.org.au/> for more genetic information.

This patient information sheet is available from: <https://www.aci.health.nsw.gov.au/networks/clinical-genetics>