

ACCESSING YOUR HEALTH RECORD

You are entitled to request access to your personal information including your health record held by NSW Health services. Normally you will be asked to apply for access in writing and provide identification such as your drivers license. You may be charged a fee if you request a hard copy of your personal information or health record. Requests for information will be responded to as soon as possible or in most cases within 28 days.

Access to your personal information may be declined in special circumstances, for example, where giving access would invade the privacy of another person, or put you or another person at risk of mental or physical harm.

If upon reviewing your health record you believe the information we hold about you is incorrect or an error has been made, please let us know and we will correct it or add a note to your health record.

Requests to see your health record should be addressed either to the Health Information Service or to the manager of the health service facility you attended.

CONTACT US

If you have questions regarding this information please speak to your NSW Health genetics health professional.

If you have questions or a complaint about the privacy of your personal information, please contact the Privacy Contact Officer in your local health district, health organisation or specialty health network.

www.health.nsw.gov.au/patients/privacy/Pages/privacy-contact.aspx

FURTHER INFORMATION

If you would like further information please visit:

Centre for Genetics Education www.genetics.edu.au

Genetic Alliance Australia www.geneticalliance.org.au



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Privacy leaflet for patients of NSW Health Genetics Services

Clinical Genetics Network



COLLECTION OF YOUR PERSONAL INFORMATION

We collect information directly from you when possible. If this is not possible, or in an emergency, we may also need to collect information from someone else such as a member of your family, friend or carer.

Your personal information is combined with your family information and is used to estimate the risk that you, genetic relatives, or future children will be affected with a condition. In some cases you may be asked to obtain information from your relatives about their medical history.

In each NSW Health genetics service, there are separate files which form part of your extended medical record. Due to the nature of genetic information, they are stored as family files rather than individual files. These files include genetic test results, family information, as well as other relevant information.

If it is determined that you are genetically related to another family previously seen by a NSW Health genetics service, your information may be added to their family file. This increases the accuracy of the information we have about a particular family.

SECURITY OF YOUR INFORMATION COLLECTED BY NSW HEALTH GENETICS SERVICES

Your information may be kept in a variety of ways. Your information may be held as a paper medical record, and/ or an electronic medical record and stored in the Genetics Information System (GIS). This is a password protected state-wide computerised database for patients of NSW Health genetics services.

Some information may also be held in the form of an image including x-ray or photograph, or as an audio or video recording. Currently these are not saved in the GIS. Instead they are saved on secure local systems which are password protected.

The information in the GIS is stored by NSW Health and is only accessible to the staff within the NSW Health genetics services. Staff are bound by strict privacy rules and policies and will only access your health records in the course of providing genetic counselling services to you and your family. Privacy laws also allow for the use and disclosure of health information for other lawful purposes.

Staff are required to follow NSW Health policies and strict rules regarding the secure storage of personal health information in all formats in order to protect your information from unauthorised access, loss or other misuse.



USING YOUR PERSONAL INFORMATION TO PROVIDE HEALTH CARE FOR A RELATIVE

The information gained through your genetic consultation may be relevant to any genetic relative(s). Therefore, the genetic health information that we collect about you may assist in the health care of some of your family members.

In most cases, patients themselves choose to notify their genetic relatives of the outcome of their genetic consultation, or otherwise give consent for health practitioners to contact family members. When possible, this will occur without identifying you.

In rare circumstances where a patient does not give consent, privacy law allows for the use, or disclosure of, genetic information only when the authorising medical practitioner has a reasonable belief that this is necessary to lessen or prevent a serious threat to the life, health or safety of a genetic relative, and in accordance with NSW Genetic Health Guidelines issued by the NSW Privacy Commissioner. The Guidelines require that prior to disclosure the medical practitioner takes into consideration a range of factors including, the genetic condition involved, relationships within the family, and the health care setting.

If you have concerns or would like to discuss the sharing of your genetic information with other NSW health genetics services for the purpose of treating your relatives, please speak with your NSW Health genetics health professional.

OUR OBLIGATIONS

We are committed to treating the personal and family information contained within your health record in accordance with privacy law.

USING YOUR PERSONAL INFORMATION TO PROVIDE YOU WITH HEALTH CARE

Privacy laws also allow for the use and disclosure of health information as part of your health care and for other lawful purposes.

Within the healthcare setting your information may be used or given to others as follows:

- to other treating health services, hospitals or medical specialists involved in your care and treatment
- to your nominated GP, including information provided with your discharge referral documents
- to contact you at home regarding follow-up appointments
- to your carer to assist them with your care
- to the Ambulance Service of NSW
- to process pathology tests, x-rays, and so on
- to contact you for feedback on the services you have received from us to help us evaluate and improve our services
- for billing and debt recovery
- to pastoral care workers, including hospital chaplains, providing spiritual and pastoral care
- to students and other staff for training purposes
- to other health services and authorised third parties to help prevent a serious and imminent threat to someone's life, health or welfare, such as in an emergency
- to claims managers and associated persons for the purpose of managing a complaint, legal action, or claim brought against the health service or a treating health professional
- for purposes relating to the operation of the NSW health service and treatment of our patients, including funding, planning, safety and quality improvement activities.

If you do not wish for us to collect, use or disclose certain information about you, you will need to tell us and we will discuss with you any consequences this may have for your health care.