

## Clinical Services Plan Project

## Frequently asked questions

## What are genetic disorders?

Genetic disorders or conditions are ones which are caused by an altered gene or set of genes or chromosome. Genetic conditions are sometimes passed from one generation to the next (called hereditary or inherited conditions). Examples of genetic conditions include cystic fibrosis, muscular dystrophy, Fragile X syndrome, neural tube defects, haemophilia and Huntington's disease. Some may be preventable with testing and family planning and some may not. Some may be treatable or have management recommendations and some may not.

If you would like some more, general information on genetic disorders you can find some [here](#). If you would like some more, general information on genetic testing you can find some [here](#). The NSW Centre for Genetics Education also has [good information](#) for the public on genetic testing.

## What is GSWA?

Genetic Services of Western Australia (GSWA) is the statewide, public clinical genetic service which provides genetic counselling, genetic testing and family planning around genetic and inherited conditions.

Clients might see GSWA for counselling, genetic screening/testing or diagnosis/management of a genetic condition. Clients might see a geneticist or genetic counsellor or both.

Clients are usually referred to GSWA by General Practitioner (GP) or a specialist doctor such as an oncologist (cancer specialist). Occasionally patients may refer themselves to GSWA.

The sorts of reasons people might attend GSWA include (but are not limited to):

- Having a strong or unique family history of cancer
- A family history sudden unexplained cardiac death
- A family history of a specific genetic disorder, particularly when considering pregnancy.
- An adult with features suggestive of a specific genetic disorder.
- A child with features suggestive of a specific genetic disorder.
- A child with a known family history of a genetic disorder who needs assessment
- Genetic Counselling for families/carers following a genetic diagnosis in a child regarding adjustment and coping; talking with children/family/friends/school; pregnancy planning and decision-making.

GSWA consists of 3 subspecialty sections:

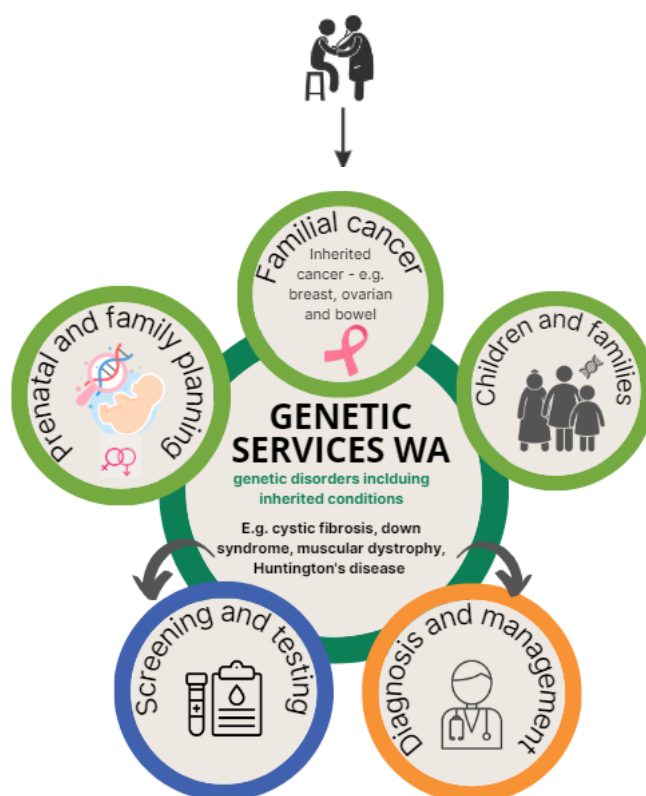
- Genetic Paediatric Services
- Familial Cancer Program
- Obstetrics and General Genetic Services

Hospitals where GSWA services are available:

- Fiona Stanley Hospital
- King Edward Memorial Hospital
- Perth Children's Hospital
- Sir Charles Gairdner Hospital

Plus, outreach clinics in:

- Albany
- Bunbury
- Geraldton
- Joondalup
- Kalgoorlie
- Karratha
- Port Hedland
- Rockingham



## Clinical Services Plan Project

### Who do we want to hear from?

#### We want to hear from:

- Patients or clients of GSWA. Those who have attended an appointment in the last 10 years (since 2014).
- People who have been referred to GSWA by a healthcare professional (GP or specialist) in the last 10 years but you did not attend an appointment.
- Patients or carers of patients or clients of GSWA.
- Patients or carers of people who have been referred to GSWA.
- People who work for community, peer support or consumer advocacy organisations that support people living with genetic conditions who may have attended GSWA.

### Why are we looking for feedback?

A **clinical service plan** is being developed for GSWA to lay out the future direction and key focus areas of the service. We want to gather feedback from people who have experience with the service as we feel that is the best way to identify what is really needed by the people who use the service. We want to try to make sure the service caters to the needs of its clients.

### How can I give my feedback?

You can take part in our **online survey** [here](#) (5-15 minutes) or you can take part in a **community conversation** or both. We are holding a series of group conversations in August and we are interested in talking to any GSWA users but particularly want to speak to Aboriginal people, people from Culturally and Linguistically Diverse backgrounds and people living in regional or remote WA. You can register for a group conversation [here](#).

If you do not feel comfortable to attend a group then you can request an individual phone interview by contacting the Health Consumers' Council on (08) 9221 3422 or [info@hconc.org.au](mailto:info@hconc.org.au).

### What if I don't speak English?

Unfortunately, our survey is in English only. However, we still want to hear your feedback and can contact you on the telephone using an interpreter. You can call the Telephone Interpreting Service (TIS) on 131 450, advise of your language and ask them to call Health Consumers' Council on (08) 9221 3422.

### What will I get for participating?

Consumers (patients and carers) who attend interviews or group conversations will be paid for their time. If you like we can also keep you up to date with the progress on this project.

### Can I participate anonymously?

You can participate in the survey anonymously. If you attend an interview or group conversation, then we will need your name and contact details. However, these will be stored securely at the Health Consumer's Council and not shared with the GSWA or the Department of Health. All feedback passed on to Department of Health will be deidentified (no names) and taking part in this feedback will not be shared with your medical team or affect your future appointments in any way.

### Who is the Health Consumers' Council?

Health Consumers' Council (WA) Inc, (HCC) is an independent, not for profit organisation passionate about ensuring the consumer is at the heart of our state's health care system. Our Engagement Program provides support to ensure people can have a say in health policy, planning and review. The project is being undertaken by our Engagement team as an independent contractor to Department of Health. Our consumer and community engagement professionals are patients and carers themselves and will be taking what you say and reporting it back to the system so that it can be fed into the new Clinical Services Plan.

HCC also provides an Individual Advocacy Service during office hours Monday to Friday to help you navigate our health system. We also provide systemic advocacy for the WA Community by participating on a large range of committees and working groups to ensure the consumer voice is heard at the highest level.