



Familial Cancer Registry

Information Sheet

What is the Familial Cancer Registry?

The Registry is for people at risk of inherited cancer or familial endocrine tumour syndromes. The Registry provides clients with the following:

- The latest information on inherited cancer
- A reminder service for the client or the client's doctor so that surveillance is done on time
- A newsletter on topics of interest, new information and local research projects
- Contact with others who have had similar experiences or procedures.

The Registry does not take the place of the doctors who already care for you.

Who can join the Registry?

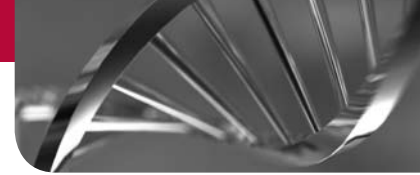
People who most benefit are those from families where there is a history of cancer.

This means if you have:

- A family member who develops cancer at a young age (younger than 50 years old)
- A family member who develops a second cancer
- More than one family member on the same side of the family who develops cancer (e.g. grandparents, parents, children, uncles or aunts, cousins).

Will I be asked to sign a consent form?

Yes. If you wish to join, you will be asked to sign a consent form. This allows us to collect your relevant medical records.



What information does the Registry collect?

The Registry will collect only cancer-related information to keep up-to-date records of your regular surveillance. If we do not receive reports we will contact either you or your doctor to see if the scheduled surveillance has taken place.

We would also like to know if any family members develop a new cancer. This information may influence the type of surveillance you and other family members require.

How does the Registry know which doctors to contact?

We will ask for the details of the doctors you see for your surveillance and your GP. We may write to them to ask for information. You can ask us not to contact or send information to specific doctors.

Is my personal information kept confidential?

- Registry and Genetic Services staff have to sign confidentiality agreements
- The information collected is stored in a secure database
- Other than your chosen doctors, we will not give your information to other people, including insurance companies, employers or government agencies

Can I remove my name from the Registry?

Yes. At any time a person can have their name taken off the Registry. Names may also be taken off if it is found by genetic testing, that the person does not have an increased risk of developing cancer.

Who manages the Registry?

The Registry is an integral part of the Familial Cancer Program (FCP) at Genetic Services of WA.

Who should sign the consent form?

You can sign your own consent form if you are over 18 years. If a person is under 18 or is unable to sign, a parent or legal guardian may do so on their behalf.

Once a child reaches the age of 18, we will contact them and ask them to sign a consent form on their own behalf.

Who should I contact if I have a complaint?

If you have any complaints regarding the Registry you can contact the Head of the FCP.

How do I join the Registry?

People may be referred to the Registry by their doctor, FCP staff, a relative, or by self-referral.

If you have questions, the Registry Coordinator or a Genetic Counsellor can assess your risk, discuss surveillance recommendations and advise if genetic testing is available.

If you would like more information you can contact us at:

Familial Cancer Registry
Familial Cancer Program
Genetic Services of Western Australia
374 Bagot Road, Subiaco WA 6008
Telephone: (08) 9340 1603
Facsimile: (08) 9340 1725
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