

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 with a history of cancer. This means people who 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, cousins, uncles or aunts).

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 your GP and the doctors you see for your surveillance. 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?

Yes. 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.

