

Information about your medical care team

Your GP

Name

Address

Your specialists responsible for screening procedures
e.g. colonoscopy, mammogram

Name

Address

Name

Address

Your appointment at a family cancer clinic

This is where you are given your genetic risk assessment

Attended on:

Appointment yet to be made

Your personal information and the Victorian Family Cancer Register

Data we may record about you

Your consent to join the Register allows us to collect your personal information from your family cancer centre and medical practitioners involved in your care. The information we will collect is:

- Name
- Contact details
- Date of birth
- Your gender and position in the family
- Any cancer diagnosed and at what age
- Cancer related gene test results
- Details of recommended follow up appointments including treating doctor, medical procedure and results

Protecting your data

Your privacy is important to us and we take the issue of confidentiality very seriously:

- The Victorian Family Cancer Register complies with the Victorian Health Records Act (2001) and the Cancer Act (1958).
- The Victorian Family Cancer Register stores electronic health information on a secure database at the Cancer Council Victoria. Hard copy information that identifies you is stored in a lockable area with access restricted to authorised staff.
- You have access to your own information.
- Your family members do NOT have access to your information.

Complaints about information privacy

If you have concerns about the privacy of your health information held on the Victorian Family Cancer Register or access to this information please contact the Director of Registry Systems at the Cancer Council Victoria on 9635 5318.

If you prefer, you may call the Office of the Health Services Commissioner (HSC) on 8601 5200 or 1800 136 066 (toll free), or email hsc@dhs.vic.gov.au

Changing your membership options

You may change your membership options or withdraw at any time.

Family Cancer Centres

Austin Health Clinical Genetics Service

Family Cancer Centre
Heidelberg Repatriation Hospital
300 Waterdale Road
Heidelberg West VIC 3084
Ph: (03) 9496 3027 Fax: (03) 9496 4385
Email: genetics@austin.org.au
www.austin.org.au/genetics

Peter MacCallum Cancer Centre

Familial Cancer Centre
Level 3, 10 St Andrew's Place
East Melbourne Vic 3002
Ph: (03) 9656 1199 Fax: (03) 9656 1539
Email: familialcancer@petermac.org
www.petermac.org

Royal Melbourne Hospital

Familial Cancer Centre
Level 2 Centre, Grattan Street
Parkville VIC 3050
Ph: (03) 9342 7151 Fax: (03) 9342 4267
Email: FamilyCancer@mh.org.au
www.mh.org.au/RMHgenetics

Southern Health / Monash Medical Centre

Familial Cancer Centre
246 Clayton Road
Clayton Vic 3168
Ph: (03) 9594 2009 Fax: (03) 9594 6022
Email: familial.cancer@southernhealth.org.au
www.southernhealth.org/fcc/



 Cancer Council
Helpline
13 11 20
www.cancervic.org.au

Victorian Family
Cancer Register
1 Rathdowne Street
Carlton Vic 3053
Ph: (03) 9635 5176
Fax (03) 9635 5060
VFCCR@cancervic.org.au



Joining the Victorian Family Cancer Register



**Victorian Family Cancer
Genetics Service**

Cancer in the family

One in three Australians will develop cancer by the time they are 75. It is therefore not uncommon for several members of the same family to develop cancer, though in most cases the cancers will be unrelated.

However, for a small number of families who carry an inherited faulty gene, the risk of developing cancer is much higher than in the average population.

In Victoria, those found with an increased genetic risk may choose to join the Victorian Family Cancer Register (VFCR).

This leaflet is for those with a genetic risk of cancer who wish to learn more about the benefits of joining the VFCR, and how the Register manages personal information. A consent form is also attached.



The role of the Victorian Family Cancer Register

Located at the Cancer Council Victoria, the Victorian Family Cancer Register (VFCR) works with family cancer centres to help ensure you and your family receive the best advice, medical care and follow-up. Our services to members include:

Screening appointment reminder service (Boxes 1 and 2 on consent form)

You can choose to receive reminders for tests and medical procedures recommended for you. Copies of these reminders can also be sent to your nominated doctor.

Please note: we do not send reminders to public hospitals or services such as BreastScreen, which organise their own reminders.

Sharing information to help your family (Box 3 on consent form)

With your permission, doctors and other medical professionals caring for members of your family can access relevant health information about you through the Register. In particular, information from your gene test result can indicate if other family members will benefit from testing.

Information about gene test results are important for your family, especially your children. If you decide not to share your information through the Register please consider storing your gene test somewhere safe or give a copy to your children.

Opportunities to participate in cancer genetic research (Box 4 on consent form)

From time to time we write to registrants about research projects approved by the Cancer Council's ethics committee. If you tick this consent box, we'll let you know of any current research for which you may be eligible. You can then decide if you want to participate or not.

Publications

We send a newsletter twice a year to all members. We also provide new publications of booklets, for example, the FAP (Familial Adenomatous Polyposis) booklet.

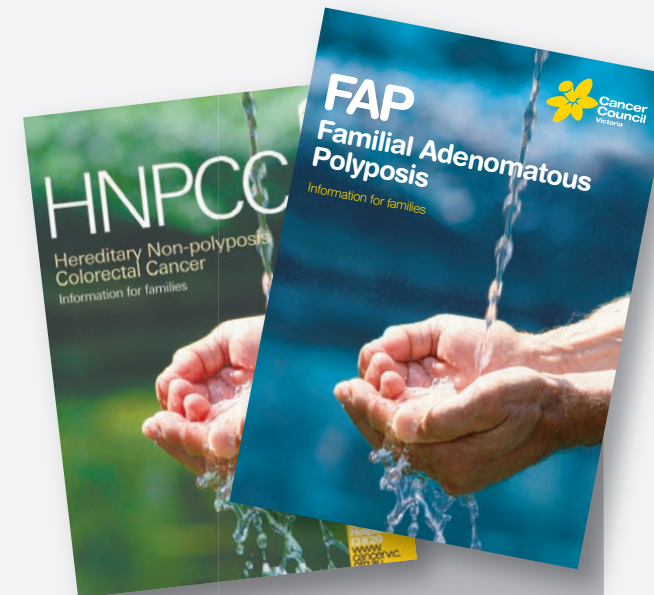
Joining the Victorian Family Cancer Register

If you would like to join the Register, please read the section **Your personal information and the Victorian Family Cancer Register** and complete both sides of the consent form.

If you have questions or need help completing the consent form please call our Registration Coordinator on 9635 5176.

Send the completed form to:

**Victorian Family Cancer Register
Cancer Council Victoria
1 Rathdowne Street
Carlton Vic 3053**



We send a newsletter twice a year to all members and also provide new publications of booklets, for example, the FAP (Familial Adenomatous Polyposis) booklet.

Consent form

By completing the information below, you are consenting to join the Victorian Family Cancer Register. Information about you will be included on the Register.

Title Mr Mrs Miss Ms Dr

Surname

Given name

Date of birth/...../.....

Address

..... Postcode

Telephone

home

work

mobile

email

Your signature

Date/...../.....

The following services are offered by the Register. Please tick the boxes if they apply to you:

- I would like to receive reminders for my screening appointments.
- I would like my doctor to receive reminders for my screening appointments.
- I agree that the Register may share my medical information with other family cancer registers, medical doctors and family cancer centres involved in the care of my family.
- I would like to consider participation in cancer genetic research. Please send me information if a project becomes available.

Send the completed form to:

**Victorian Family Cancer Register
Cancer Council Victoria
1 Rathdowne Street, Carlton Vic 3053**