• It must be scientifically sound.

• It must be likely to contribute to the control of cancer or to the improvement in the care of cancer patients.

• The HREC must approve access to the information. They will only do this if they are sure that there are adequate safeguards for the rights of the patients identified and the confidentiality of the information. They must also be satisfied that it is really necessary that identified information is used.

• The researchers must undertake to only use the information they have been granted access to. They must also agree to protect the confidentiality and privacy of the information to the same degree as the Victorian Cancer Registry itself.

How do I access my own data?

The Improving Cancer Outcomes Act 2014 allows individuals access to their personal record held by the Victorian Cancer Registry, and enables them to correct any information that is incomplete, incorrect or out of date.

To make a request for individual information with consent, applicants should apply in writing either by email to VCR@cancervic.org.au, or a letter posted to the address below.

How do I apply for information under the FOI Act?

Requests for information held on the Registry not specific to a particular individual, or without appropriate consent, need to be processed under the Freedom of Information Act 1982 (Vic)(FOI Act).

To make an FOI request, applicants should apply in writing either by email to VCR@cancervic.org.au, or a letter posted to the address below.

Where can I get more information about the Registry?

If you would like to find out more about the Victorian Cancer Registry, if you have any concerns about its functioning, or for assistance with access requests, please contact the Director on (03) 9514 6292 or Fax: (03) 9514 6751

The Victorian Cancer Registry is managed by, and located at,

The Cancer Council Victoria

615 St Kilda Road

Melbourne Victoria 3004

Tel: (03) 9514 6100

Email: VCR@cancervic.org.au

Internet: www.cancervic.org.au

What can I do if I have a complaint?

If you have a complaint about the privacy of health information held about you by the Registry, or about access to this information, please contact the Director of the Victorian Cancer Registry on (03) 9514 6292 who will try to address your concerns.

If you find this difficult or are still unhappy, then call the Office of the Health Services Commissioner (HSC) on 1300 582 113 (toll free). The HSC is an independent, impartial statutory authority with responsibility for health services and the privacy of health information in Victoria.

Updated March 2018
What is the Cancer Registry?
The Cancer Council Victoria collects details of all cancers diagnosed in Victoria on behalf of the Secretary to the Department of Health and Human Services. The Improving Cancer Outcomes Act 2014 (Vic) requires the collection of this information. The information is recorded in the Victorian Cancer Registry (the Registry), and is kept confidential and is held under tight security.

Data has been collected for all cancers diagnosed in Victorian residents since 1982.

What is the aim of the Registry? 
The aim of the Registry is to keep up-to-date and accurate information on all cancers in Victoria. This information is used to improve cancer prevention, control and treatment.

What information is on the Registry? 
For each patient with cancer the Registry collects the following information:

- name and address
- date of birth
- country of birth
- whether or not the person is of Aboriginal or Torres Strait Islander descent
- details about the cancer
- the treating hospital and doctor.

Personal details, such as names and addresses, are needed to make sure that what we record for each person is correct. This helps us to be sure that each new cancer is only counted once in our figures.

How does information come to be on the Registry? 
When any hospital diagnoses or treats someone with cancer they must, by law, send details of the cancer to the Registry. This also applies to pathology services and cancer screening registers.

What is information on the Registry used for? 
The information collected by the Registry is used to:

- Monitor the number of new cases and deaths from cancer in Victoria each year and publish regular reports.
- Publish occasional reports on particular cancers or aspects of cancer. A list of publications is available on request.
- Add Victorian figures to the national cancer database.
- Help in planning services for the control of cancer e.g. screening programs.
- Help in planning and improving services to care for cancer patients.
- Measure the quality and effectiveness of cancer treatments.
- Measure how well cancer control programs are working.
- Develop education programs e.g. sun protection for schools and Victorians working out of doors.
- Provide data for research.
- Help with studies to find out what causes cancer.

Who can access information on the Register? 
Our regular reports are available to the public. They do not disclose names of cancer patients or any other identifying information.

More detailed information is given to the Victorian Department of Health and Human Services, local government authorities, hospitals, doctors and researchers. This information does not include the names of patients.

Identified information (containing patient’s names and other details) is given to:

- The health institution who originally provided it.
- The Federal Government’s Australian Institute of Health and Welfare (AIHW) for compiling national cancer figures. The AIHW reports do not include any identifying information and are available to the general public.
- The Family Cancer Centres (of the Victorian Family Cancer Genetics Service) to assess the risk of cancer to a person by verifying cancers in their family.

Researchers can ask for identified information about cancer patients. However, all requests must be approved by the Human Research Ethics Committee (HREC) of The Cancer Council Victoria or another recognised and relevant HREC. These are groups of independent experts whose job is to weigh the public interest in the research against the individual interests in privacy. Permission will only be given if the project meets strict conditions, including:

- The research is in the public interest.
- The research is scientific and aims to improve cancer patients’ health.
- The research has an acceptable level of risk.
- The research will not cause undue burden on the participants.
- The research is likely to benefit cancer patients.
- The research meets the criteria for confidentiality.
- The project meets the conditions set by the HREC.

Any other identifying information is given to:

- The Department of Health and Human Services.
- The Director for public health reporting purposes, in order to help improve cancer prevention, control and treatment.

They do not disclose names of cancer patients or any other identifying information.

More detailed information is given to the Australian Institute of Health and Welfare (AIHW) for compiling national cancer figures.