

## What is the Cancer Registry?

The Cancer Council Victoria collects details of all cancers diagnosed in Victoria. The law (Cancer Act 1982) requires us to do this, so the State has accurate information on cancer rates. The Victorian Cancer Registry (the registry) keeps this register for the Cancer Council.

Data has been collected for all cancers in Victoria since 1982.

All information is kept confidential and is held under tight security.

## What are the aims of the Cancer 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 Register?

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 Register?

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 Register used for?

The aim of the registry is to keep up-to-date and accurate information on all cancers in Victoria.

The information we collect 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 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 doctor or 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.

Any person can contact the registry to confirm whether we hold information about them and/or to access their records. A person must contact the registry and we will inform them of the procedure.

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. This is a group 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:

- 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.

## Where can I get more information about the Registry?

If you would like to find out more about **The Victorian Cancer Registry** and the way it operates or if you have any concerns about its functioning, please contact the Director of Information Systems on (03) 9635 5318.

The Victorian Cancer Registry is managed by **The Cancer Council Victoria**.

The Cancer Council Victoria  
1 Rathdowne Street  
Carlton Victoria 3053

Tel: (03) 9635 5000  
Fax: (03) 9635 5270  
Email: [enquiries@cancervic.org.au](mailto:enquiries@cancervic.org.au)  
Internet: [www.cancervic.org.au](http://www.cancervic.org.au)

For information about cancer you can call the **Cancer Information and Support Service** on 13 11 20 (toll free).

## 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 Cancer Registry or about access to this information please contact the Director of Information Systems on (03) 9635 5318 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 (03) 8601 5200 or 1800 136 066 (toll free). The HSC is an independent, impartial statutory authority with responsibility for health services and the privacy of health information in Victoria.

# The Victorian Cancer Registry

