

What is the Victorian Cancer Biobank?

The Victorian Cancer Biobank is a collection of blood and tissue samples, taken from healthy individuals or patients diagnosed with cancer or at risk of developing cancer. It also includes some information about the health and treatment of the donors.

Samples and information from the Biobank are available for research into cancer including its causes, development, diagnosis and treatment.

The overall aim of the Biobank is to improve our knowledge of cancer and cancer-related diseases as well as our ability to manage cancer in the future.

The Victorian Cancer Biobank is a not-for-profit consortium of Tissue Banks, supported by The Cancer Council Victoria and the Victorian Government. It has been established to increase the collection of normal and cancer tissue and support the sharing of tissue amongst researchers located in a number of institutions and organisations.

Confidentiality

To protect your privacy, only authorised Biobank personnel will have access to your personal information. When materials or information are released to researchers they will be labelled with a unique number only. Researchers will not be able to find out who you are unless you specifically allow the disclosure of your personal information to particular researchers.

Do you have a choice?

The decision to donate to the Victorian Cancer Biobank is entirely up to you and your treatment will not be affected in any way by whether you decide to participate or not.

If you decide to donate to the Biobank and later change your mind, just let us know.

Your information and materials can be removed from the Biobank if you wish, or if you prefer, materials already collected can be retained in a fully de-identified form. It will not be possible to remove materials from the Biobank that have already been used for research.

If you are interested in participating, please contact the Biobank representative shown below. A detailed Patient Information Sheet will be provided and discussed with you and your written consent will be required.

Enquiries

Victorian Cancer Biobank
1 Rathdowne Street, Carlton Victoria 3053

info@viccancerbiobank.org.au
www.viccancerbiobank.org.au
phone: +61 3 9635 5091



Information for prospective donors

viccancerbiobank.org.au



Bill Kennedy, Biobank donor

What will the tissue, blood and information be used for?

The aim of the Biobank is to build up a large collection of cancer specimens, linked to medical information about individuals with cancer, that can be used for future research.

Researchers from within Australia or even overseas can apply to the Victorian Cancer Biobank for biospecimens and information to use in a cancer research project. Before it is provided, an impartial panel of scientists and doctors must agree that the project is scientifically worthwhile and a Human Research Ethics Committee must approve the project, having considered the interests of donors to the Biobank.

Because information and materials stored in the Biobank are collected for future research, it is not possible to say exactly which projects your specimens may be used for. However, only projects that investigate the causes of cancer and/or develop improved methods for the detection, diagnosis or treatment of cancer will be approved.

If you agree, the Victorian Cancer Biobank will collect:

- Fresh normal and cancer tissue
- Permission to use tissue stored in paraffin wax blocks
- A blood sample
- Information about your health relevant to cancer

What will happen if I agree to take part?

Normally, when a surgeon removes tissue it is sent to a Pathology laboratory where a Pathologist examines it. Representative sections of the tissue specimen are taken and preserved in paraffin wax. The Pathologist examines the tissue under a microscope then prepares a report that is used to plan future treatment. Tissue that is not needed for this process is usually discarded. In most cases it is this tissue that would be destroyed that is banked.

If you agree to participate, the Pathologist may give the Biobank a small sample of cancer tissue and some of the normal surrounding tissue that is not needed to make your diagnosis. However, there is no guarantee that any of your tissue will be taken for biobanking. It is up to the Pathologist to decide. If there is any excess tissue it may be banked fresh or stored frozen or preserved in paraffin wax for future research.

We would like to collect a small amount of blood (25-50mls or approximately 2-4 tablespoons) to match with the tissue. If possible this will be collected at the same time as other routine blood tests.

We would also like to ask you some questions and gather information from your health records relevant to your cancer that may be useful in research. This information may be obtained from pathology reports, medical records or cancer registries and will include your treatment and progress over time.

Are there any risks?

There are no physical risks in collecting tissue for the Biobank that are additional to the risks of your operation. Only tissue that is not needed for your treatment will be collected for the Biobank. No additional tissue will be taken for research purposes.

Collection of a blood sample can sometimes cause local pain and bruising. All procedures will be carried out by suitably qualified staff and your welfare is their priority.

The results of research performed on your tissue are intended to improve our understanding of cancer and to provide general benefit to cancer patients.

As research can often take many years, it is probable that there will not be any information from research conducted on your tissue that will have specific relevance to your health. However, if information with health implications for yourself or your family becomes available as a consequence of being a Biobank donor, the researcher is required to inform the appropriate Human Research Ethics Committee and the Biobank. The committee will examine the research data and decide whether or not it may be in your interests for you to be contacted. If this knowledge is of medical significance to you and/or your family this can be communicated to you, if you choose, via your doctor. In this case, it is important that you supply up-to-date contact information to the Biobank.

If any discoveries are made using Biobank materials that can be commercialised and generate money, a proportion may be returned to cancer research. However, there will be no money returned to tissue donors or the Biobank.

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