

MELANOMA INSTITUTE AUSTRALIA BIOSPECIMEN BANK

PATIENT INFORMATION



ABOUT THE BIOSPECIMEN BANK

The BioSpecimen Bank is a collection of blood and tissue samples taken from people diagnosed with melanoma and other types of skin cancer, with their consent. Information about the health and treatment of tissue bank donors are recorded.

The BioSpecimen Bank underpins research programs to find better treatment and ultimately a cure for melanoma.

WHO CAN PARTICIPATE?

All patients of Melanoma Institute Australia who have been diagnosed with skin cancer, including melanoma, are invited to become donors to the BioSpecimen Bank. Samples and information are made available from the BioSpecimen Bank for research into skin cancer including its causes, development, diagnosis and treatment.

The BioSpecimen Bank is supported by funds from the National Health and Medical Research Council of Australia (NHMRC), the Cancer Institute NSW and donations.

WHAT WILL THE TISSUE, BLOOD AND INFORMATION BE USED FOR?

The aim of the BioSpecimen Bank is to build up a large collection of melanoma and skin cancer specimens, blood samples and information about people with skin cancer that can be used for future research. Researchers from within Australia or even overseas can apply to the BioSpecimen Bank for materials and information to use in a skin cancer research project. Before it is provided, an impartial panel of other scientists and doctors must agree that the project is worthwhile and a Human Research Ethics Committee must approve the project, having considered the interests of the donors to the BioSpecimen Bank.

Because information and material stored in the BioSpecimen Bank 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 skin cancer are supported.

CONFIDENTIALITY

To protect your privacy, only authorised BioSpecimen Bank 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, and researchers will not be able to find out who you are.

WHAT WILL HAPPEN IF I AGREE TO TAKE PART?

Normally, when surgery to remove any skin tumour is performed, the tissue removed is examined by a pathologist who prepares a report that is used to plan future treatment. Only a proportion of the tissue removed is required for this process. The remainder is either stored in wax blocks in the pathology department or it is discarded.

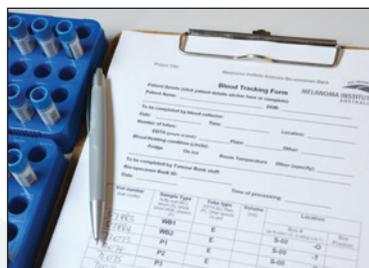
If you agree to be a donor, we will take a sample of tissue that is removed during your operation and is not required by the pathologist. We will store this, frozen in the BioSpecimen Bank. We will also ask your permission to have access to some of the tissue which is stored in wax blocks.

We would like to collect a small amount of blood 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 gather some information from your health records relevant to your skin cancer that may be useful in research. This information may be obtained from your pathology reports, medical records or cancer registries and will include your treatment and progress over time.

IF YOU AGREE, THE BIOSPECIMEN BANK WILL COLLECT:

1. Fresh tumour tissue.
2. Permission to use other stored tissue.
3. A blood sample.
4. Information about your health relevant to skin cancer.



ARE THERE ANY RISKS?

There are no physical risks in collecting tissue for the BioSpecimen Bank that are additional to the risks of your operation. Only tissue that is removed for your treatment will be entered into the bank. No additional tissue will be taken.

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 the research performed on your tissue are intended to improve our understanding of melanoma and to provide general benefit to skin 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 you or your family becomes available as a result of being a tissue bank donor, this can be communicated to you, if you choose, via your doctor.

If any discoveries are made using BioSpecimen Bank materials that can be commercialised and generate money, a proportion will be returned to skin cancer research. However, there will be no money returned to tissue bank donors.

DO I HAVE A CHOICE?

The decision to donate to the BioSpecimen Bank is entirely up to you and your treatment will not be affected in any way whether you decide to participate or not. If you decide to donate to the BioSpecimen Bank and later change your mind, just let us know.

Your information and materials can be removed from the BioSpecimen Bank 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 BioSpecimen Bank that have already been used for research.

If you are interested in being a donor for the BioSpecimen Bank, you will be given a patient information sheet with more details. If you decide to participate, you will be asked to sign a patient consent form.

