

MIA Biospecimen Bank

Patient information

About the MIA Biospecimen Bank

A biospecimen bank is a collection of samples from body organs or fluids (e.g. from the skin, bowel, blood, etc) which are stored for current and future research purposes.

Melanoma Institute Australia (MIA) began its own biospecimen bank in 1998. The MIA Biospecimen Bank underpins hundreds of approved research projects at MIA and through collaborations which aim to improve our understanding of tumour biology for better prevention, diagnosis and management.

In addition to collecting samples, the MIA Biospecimen Bank also records information from any pathology reports associated with the samples and accesses information in our Melanoma Research Database about the health and treatment of the patients who donate their specimens.

The MIA Biospecimen Bank is supported by grants from the National Health and Medical Research Council of Australia (NHMRC) grant and Office for Health and Medical Research NSW Health. It also receives support from Macquarie University and donations to MIA.

What will the samples and information be used for?

The aim of the MIA Biospecimen Bank is to build up a large collection of valuable samples that can be used for ethically-approved future research projects. Researchers from Australia or overseas can apply to the Biospecimen Bank for materials and information to use in a skin cancer research project.

Because information and material stored in the Biospecimen Bank are collected for future research, it is not possible to say exactly which projects your samples may be used for. However, only projects that investigate skin cancer are supported.

Who can participate?

All patients of MIA who have been diagnosed with skin cancer (including melanoma) or non-cancerous naevi are invited to become donors to the MIA Biospecimen Bank.



Confidentiality

To protect your privacy, only authorised MIA 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 as a frozen sample 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.

If you are asked to provide a stool sample, you will be provided with a collection kit and instructions on how to collect and return the sample to the Bank. 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 MIA Biospecimen Bank will collect one or more of the following:

- frozen tumour tissue and normal tissue
- permission to use other stored tissue
- a blood sample
- · a stool sample
- information about your health relevant to your tumour.

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. Having a blood sample taken may cause some discomfort, bruising, minor infection or bleeding. If this happens, it can be easily treated. All procedures will be carried out by suitably qualified staff and your welfare is their priority.

The results of the research performed on your samples are intended to improve our understanding of skin cancer and to ultimately benefit future patients.

Will any research findings be returned to me?

As research can often take many years, it is unlikely that research conducted on your samples will have specific relevance to your health and treatment. However, if information with health implications for you or your family becomes available as a result of your sample donation, this can be communicated to you, if you choose, via your doctor.

Do I have a choice?

The decision to donate to the MIA Biospecimen Bank is entirely up to you. Your clinical care will not be affected in any way whether you decide to participate or not. If you decide to donate 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 MIA Biospecimen Bank, please speak with a member of your clinical team and 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.

Thank you for your interest in donating to the MIA Biospecimen Bank. MIA is committed to research with an aim of zero deaths from melanoma, and our biospecimen samples are an important contribution that will help us achieve our goal.

Please note: The information in this brochure is of a general nature and should not replace the advice of healthcare professionals. All care has been taken to ensure the information presented here is accurate at the time of publishing (July 2021).