



Children's Cancer Centre Biobank



The Children's Cancer Centre Biobank is a valuable collection of biological samples such as tissue collected during surgery, blood and bone marrow. These samples are linked to health information contained in hospital medical records.

Health information used may include age, gender and information about test results and medical care.

Samples and health information in the Biobank are given to scientists in Australia and around the world. Researchers rely on these types of samples and health information to make research discoveries and medical breakthroughs. They hope to find new ways to better prevent, detect and treat different conditions.

Our Biobank includes samples and health information from people with cancer, bone marrow disorders, primary immunodeficiency disease and neurofibromatosis. It also includes samples and health information from their siblings, parents and relatives.

We are asking for your consent to donate your samples and use your health information for research. It is up to you whether you take part. You can say no if you want to. Your medical care will be the same whether you join the Biobank or not. When we say "you", we mean you or your child.

This information will help you make an informed decision about taking part in the Biobank.

This leaflet will cover:

- How your samples and health information will be collected and stored
- How your samples and health information will be used
- How the Biobank protects your privacy and confidentiality
- And finally, the potential risks and benefits if you decide to participate

First, let's discuss how your samples and health information will be collected.

In most cases, we will simply use any leftover blood, bone marrow, tissues or other samples that have been collected during your medical care in hospital.

In other cases, the Biobank may collect a bit more of the sample during your procedure. If part of your medical care involves collecting your bone marrow or cerebral spinal fluid, we will collect a bit more at the same time to store and use in the Biobank.

We may need to collect extra samples before asking you, we will only use these samples if we have your consent. If you need samples for your medical care, we will not use them in the Biobank. We will only use any samples that you do not need.

We also ask you to consider agreeing to some additional options. If you were born in Victoria, we ask your permission to access your Newborn Screening card that contains spots of blood taken in the first few days of life. We will also ask your permission to collect a skin sample.

We will access your hospital medical records. We will use your health information contained in your medical records after removing any information that can identify you. Health information used may include your age, gender, and family health history, as well as information about your test results and medical care.



So how will we store your samples and health information?

Your samples and health information are kept in a secure location and database at Murdoch Children's Research Institute (MCRI) that can only be accessed by certain people. The samples will be safely preserved for many years or until a researcher requests them. There is no time limit as to how long your samples and health information may be stored in the Biobank.

How will we use your samples and health information?

We will give samples and health information in the Biobank to scientists at the Melbourne Children's Campus which includes The Royal Children's Hospital, MCRI, and the University of Melbourne Department of Paediatrics. Samples and health information may also be given to researchers at other institutions in Australia and overseas. We hope that this will help them make research discoveries and medical breakthroughs that can find new ways to better prevent, detect and treat different conditions. If researchers want to use samples and health information from the Biobank, they will have to undergo lots of checks. This includes scientific and ethical reviews.

Samples from the Biobank can be used to support a wide variety of studies such as animal, stem cell and genetic research. We may use samples to make cell lines in the laboratory and in animals. We may also use your samples to make a special stem cell line called an induced pluripotent stem cell line. These cell lines may help us better understand disease and test new treatments.

Samples may be used for genetic research which involves testing and studying genetic material, usually DNA. Genetics is the study of genes and how certain traits or conditions are passed down from one generation to another. Many health conditions or diseases are caused by a change in one or more genes. These

conditions may emerge at birth or may appear later in life. However, sometimes a gene can change without causing a health problem. If the Biobank gets told about a change in your genes that might be an important risk factor for disease, you will be contacted by your doctor or a genetic counsellor to discuss this with you. This could happen many years after your sample was collected. If you don't want this to happen you should not participate in the Biobank.

How does the Biobank protect your privacy and confidentiality?

Your name and other identifying information are removed from your samples and replaced with a unique code. Only staff at the Biobank can use this code to your identifying information. When we share your samples and health information with other researchers, we use this code so they will not know who you are. Researchers also have to enter into an agreement with MCRI to make sure they use the samples and information properly for their own research purposes. When we send your samples and health information to overseas laboratories they will not be protected by Australian laws and regulations.

Your privacy is important to us. We will make every effort to protect your personal health information. You can read more about our Privacy Policy available at www.mcric.edu.au/privacy-policy.

What are the potential risks and benefits in participating in the Biobank?

Participating in the Biobank may not directly help you. However, it will help researchers in Australia and around the world understand more about different diseases and how to detect, prevent and treat them.

If you happen to join a clinical trial, we can use the samples in the Biobank for the clinical trial. This way we will not need to collect extra samples.

If you provide consent, there are some small risks of having a skin sample collected, your doctor will explain these to you before the procedure.

Your samples and health information will never be sold. You will not receive money or other forms of payment for use of samples and health information.

If your child is giving their samples and health information to the Biobank, make sure you tell them about this when they turn 18. We will keep using their samples and information after they turn 18 unless they tell us not to.

At any time, you can ask the Biobank to destroy samples and health information that are stored with us. But we will not be able to destroy any samples and health information that have already been used or shared with researchers.

What's next?

If you would like to contribute to the Biobank we will give you our information statement to read.

You can ask us questions before you make a decision.

Choosing to participate in the Biobank will help researchers make a difference to medical research and to the health of future generations.

Scan the QR code to learn more about how researchers are using the samples and health information from the Biobank:

