



What happens to your samples and clinical data after you consent to the Kolling Institute Tumour Banks

How long will my samples be stored for?

Your samples will be stored until they are used in ethically approved research.

Will I know when my samples are being used in the future?

You will not be contacted when your samples are used, however you can obtain information on the research conducted on samples stored in the Kolling Institute Tumour Bank. Visit our website for more information: www.kollinginstitute.org.au

Research findings will be published in medical and scientific journals and presented at conferences. Findings will always be provided in such a way that you cannot be identified.

Similarly, research is conducted in such a way that results are unlikely to be of direct benefit to your medical care.

Will drug companies be able to use my samples for profit?

Research involving your blood or tissue samples may result in a product or treatment that is ultimately profitable for a company. You will not receive any financial benefit from discoveries arising from the use of your samples or data.

What happens if I suffer injury or complications as a result of the Kolling Institute Tumour Banks?

There is no physical risk in collecting tissue for the Kolling Institute Tumour Banks beyond that of your hospital procedure. The collection of a blood sample will occasionally cause bruising.

How can I get further information?

If you have any further questions about the Kolling Institute Tumour Bank, please contact us at the Kolling Institute of Medical Research.

Thank you for taking the time to consider participating in the Kolling Institute Tumour Banks. If you wish to take part, please sign the associated consent form. This information brochure is for you to keep.



The Kolling Institute Tumour Banks have been approved by the Northern Sydney Local Area Health District HREC. Any person with concerns or complaints about the conduct of the Kolling Institute Tumour Banks should contact the Research Office on (02) 9926 4590 and quote reference number LNR/15/HAWKE/244

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www.kolling.usyd.edu.au/research/tumour-bank/index.php



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KOLLING
Institute of
Medical Research

Medical research *matters*TM



**Tumour
Banking
for the
Future:**

*patient & family
information
brochure*

NORTH SHORE
PRIVATE HOSPITAL

What is Tumour Banking?

An important part of cancer research involves the identification of genes and proteins associated with specific cancer types (called cancer biomarkers). These can be discovered by analysing cancer cells growing in the laboratory, or by comparing blood samples from cancer patients with those from healthy people. Cancer biomarkers can also be discovered in samples of tissue from patients with cancer which are obtained when a tumour is removed surgically, or when a tiny sample of tumour (biopsy) is taken to help in the diagnosis.

A Tumour Bank is a collection of deep-frozen samples of tumour tissue, corresponding normal tissue, blood and linked patient information .

These tumour collections offer unique opportunities to researchers to learn about changes that occur in cancer cells. They will provide our researchers with the means to develop new methods for cancer diagnoses and treatment.

Who is being asked to participate?

We are asking people who are:

- Having surgery to remove a malignant tumour.
- Having surgery to remove a benign tumour.
- Having surgery to reduce their risk of developing cancer.
- At high risk of developing cancer but not having surgery

What are we requesting from you?

We are asking you to give consent for the collection of a sample of your tissue, blood or other fluid and associated clinical data for storage in the Kolling Institute Tumour Banks. Your participation in the Kolling Institute Tumour Banks would mean that your specimens and health data are stored for future research.

Please read this information brochure carefully. Feel free to ask questions and to discuss the Kolling Institute Tumour Banks with a relative, friend or your local health care worker.

Once you understand the purpose of the Tumour Banks and if you agree to take part, you will be asked to sign a consent form.

Why is Tumour Banking for the Future important?

As research takes many years and innovations are occurring every day it is important to bank for future research programs so that our understanding of cancers, diagnostic procedures and treatment has a strong foundation.

What is the difference between a Tumour Bank and a Clinical Trial?

A Tumour Bank collects and stores your specimens and associated clinical data for future research whereas a clinical trial is asking you to trial new treatments, tests or interventions as a way to manage, treat, prevent or detect diseases and/or medical conditions. For more information on clinical trials you can visit the Australian Clinical Trials website: <https://www.australianclinicaltrials.gov.au>

Do I have to participate?

The decision to donate to research is entirely up to you. You can withdraw at anytime by contacting the Kolling Institute Tumour Banks. If you decide to withdraw, your samples and collected health information will be destroyed.

Your decision to say no or to withdraw consent will not affect your medical treatment, your relationship with your Hospital and medical attendants, the University of Sydney or your dealings with Medicare Australia.

To withdraw from the Kolling Institute Tumour Banks please contact the Tumour Bank Office on 9926 4771.

What does participation involve?

If you agree to participate, you will be given the option to have all or some of the following collected:

- A small piece of tissue and/or fluid from the sample removed during your procedure that is not needed for your diagnosis, will be banked.
- A blood sample (approx. 20mL or two tablespoons).
- If you give your permission, a small portion of your tissue may be maintained under special laboratory conditions to monitor the response of your cells to new treatments. If animal models are to be used, all studies will be approved by both human and animal research ethics committees.

You will also be given the option for the Kolling Institute Tumour Banks to request access to relevant health information about you from the following possible sources:

- Hospital, pathology, emergency department records.
- State and national databases such as:
 - Admitted Patients Data Collection; Registry of Births, Death and Marriages; and the NSW Cancer Registries.
 - Medicare Benefits Scheme records (your visits to health professionals) and the Pharmaceutical Benefits Scheme (your use of prescription medicines).

What will happen to my samples and data?

Your samples and health data will be stored in the Tumour Banks at the Kolling Institute of Medical Research at Royal North Shore Hospital until they are requested by researchers. Future research will examine causes of disease, prevention, diagnosis, treatment and genetics.

All research projects must be approved by a Human Research Ethics Committee before researchers can access your samples or data.

Your samples and other information will be given a unique identification code used by researchers. This maintains your confidentiality. All information is kept confidential and is stored securely.

Can my stored samples also be used in clinical trials?

You can request to have your samples released from the Kolling Institute Tumour Banks and transferred for use in clinical trials. However, as your samples have been collected for research purposes, even though all possible care is taken during the collection and storage process, we cannot guarantee that samples collected will be fit for a purpose other than research. Transfer of your samples may exclude them for use in future research projects and may not be possible if your samples have already been allocated to a research project. Should you choose to transfer your samples from Kolling Institute Tumour Banks to a clinical trial please contact the Tumour Bank Office on 9926 4771 to obtain a Request to Transfer Form.