

ARE THERE ANY RISKS?

There are no physical risks in collecting tissue for the 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 research performed on your tissue are intended to improve our understanding of breast cancer and to provide general benefit to breast 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 Tissue Bank donor, 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 Tissue Bank.

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

DO YOU HAVE A CHOICE?

The decision to donate to the Breast Cancer Tissue 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 Bank and later change your mind, just let us know.

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

COMPLAINTS

If you have any concerns about the conduct of the study, or your rights as a participant you may contact:
The Secretary, Human Research Ethics Committee at the Health Care facility where you were recruited.

This leaflet was written in consultation with the Breast Cancer Action Group NSW



Information for
prospective donors

WHAT IS THE BREAST CANCER TISSUE BANK?

The Breast Cancer Tissue Bank is a collection of samples of breast cancer and normal breast tissue as well as blood, taken from women diagnosed with breast cancer. It also contains some information about the health and breast cancer treatment of Tissue Bank donors.

Samples and information are made available from the Bank for research into breast cancer including its causes, development, diagnosis and treatment. The overall aim of the Bank is to improve our ability to manage breast cancer in the future.

The Breast Cancer Tissue Bank is supported by funds provided by the National Health and Medical Research Council of Australia (NHMRC), the National Breast Cancer Foundation (NBCF) and the Cancer Institute NSW.

WHO IS INVITED TO PARTICIPATE?

Women who have been diagnosed with breast cancer and who are undergoing an operation to remove the cancer are invited to become donors to the Breast Cancer Tissue Bank.

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

The aim of the Tissue Bank is to build up a large collection of breast cancer specimens and information about women with breast cancer that can be used for future research.

Researchers from within Australia or even overseas can apply to the Tissue Bank for materials and information to use in a breast 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 donors to the Bank.

Because information and materials stored in the 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 breast cancer are supported and information about research projects that use Tissue Bank materials is publicised on a website (www.abctb.org.au).

CONFIDENTIALITY

To protect your privacy, only authorised Tissue 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 breast cancer surgery 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 discarded.

If you agree to be a donor, we will take a small sample of breast cancer tissue and some of the normal surrounding tissue that is removed in your operation and is not required by the Pathologist. We will store this frozen in the Tissue Bank. We would also like 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 (10-20mls or approximately 2 -4 teaspoons) 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 breast cancer that may be useful in research. This information may be obtained from your pathology reports, medical records or the ACT or NSW Cancer Registry and will include your treatment and progress over time.

If you agree, the Breast Cancer Tissue Bank will collect:

1. Frozen breast cancer and normal tissue
2. Permission to use other stored tissue
3. A blood sample
4. Information about your health relevant to breast cancer