

What will happen to the results of the research?

Results, including DNA analysis, will not be relayed back to you, your hospital doctor or your GP. Studies that are being carried out on tissue that has been gifted to the Tissue Bank are listed on our website as well as links to the scientific publications that report the results of the research.

What if I want to change my mind?

You are free to withdraw your consent at any time, without giving a reason. This will not affect your care. If you wish to withdraw consent, contact the Tissue Bank and you will be sent a withdrawal form to complete and return. On receipt of this, we will remove and safely dispose of your research samples. If consent is withdrawn after donation it is possible some of the samples may already have been issued to researchers. In this case the Tissue Bank will request the immediate return of any unused tissue from researchers for disposal. If tissue samples have been used by researchers prior to you withdrawing your consent no further action can be taken.

How can I contact the Tissue Bank?

If you have a concern or question that you wish to discuss you can contact the Tissue Bank at the address below:

Mail: Tayside Tissue Bank, Medical Research Institute, Jacqui Wood Cancer Centre, Ninewells Hospital & Medical School, Dundee, DD1 9SY

Phone: 01382 632698

Website: www.tissuebank.dundee.ac.uk

What are my rights?

If you believe that you have been harmed in any way by donating tissue you have the right to make a complaint and seek any resulting compensation through the University of Dundee who act as the research sponsor. Details about this are available from the Tissue Bank. In addition, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process by writing to:

Complaints Office, Level 9, Ninewells Hospital, Dundee DD1 9SY
or telephone: Freephone 0800 027 5507.

Thank you for taking the time to read this Patient Information Sheet



NHS Tayside & University of Dundee

Patient Information Sheet for the Collection and Storage of Tissue for Research

We invite you to donate any tissue left over after your procedure for use in medical research. Before you decide you should understand why research using tissue is performed and what it would involve for you.

Key Points:

- Donating tissue is entirely optional.
- Your decision will not affect your treatment or care.
- No extra tissue is taken.
- Your procedure will not be prolonged or altered in any way.

Why am I being invited?

Often doctors need to remove tissue as part of your treatment, for example during a surgical operation or biopsy procedure. Doctors will not take more tissue than is needed for your care but sometimes there is surplus tissue or body fluid left over that is not required for your diagnosis or treatment. This tissue, which would otherwise be discarded, is a valuable resource for medical research. We ask your permission to collect, store and use any surplus tissue that may arise from your procedure so that it is available to medical researchers.

What is a Tissue Bank?

A Tissue Bank is a collection of such surplus samples that have been gifted by patients for use in medical research by doctors and scientists. The Tayside Tissue Bank at the University of Dundee stores these samples and shares resources with similar Tissue Banks. It is a founding member of the Breast Cancer Campaign Tissue Bank. Any tissue you donate may be divided between these Tissue Banks, which are maintained in collaboration with other institutions including charities.

1. Read this leaflet

2. Consider donation

3. Ask any questions

4. Make your decision

5. Let the Nurse know



Tayside Tissue Bank



Have you had permission to contact me?

Yes. The East of Scotland Research Ethics Committee REC 1, which has responsibility for scrutinising proposals for medical research in Tayside, has examined this proposal and raised no objections from the point of view of medical ethics. Monitors from the University of Dundee and NHS Tayside also check that research is properly conducted, records are kept and that the interests of those taking part are adequately protected.

What would I have to do?

Read this information sheet and consider whether you wish to give permission for your tissue to be used for medical research. When you come into hospital or attend a clinic you will be asked if you wish to let your surplus tissue be used. The Nurse / Doctor will record your decision and, if appropriate, assist you in completing a consent form.

Do I have to take part?

No. Donating tissue (including blood) to Tissue Banks is entirely voluntary. Giving or refusing consent for the collection, storage and use of surplus tissue for research will not affect your care or treatment in any way.

What will happen if I take part?

The procedure that your doctor has planned will take place as normal (if this has already happened the samples could still be useful). After the tissue has been removed and examined by a specialist (a Pathologist) and enough kept for any further testing that may be required, a small piece of any left over tissue may be stored in the Tissue Bank. In addition, to this tissue sample the Tissue Bank may ask that a blood sample of up to 20 ml (just over 1 tablespoon) is also collected.

What are the advantages of taking part?

While it is unlikely the research will help you directly, we hope that the information that medical researchers obtain from your tissue will help improve the diagnosis and treatment of other patients in the future.

What will happen to any tissue that is taken?

Your tissue (including blood) may be used in a number of research projects in universities, the NHS or medical research companies. It will not be sold for profit but may be used in research that could lead to the development of new drugs or treatments. Whilst samples are never sold to researchers, they may be asked to pay for the cost of storing and transporting any tissue samples they request. Before donated samples are released to any researcher (worldwide) they must provide a written explanation of what they intend to do with the tissue. This must satisfy a panel of doctors and scientists that the research is well planned and of medical value.



Will any genetic tests be done?

Sometimes samples are used for genetic testing which may help to identify inherited factors that influence the development of disease. No samples will be supplied for research into reproductive cloning.

What about my personal information?

We collect data relating to your medical records, such as diagnosis, treatment and demographic details (e.g. age, gender, postcode and number of children). All information that is collected is kept strictly confidential. Your name and other identifying information is removed from any records that are given to researchers so that you cannot be recognised from them. Researchers using the tissues will be given a copy of your anonymised information to help make your tissue donation as useful as possible. Should our collaborative arrangements with other institutions end, your tissue and information may be transferred to one of the research institutions or charities we work with. If your tissue and information is transferred it will be held by the Tissue Bank administrators in the same way as we currently hold it and can only be used for further medical research.

Version 6: 14 March 2013