

Donating tissue or cells for research

The purpose of this leaflet

This leaflet tells you about:

- what happens to tissue samples and samples containing human cells collected from patients during treatment, and
- how to give permission to allow surplus tissue or cell samples to be used for research and teaching.

Introduction

Cambridge University Hospitals NHS Foundation Trust (‘the Trust’) is a leading teaching hospital and bio-medical centre, where many tissue and cell samples are taken from patients each day for laboratory tests. Examples of these specimens include blood samples, tissues removed during operations, and urine

The Trust is also a major centre for research into the causes of diseases and their treatment. For detailed information about our research, please visit our website; http://www.cuh.org.uk/tissue-bank

Some research projects use tissue samples taken with permission specifically for that project. However, many projects benefit from the use of tissue samples that are no longer needed after the necessary diagnostic tests have been completed, provided you give us permission to do this.

The information in this leaflet will help you to understand what happens to your tissue after it has been collected. If you have any specific questions please do not hesitate to ask your nurse or doctor who will be very happy to discuss these with you.

What are tissue samples?

Tissue and cell samples include blood, urine, saliva and solid tissue such as appendix, skin or muscle.

How is a diagnosis made?

Samples of urine, saliva and blood may be used to examine the contents of the cells or their chemical content.

Most solid tissue samples are first placed in a chemical solution (formalin) to preserve them. Small samples (biopsies) are analysed in their entirety.

Sometimes pieces (about the size of a postage stamp) are chosen from larger samples by the pathologist to examine under the microscope. These small tissue
pieces are placed into plastic containers and covered by hot wax, which cools and becomes hard; these are called tissue blocks. Thin slices from tissue blocks are later cut and placed on slides for examination under a microscope to help the pathologist make the diagnosis. Other tests may also be done on this tissue. The pathologist sends the tissue diagnosis report to your doctor (the pathology report).

**What happens to your tissue after the tissue diagnosis has been made?**

Samples of urine, saliva and blood are only kept for a few weeks and are then disposed of by incineration. Tissue blocks and slides are routinely stored for at least 10 years by the Trust’s histopathology department. Some samples may also be stored, frozen, in small tubes for future analysis. The tissue blocks, slides and frozen material are stored for a long period because they may help with your treatment in future years. In some cases, the tissue could also be used to help make a diagnosis in another family member because some diseases run in families. If a patient moves to another hospital for treatment the pathology blocks and slides can be sent to that hospital to help subsequent diagnosis and treatment.

Any portion of the tissue sample that is not used for diagnostic tests is referred to as ‘surplus tissue’. This is usually kept for one to two months after which it is disposed of by incineration.

**What else can happen to your surplus tissue?**

Surplus tissue is essential for clinical research, for controlling the quality of laboratory tests and for training doctors and laboratory scientists.

We need your help to make this happen. With your donation to the Trust’s *Human Research Tissue Bank* we hope to make advances that will benefit other patients and future generations.

**If I agree to donate my surplus tissue what would it be used for?**

All research using human tissue must be approved by the National Research Ethics Service and the Trust’s Research and Development Department. This ensures that the tissue samples are treated in an appropriate way, and used for a worthwhile purpose.

**How can I donate my surplus tissue to the Trust’s Human Research Tissue Bank for teaching, quality control and research?**

At some stage during your visit to the Trust, you may be asked to sign a form indicating whether you wish to donate surplus tissue. We also request that we can review your medical notes for research purposes. Please remember that our priority is making a diagnosis and treating your disease. Your medical treatment will not be affected in any way if you do not want your surplus tissue to be used for non-diagnostic purposes.
Is the information about me and my tissue treated confidentially?

Unless you have specifically given your consent for researchers or relevant regulatory authorities to access your medical records, complete confidentiality is guaranteed. All surplus tissue, together in some cases with information from medical notes, is given to doctors or scientists with no information that can identify the donor. The researchers can never know that the tissue, the information, or the research results link back to you.

For how long and where is surplus tissue stored?

Surplus tissue can be used for research as soon as it is taken from your body but it can also be stored for many years before it is used. Surplus tissue collected for teaching and research is placed in a ‘Tissue Bank’. The Trust’s Human Research Tissue Bank is licensed by the Human Tissue Authority with Licence Number 12315 (http://www.hta.gov.uk/) and as such is strictly regulated.

Will I always know what research is being done on my tissue?

The research projects that are currently being undertaken are described on our website (as shown on page 1). However, because medical science changes so quickly, it is not possible to tell you about future research projects that may also use your tissue.

Could genetic research be performed on my tissue?

Yes, but those doing the research cannot trace your genetic information back to you. Many diseases are caused by abnormalities in genes. For example, tumours often grow because a genetic abnormality develops in a very small area of your body. To discover why a tumour has developed, we compare genes in tumours and genes in normal tissue from the same patient. If we find differences between these sets of genes, it may help us find the cause of this type of tumour. Once the cause of a disease is known, there is a better chance of developing more specific treatments. Your genetic information will be kept anonymous.

Could my tissue be used by any other organisations?

Yes. Our research is often done in conjunction with other hospitals, universities, or in some cases commercial companies, so there is a possibility that your tissue could be sent to another organisation for a specific research project. These projects are always reviewed and approved by the National Research Ethics Service. In all cases, the tissue is anonymised, so the receiving organisation will not know your personal details.

Can I change my mind?

Yes, at any time. If you no longer want your surplus tissue to be used for research, you can withdraw your consent by contacting PALS below. Your surplus tissue will then be disposed of in an appropriate manner.
Further information

Information on the National Research Ethics Service can be found at: http://www.nres.npsa.nhs.uk/

Further copies of this leaflet can be downloaded from our website: www.cuh.org.uk or by contacting us at:

Patient Advice and Liaison Service, 
Addenbrooke’s Hospital, 
Cambridge, CB2 0QQ 
Tel: 01223 212756

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. 
For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk. 
Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

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Authors: Tissue Bank Manager
Pharmacist: n/a
Department: Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk

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