

Information about The Use of Surplus Tissue for Medical Research and Education

We would like you to donate some of your tissue for medical research and education. This leaflet will help you to decide if this is something you want to do. Please think about this and read the information carefully.

What is tissue?

The human body is made up of many cells that are grouped together into tissue. Some tissue form organs such as the lungs, the liver or the appendix. Other tissue is present throughout the body, for example, bone, skin, urine and saliva.

Doctors or other health care staff may take tissue, as part of your care. For example, during operations or when taking a blood sample for tests. They will send this tissue to a pathologist or another specialist laboratory doctor to find out or confirm what is wrong with you.

What happens to my tissue after diagnosis?

Your tissue is sent to a pathologist or another specialist doctor who is expert in examining tissue. We do not need all of your tissue for your diagnosis. We keep some of the diagnostic tissue as part of your medical record so that we can examine it again if you are ill in the future.

The doctor will only take the tissue they need for your care. If there is some surplus (leftover) tissue that is not required for your diagnosis or treatment medical research and education could use it.

The NHS would like you to donate some of this surplus tissue for medical research and education. We would also like you to donate any surplus tissue from biopsies and surgical operations you may have had in the past.

Do I have to do this?

No. It is up to you to decide if you want to donate surplus tissue. Your decision will not affect your treatment, care or diagnosis. If you decide to take part, you can change your mind at any time. You don't need to give a reason. When you arrive at the hospital a member of staff will ask you whether or not you wish to take part.

Why is human tissue required for research and education?

As well as providing care and treatment, the NHS is responsible for making sure that medical students, nurses and other healthcare professionals get the training they need.

Doctors and scientists also need human tissue for medical research. Research is any activity that aims to discover new facts about a disease. It includes things like looking down a microscope and analysing proteins, DNA and other molecules in the tissue.

The tissue you donate may be used in all these aspects of research. In addition your tissue may be used in research with animals to model disease processes and in the creation of cell lines where your cells could be grown and cared for in a laboratory for multiple experiments possibly over months and years.

If samples are collected at different stages of a disease, it helps to understand how a disease or problem starts or develops. They can also try out different drugs and tests on the tissue. They may find new medicines or treatments. They may also find new ways of diagnosing a disease earlier.

It is important to highlight to you that any research that uses this tissue will conform to strict UK guidelines and regulations.

Will they use my NHS medical records?

Yes. Researchers need to know the medical history of the person who donated the tissue. The NHS needs your permission to take this information from your medical records.

However, all information that is collected will be kept strictly confidential. Any information that is given to researchers will not include your name and any other personal information so you cannot be recognised from it.

To make sure the data is complete and correct, authorised staff may inspect your medical records. All persons looking at the data and its accuracy are sworn to strict secrecy and to observe the data protection regulations.

Will my information be kept confidential?

All information collected about you complies with GDPR regulations and is held securely in line with the 2018 Data Protection Act. The NHS will take every precaution to prevent researchers from obtaining any information that identifies who you are. The only people who know your identity are NHS staff, bound by a professional duty to protect your privacy.



How long will tissue be stored?

Any tissue you donate will remain in the NHS until they use it all or you withdraw your authorisation. However, if you change your mind after your operation, some of your tissue may already have been used for research.

Where will researchers or clinical teachers use my stored tissue?

Before using your tissue and medical records, researchers must prove that they are following legal and ethical guidelines for their research

Researchers who may use tissue include those:

- In the NHS
- At universities and research institutions
- At biotechnology (pharmaceutical) companies

It also includes medical researchers outside the UK.

All research studies will be approved and monitored by an independent regulatory approved body.

Will the researchers carry out genetic tests on my tissue?

It may be appropriate for genetic tests to be carried out. A lot of research and diagnoses require the study of genetic material (genes) from healthy individuals and those with known diseases. This comparison helps to reveal genetic differences, which can then be used to develop future drugs and therapies. If new genetic research is carried out the results of this research cannot be traced back to you.

New genetic tests are also being developed in NHS laboratories that will involve looking for genetic alterations in disease. They can predict a response to a new or existing treatment. It is possible that your surplus tissue may also be used in this way. In this situation you doctor may discuss these results with you, particularly if it will affect your treatment.

Can researchers find new information about my health?

The research on your tissue will normally have nothing to do with your own care or treatment.

If any information might be of use in your current care or treatment, the doctors looking after you may discuss with you how it could be used to guide your treatment. This may include inviting you to join a medical research trial of new treatments. You would be provided with full information of any new treatments and free to decide whether or not to take part.

There is a small chance of detecting changes in your genes that are inherited and are present in all of the cells of your body. If this is the case, your doctor may recommend that you see a genetics specialist because they could indicate an inherited disease not

directly related to your current care or treatment. This is a rare situation, but if these changes are found they may also have implications for your relatives. In this circumstance your relatives would be able to discuss this with a specialist geneticist and have a test if they wanted to.

Will anyone make money from my tissues?

It is illegal to sell tissue for profit. The NHS may charge researchers a fee for your tissue but this is to cover the costs of collection, preservation and storage of your tissue. The NHS uses a considerable amount of staff knowledge and skills ('know-how') to explain what is wrong with you. This 'know-how' is valuable information for researchers. The NHS will use money it gets from researchers and your tissue to improve care to its patients.

If researchers develop a new drug, treatment or test, a pharmaceutical company or other researcher may then make a profit. It will not be possible for you to make a claim for money if you donated tissue. However, any new drug, treatment or test may help everyone in the future.

I'm still not sure if I want to take part.

If you need more information to make up your mind, talk to your doctor or nurse, or contact NHS Greater Glasgow & Clyde Bio-repository nursing staff on **0141 354 9490**.

I want to donate ... what do I do next?

When you come into hospital or attend a clinic you will be asked if you agree to let your surplus tissue to be used for medical research. Your wishes will be recorded electronically. In some cases, this may involve surplus tissue taken earlier in your care.

I do not want my tissue to be used in research.

If you do not want your tissue to be used for medical research, then when you come into hospital or attend a clinic and we ask you to let us use your surplus tissue for medical research you can say no. We will record this electronically. Your decision will not affect your treatment, care or diagnosis. You can also change your mind at any time. If you do change your mind, contact **0141 354 9490**. You do not need to give a reason. Your decision will not affect your treatment or care.

Further Information

If you have any other questions, or if you would like this document in Braille, audio-tape or in another language, please contact:

 **0141 354 9490**