

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

We would like you to donate some of your tissues and body fluids 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 tissues. Some tissues form organs such as the lungs, the liver or the appendix. Other tissues are present throughout the body, for example, the bone and skin. Body fluids such as blood, urine and saliva also contain cells.

Doctors or other health care staff may take tissues, blood samples or body fluids 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 to find out or confirm what is wrong with you. A Pathologist is a doctor who is an expert in examining tissue and body fluids.

The doctor will not take more tissue or body fluids than is needed for your care. But, if there is some tissue or body fluid left over that is not required for your diagnosis or treatment it could be used for medical research and education.

What happens to my tissue after diagnosis?

The Pathologist would normally keep some of your tissue as part of your medical record so that it can be examined again if you are ill in the future. In bigger operations and biopsies most of the tissue would not usually be kept. The NHS would like you to donate some of this surplus (left over) tissue for medical research and education. We would also like you to donate any left over 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. If samples are collected at different stages of a particular disease it helps to understand how a particular disease or problem starts and develops. They can also try out different drugs and tests on the tissue. They may find new medicines and treatments. They may also find ways of diagnosing a disease earlier.

Where will researchers or clinical teachers use my stored tissue?

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

Before using your tissue, all of the above must prove that they are following legal and ethical guidelines for their research.

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

How long will tissue be stored?

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

Will my medical notes be used?

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 notes.

All information that is collected will be kept strictly confidential. Any information that is given to researchers will have your name and any other



personal information removed so that you cannot be recognised from it.

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 anything is found that you need to know your doctor will be told.

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 today focuses on the study of genetic material from normal individuals and those with known diseases. This comparison helps to reveal genetic differences, which can then be used to develop future drugs and therapies. The results of these tests cannot be traced back to you. Researchers will only use these test results for research and education.

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 from samples at different stages of your treatment.

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 then please contact: **0141 354 9490**

If you would like this document in Braille or audio-tape format, please contact: **0141 354 9490**

If you would like this document in another language, please contact: **0141 354 9490**

如果您需要该信息的其它语言版本，请联系：

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إذا رغبت في الحصول على هذه المعلومات بلغة أخرى، الرجاء الاتصال بـ:

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਦੂਜੀ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੀਦੀ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਸੰਪਰਕ ਕਰੋ:

اگر آپ یہ معلومات کسی اور زبان میں حاصل کرنا چاہتے ہیں تو براہ مہربانی رابطہ کریں:

Eğer bu bilgiyi bir başka dilde istiyorsanız lütfen bağlantı kurunuz:

Jeśli chcesz uzyskać te informacje w innym języku skontaktuj się z:

0141 354 9490

www.nhsgbr.org.uk