Young Persons Research Bio Bank

Helping to develop better treatments for young people in the future.
Hello

As part of your routine care in hospital your doctor or nurse may take blood, urine or tissue samples to be tested to find out why you are unwell. Normally only a small amount of these samples is required for tests. We are asking if you would donate the ‘left over’ bits for medical research and teaching. The doctor will not take more tissue or body fluids than is needed for your care. This leaflet will give you all the information you need to decide. Take as much time as you want and speak to your parent/s, legal guardian or any of the doctors or nurses.

Whatever you decide it will not affect your care. No extra tissue will be removed and no one will be upset if you say no.
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 heart 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 and are called tissue.

What normally happens to my left over tissue?

The hospital 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. However with bigger operations and blood samples most of the tissue left over from testing would be destroyed.

What are you asking me to do?

We are not asking you to do anything extra, but if you agree we will use some of the tissue left over, after all the tests have been done by your doctor. We would also like you to donate any old samples that your doctor may have taken in the past, that are not needed for your care. If you say yes, this is called giving your consent. This will be recorded electronically.

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 and care in any way. 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 teaching?

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 or ways of detecting a disease earlier.
Where will researchers or clinical teachers use my stored tissue?

• In hospitals
• At universities
• At research institutions
• At companies, usually those that make new drugs

Before using your tissue, all of the above must prove that they are following the guidelines set down by law.

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

How long will tissue be stored?

The tissue you donate will remain in the hospital until it is all used or you withdraw your consent. However, if you change your mind after your treatment, 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 hospital 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 drug 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 tissue … 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.
NHS Greater Glasgow & Clyde
Children’s Research Bio Bank

CONSENT FORM FOR YOUNG PERSON
(to be completed by the child and their parent/guardian)

Please circle Yes No
Have you read about this project? Yes No
Has somebody else discussed this project with you? Yes No
Do you understand what this project is about? Yes No
Have you asked all the questions you want to? Yes No
Have you had your questions answered in a way you understand? Yes No
Do you understand it’s OK to stop taking part at any time? Yes No
Are you happy to take part? Yes No

If any answers are ‘no’ or you don’t want to take part, then thank you and stop here.

If you do want to take part, please write your name and today’s date

Your name ____________________________________________

Your parent or guardian must write their name here too if they are happy for you to give consent

Print Name ____________________________________________

Sign

Date / /
CONSENT FORM FOR PARENTS

Please tick box

1. I confirm that I have read and understand the information sheet

2. I understand that my child’s participation is voluntary and that they are free to withdraw their consent any time, without giving any reason, and without their medical care or legal rights being affected.

3. I understand that relevant sections of my child’s medical notes will be accessed and de-identified when given to researchers with the tissue sample.

4. I understand that my child’s surplus tissue may be used for genetic research.

5. I agree for my child’s surplus tissue to be used for medical research.

Name of Child

________________________________________________________________________

Signature of child (if appropriate)

________________________________________________________________________

Name of Parent/Guardian

________________________________________________________________________

Signature of Parent/Guardian

________________________________________________________________________

Date / /