



Donation of surplus tissues for research purpose

Information Sheet for adult donors (Patient Donor)

The University Hospital Southampton NHS Foundation Trust and University of Southampton partnership has established a Biorepository, which stores human biological samples for medical research. We would like to invite you to consider donating surplus tissues, used medical device or implant after it is removed, or microbiology specimen investigating bacteria, viruses and fungi, which would otherwise be disposed of. We would also like to invite you to provide a blood, urine or other required samples to the Southampton Research Biorepository.

Before you make a decision please read the following information carefully and discuss it with your family, friends or other people that you think appropriate, if you wish. If you have any questions at a later date please contact the Southampton Research Biorepository Manager on 023 8120 4989

What is the Southampton Research Biorepository (SRB)?

In recent years, we have made great progress in understanding diseases. But, we still need to do more research to figure out what causes diseases and to develop better methods for diagnosis and treatment. To do this, it is important to have samples from many patients, such as tissue (pieces of body tissue), blood, and others. The SRB works to collect these samples from people with different types of illnesses. They are allowed to do this because they have the approval from the ethical committee. With these tissues, researchers can study a variety of diseases and help improve care and treatments for patients in the future.

What will happen if I agree?

When you have surgery that involves taking out tissue or body fluids, the samples are usually sent to a laboratory in the hospital to help with your diagnosis. Sometimes there is extra material that isn't needed for diagnosis, which would normally be thrown away. This extra material can be put in a special, safe place - the SRB, that has been approved by the Human Tissue Authority. This place will make sure the tissue or fluids are kept in good quality.

In some medical procedures, healthy body parts (like breasts) or tissue related to epilepsy may need to be removed. We would like your permission to keep these parts or tissue for medical research purposes. This means they can be compared to unhealthy parts or tissue and can be used as a comparison to measure how the unhealthy parts or tissue respond to treatments.

Sometimes surgeries involve taking out a medical device, like an implant or a catheter, from a patient's body. These devices are usually thrown away after they are removed. However, sometimes they can provide useful information that can be used for research. In this case, we will ask for your permission to collect the device so that it can be examined in the hospital laboratory and used for research.

If you have had surgery in the past, the pathology lab may have kept some of your samples as part of your records. Those samples can still be very helpful for researchers. We may ask if we can access these samples with your approval. The pathology department will make sure that there are still enough samples left for storing in your records.

We would like to ask for your permission to take a small extra amount of blood in addition to the normal blood sample taken for your medical care. On occasion, depending on the research being conducted, we may also ask for you to provide other bodily fluids such as urine. These samples will be used for research purposes.

When you send a sample to the SRB, it will be given a unique code that is connected to your hospital or NHS number. Researchers won't be able to figure out who you are. The SRB will keep a connection to your identity for record-keeping and to make sure consent has been given. In some cases, your anonymity may be broken but only with permission from the National Information Governance Board for Health and Social Care.

For clinical areas where the hospital electronic notes system is in used, a record will be created on the system to show that you have agreed to have a sample stored, along with any extra conditions you have set.

We will ask you for some information about your health, such as any illnesses or treatments you've had, in order to help researchers. We may also need to look at your hospital records

and may contact your doctor for more information. You don't have to do anything else unless we ask you to take part in a different research project, and you can decide whether you want to do this based on the information we give you at the time.

Your samples and their related medical data will be used mostly by local scientists. Some anonymous information may also be shared with scientists from different places, like universities, hospitals, or businesses that do medical research. Any research done by outside organizations will only be what has been approved by our ethics committee first.

We may do tests to see if your genetics are linked to any illnesses. Your cells will not be used for any experiments that make clones. Your samples can be used to create cells that can live in the laboratory forever. Normally, cells die shortly after they are taken out of the body. If you do not want this to happen, you can state so on the consent form.

When you sign the consent form, you can choose to agree to provide samples from any future autopsy for research. Most people will never need this section, but it has been included in the form just in case. Your family can also decide not to give samples for research.

Do I have to say yes?

It is totally up to you if you want to permit extra and other samples to be used like this.

Is there any research that my samples will not be used for?

The SRB has a committee that is made up of both experts and members of the public. This committee's job is to provide guidance, rules, and decisions for the SRB. There is another committee known as the Access Committee that will only allow access to your samples if researchers have followed strict ethical and legal rules. Your tissue cannot be used for reproductive cloning, research related to ending pregnancy, testing cosmetic products, or transplantation. The researchers can only use the samples for the research they said they would do, and will be required to follow a strict agreement. Information about all research projects that the SRB approves will be available from the SRB Manager and on the Southampton Centre for Biomedical Research website.

Will information about me be given to people outside of the Trust?

No, all information about you will remain confidential and will be stored in accordance with the UK Data Protection Act 2018. Under the Data Protection Act you are entitled to see what is recorded about you. No information will ever be released to an insurance company.

Researchers will NOT be provided with any personal information such as your name, address or phone number. The information they will be given for their work will relate to your health and treatment and will NOT be directly linked to your identity. Access to personal identifiable data will be restricted to approved sources within the Trust only. Approved sources are limited to University Hospital Southampton NHS Foundation Trust staff or those with honorary contracts authorised to work at University Hospital Southampton NHS Foundation Trust. Anonymised information may be shared with researchers outside of the University Hospital Southampton NHS Foundation Trust for research purposes only.

Are there any benefits to me donating samples?

Your donation of tissue can help improve medical understanding and possibly lead to the development of new drugs. However, it usually takes a long time and a lot of money to get

these drugs to market, so individual donors will not be rewarded with any money. In the end, everyone could benefit from your donation, even if you don't get any direct benefit yourself.

Does the SRB benefit financially?

The SRB is part of a team that works together between the University Hospital Southampton NHS Foundation Trust and the University of Southampton. The SRB doesn't make a profit, instead the researchers using the SRB pay any associated costs. The benefit of the SRB to the Hospital Trust is that tissues can be used for research to help progress medical knowledge and patient care.

What are the risks to me?

There is no more danger to your health from giving a sample for research than from giving a sample for routine care. If you prefer, you can only let us use extra sample from tests done for routine care. We may collect more samples from you during your stay if you agree. These samples will be taken at the same time as any routine tests (like giving blood).

Will I be told the results of individual research tests on my samples?

No, we won't give you or your doctors the individual results of our research on your samples because that's not part of your regular medical treatment. If someday the research points to a test or treatment that may be helpful to you and your family, then the doctors will let you know.

The overall results of the research will be put on a website, and may even be printed in scientific and medical journals.

What happens if I change my mind?

You can change your decision at any moment by calling the SRB on 023 8120 4989. You don't need to give a reason. It will not have any effect on your care or treatment. Any sample stored by us will be disposed of in line with hospital policy. Any information kept about your sample will also be deleted and not used again. If you decide to change your mind after a while, it is possible the samples may have already been used by researchers. We cannot get back any samples or data from researchers if this has happened.

What else do I need to do now?

If you have enough information and you want to agree, you will be asked to sign a paperwork. If you don't agree, then you don't have to do anything. No samples will be kept or used unless you give your permission by signing the agreement.

Contact information

If you require any further information or have any questions, please contact the SRB Manager, University Hospital Southampton NHS Foundation Trust, Southampton Centre for Biomedical Research, MP 218, Level C, West Wing, Tremona Road, Southampton, SO16 6YD. Telephone: 023 8120 4989.

Feedback

We appreciate and encourage feedback.

If you would like to provide written comments about the SRB, please write to Prof Saul Faust, National Institute of Health Clinical Research Facility Director, University Hospital Southampton

NHS Foundation Trust, MP 218, Level C, West Wing, Tremona Road, Southampton, SO16 6YD.
Telephone: 023 8120 4989.

If you need advice or are concerned about any aspect of care or treatment, please speak to a member of staff or contact Patient Support Services:

Phone on 023 8120 6325

Email at patientsupportservices@uhs.nhs.uk

Speak to the local ward staff and ask to be put in touch with Patient Support Services

Call in to the Information Point just inside the main entrance of Southampton General Hospital

Write to the address below:

Patient Support Services
C Level Centre Block
Mailpoint 81
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD