

The King's Liver Research Tissue Bank



Information for patients

This leaflet explains why we have asked you to donate to our Tissue Bank and how we use donated samples. If you have any queries, please do not hesitate to speak to a member of the Tissue Bank staff.

Confirming your identity

Before you have a treatment or procedure, our staff will ask you your **name** and **date of birth** and check your **ID band**. If you don't have an ID band we will also ask you to confirm your address.

If we don't ask these questions, then please ask us to check.

Ensuring your safety is our primary concern.

The Institute of Liver Studies at King's College Hospital is a specialist centre which cares for patients with a wide variety of liver diseases, referred from all over the United Kingdom and the world.

Our aim is to give patients with these diseases the best possible treatment. Through medical research we are working to improve our ability to diagnose them, improve our understanding of why they happen and develop the most effective treatments.

To make this possible, it is very important to have access to blood and tissue samples. These are used by research teams here and in other centres around the world to investigate these problems.

We have set up a Tissue Bank where we store blood samples and leftover tissue, which is then available for use in research programmes. We would like you to consider whether you would be happy to donate to the Tissue Bank. It has been approved by the National Health Service Research Ethics Service and is licensed by the Human Tissue Authority.

What would I have to do?

If you are happy to take part, we will ask you to sign a consent form to confirm this in writing.

We would then take a small extra blood sample when your have your routine blood samples taken. We take 10-30ml, which is about two-six teaspoons.

If you have a liver transplant we would also take small daily blood samples over the first two weeks after the operation; a total of 50 ml (10 teaspoons).



In the future, if you are still coming to King's, we may ask to take more samples; we would at most ask for two further small blood samples. At most, we would ask for two more small blood samples over the course of a year.

We would also ask you for permission to use any leftover tissue from liver biopsies or surgical specimens for the Tissue Bank.

We will not take any extra samples or do any extra procedures to take this tissue.

What will happen to the samples I donate?

We will separate DNA (genetic material) from some of the blood sample, and store this and other portions of the blood and tissue in a special facility here at King's College Hospital. These samples can be used in research for more than 10 years after collection.

All samples are fully anonymised; this means that no samples are given to researchers with information that will allow anybody to work out who donated them. We will collect a small amount of information from medical records which we may also give out – but again nobody who studies the samples will be able to find out the name of the donor.

Because we work with other units around the world on the study of particular illnesses, we may give samples and data to researchers outside the Trust for special research. However, a special committee will very carefully assess who is able to use the samples, to make the very best use of them. The Tissue Bank is 'not for profit', which means no one involved in its work will profit financially from the use of its stored material.

What sort of research will be carried out on the donated samples?

We may carry out a wide variety of research on the samples you donate. These may include studies that look at the basic functions of the liver or at how particular diseases develop and the best ways to treat them. These research studies may include genetic tests.

No samples will be used in research involving animals or human embryos or outside of healthcare or for commercial gain.

What happens if the samples I donate are used in research?

You can decide what happens if your samples are used in research. If you wish, we will write to you to let you know if they are used and to tell you about the results of the study. If you do not want us to contact you, then you simply sign the consent form to confirm this.

At some point in the future, we may test your samples and get results that could help us to look after you better. If this happens we will write to you and ask you to visit our outpatients department, where we can discuss this in more detail.

Will the medical care I receive be affected if I choose to donate?

No. If you choose to donate to the Tissue Bank, all we will do is take an extra blood sample.

If at any time you do not want your samples to be stored or used, you can tell us without having to give a reason and the samples will be removed and destroyed. This will not affect the care that you receive.



Key facts

- Taking part is completely voluntary.
- You do not need to make any extra visits to the hospital.
- Blood samples and tissue will be stored and may be used in future research.
- All samples stored and tested will be fully anonymised.
- You can change your mind at any time if you do not want your samples to be used.

Who can I contact with queries and concerns?

If you have any more questions about the Research Tissue Bank, please ask to speak to a member of the Tissue Bank staff.

Institute of Liver Studies

Direct Telephone: **020 3299 4160**

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road – staff will be happy to direct you.

Tel: **020 3299 1878**

Email: **kch-tr.pals@nhs.uk**

You can also contact us by using our online form at
www.kch.nhs.uk/contact/pals

If you would like this leaflet in a different format or language please contact PALS on 020 3299 1844.



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