

# Donating tissue samples for medical research

## *Patient Information*

## Central England Haemato-Oncology and Oncology Research BioBank

### ***Introduction***

Research Tissue Banks can be very useful for researchers to study actual samples from patients in the laboratory in order to find new ways to diagnose, treat and prevent disease. Your doctor has agreed to help collect samples from patients for the Central England Haemato-Oncology and Oncology Research BioBank situated at the Birmingham Women's Hospital.

### ***What are we asking you to do?***

You are being asked because you have been referred to a specialist doctor to either help determine whether you have a blood disorder or to examine a sample of your tissue. Usually any remaining tissue not used for diagnosis is destroyed by the hospital. We are asking your permission (consent) to store any remaining tissue not used for diagnosis in the Central England Haemato-Oncology and Oncology Research BioBank. These samples may be used in current and future research related to any condition that you have.

In addition we may also ask you to consent to the donation of a small extra sample for the Central England Haemato-Oncology and Oncology Research BioBank. This sample will be taken at the same time as your diagnostic sample or routine follow up clinics and therefore will not involve any additional visits.

### ***What kind of research might be done on these tissue samples?***

Tissue samples may be used in research to learn more about the causes of various disorders and how to prevent and treat them. This may include genetic research, for example, looking for changes in DNA (genes) that may cause blood or other

disorders. Your tissue will only be used for research related to any condition that you may have and will not be used for any other purpose.

Researchers can only use the samples after their research has received appropriate ethical approval (e.g. via a relevant Research Ethics Committee). This is to make sure that the research is in the interest of patients and is carried out safely.

As well as for use in current research, we would like to be able to collect tissue for use in studies in the future that have not yet been planned. This is why we are also asking if we can store samples in a tissue bank for future use.

### ***Where will my tissue samples be kept?***

Any tissue samples you donate will be stored in a licensed and ethically approved cell bank, the Central England Haemato-Oncology and Oncology Research BioBank situated within the West Midlands Regional Genetics Laboratory at the Birmingham Women's Hospital.

In the laboratory where tissue is stored, there is a named senior person who is responsible for the tissue collection.

### ***Who will have access to the tissue?***

The tissue will be made available to research teams including clinical and laboratory staff, working on specific research projects that have been given approval by a Research Ethics Committee.

We may need some clinical data from your medical records relating to your sample. This information is required to help researchers better understand the factors that may

influence the risk of getting diseases and how to develop new treatments. The research may be carried out in academic institutes, the NHS or commercial companies in the UK or overseas.

The BioBank is a not for profit organisation, however researchers may be charged for tissue and/or clinical data supplied, in order to cover costs.

### ***What about confidentiality?***

Samples kept in the tissue bank have a unique identifier (code). Researchers receiving the samples will be given details about your type of disorder but they do not know your name or any other personal details.

### ***Will you be able to tell me the results of any research on my tissue samples?***

It is unlikely that you will personally benefit from the research as it usually takes many years for research to produce advances in diagnosis, treatment or prevention of diseases. The results of the research will NOT routinely be put in your health records or told to you or your doctors. However, your doctor may be informed if research tests identify abnormalities, or other significant medical findings, which may affect your treatment and care for any blood or tissue disorder you are currently being assessed for. The BioBank will be able to identify you from your unique identifier (code).

### ***Does this mean extra visits to the hospital?***

No, you will not need to make any extra visits to the hospital. Any tissue samples we may want to use for future research will be left

over from your routine visits or taken at the same time as your routine visit.

### ***If I agree, what do I have to do?***

The first thing you need to do is give your written permission (consent) by signing the form and statements you agree to which are attached to this leaflet. You can either hand the consent form to a member of your clinical team or post to the address given on the attached consent form. Please keep this information sheet to remind you of what you were asked to do. You may wish to discuss this with a member of your clinical team before agreeing to consent. You can still change your mind at any time, even after you have signed a consent form.

### ***What if I do not wish to take part or change my mind?***

Your agreement is completely voluntary. Whatever you decide, you will be given the best appropriate treatment and care.

You can change your mind at any time by contacting your consultant or other member of your clinical team, even if you are no longer under the care of the Trust. You do not need to tell us why. This will not change your medical care.

If you tell us that you have changed your mind, all research samples remaining in storage will be destroyed.

### ***What if I have a complaint?***

Please contact the haematology or oncology research nurse at your hospital, contact details are provided on this information leaflet. Alternatively, you can contact the BioBank manager via letter or phone, contact details are provided on the

consent form.

***If you have any questions or concerns about the donation of samples and information or the possible uses of them, please ask the person discussing donation with you and seeking your consent; or contact the Haematology Research Nurse at your hospital.***

***A local contact name and number may be provided below:***

The Central England Haemato-Oncology and Oncology Research BioBank, receives funding from:



www.cureleukaemia.co.uk  
Registered charity 1100154

Central England Haemato-Oncology and Oncology Research BioBank (*Version 1.6, 09/2018*)

## Consent for Research using Tissue Samples

Thank you for reading the information about using and storing tissue and blood samples for research. **If you would like to give consent please read this form and sign below.**

I have read and understood the patient information leaflet entitled 'Donating tissue samples for medical research and have had the opportunity to ask questions.

If I consent, I agree to any excess or additional tissue, and/or marrow and/or blood samples removed during the course of my diagnosis and/or treatment to be stored and used for research. I understand that the research may involve looking into changes in DNA (genes) that may cause blood or tissue disorders.

If I consent, I agree that this tissue, test results in the tissue, and clinical information gathered about me can be stored by the local Research BioBank. The Research BioBank will be the legal custodian of this material.

I understand that tissues and clinical information can only be used in research projects if they have received appropriate ethical approval (e.g. via a relevant Research Ethics Committee).

I understand that researchers may be charged fees to cover costs for supply of tissue and/or data

I understand that some of these projects may involve researchers outside of Central England including workers in commercial companies, or other health and research organizations, but this will be on the understanding that the sample is

anonymised (i.e. there will be no means of identifying me).

I understand that I will not benefit financially if this research leads to the development of a new treatment or medical test.

I understand that my agreement is entirely voluntary and can be withdrawn at any time. If I have any concerns regarding this, I can contact a member of my clinical team.

### PATIENT

Name (block letters) .....

Date of Birth. ....

Signed..... Date .....

**Please initial the boxes against each point if you agree.**

**Excess tissue may be used in approved research projects.**

**Extra sample may be taken and used in approved research projects.**

**My medical records may be looked at by a research nurse to obtain information such as the treatment I have received and my response to this when this information is not known to the BioBank and it is relevant to the research project. I give permission for these staff to have access to my records and share anonymised data when it is relevant to the project.**

**I would not like any excess tissue to be used in approved research projects.**

### DOCTOR/RESEARCH NURSE TAKING CONSENT

Name (block letters) .....

Hospital. ....

Signed..... Date .....

**Please hand this form into a member of your clinical team once you have had the opportunity to ask questions, or alternatively please post to the address on the back of this form.**

### Contact for further information

• The local contact. Information is provided on the patient information leaflet.

• Address

Central England Haemato-Oncology and Oncology Research BioBank,  
c/o West Midlands Regional Genetics laboratory,  
Birmingham Women's Hospital NHS Trust,  
Edgbaston,  
Birmingham,  
B15 2TG.

• Phone the manager of CEHRB on  
0121 335 8036

• Fax

0121 335 8028

• If you have access to the internet you can visit the Biobank website:

<https://bwc.nhs.uk/central-england-haemato-oncology-and-oncology-research-bioba>