

## HUMAN BIOMATERIALS RESOURCE CENTRE

### Information Sheet for 13-to-17-Year-Olds

#### Introduction

- The Human Biomaterials Resource Centre (HBRC) is a 'tissue bank'. It collects and stores human samples in a secure environment for ethically approved biomedical research. The samples are usually donated by patients when they go into hospital.
- This information sheet explains what happens when a sample is donated to the HBRC. Please take time to read it carefully and ask your doctor or nurse if anything is not clear.
- If you have any questions at a later date, please contact us using the details at the bottom of this sheet.

#### What is biomedical research and why do we need a tissue bank?

- Biomedical research is carried out by scientists in order to find out more about how diseases start, how they can be detected, and how they can be treated.
- Scientists need lots of samples from children and adults with diseases to carry out biomedical research. We ask many people to give us samples, in order to make sure we have enough for research now, and in the future.
- One of the best places to keep these samples is in a 'tissue bank'. Other common words for 'tissue bank' are 'biobank' or 'bioresource'.

#### Why are we inviting you to participate?

- You have been identified as having an illness or disease that scientists are currently researching, or which is considered rare.

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

- We are inviting you to donate one or more samples to the HBRC.
- These samples may be a small bit of tissue taken when you have an operation (or which was removed during an operation you had in the past) and which is left over after the doctors have examined it. Or instead, they may be a bit of tissue that would normally be removed and thrown away, or a small amount of blood left over from a blood test.
- Sometimes we may ask whether we can take a small additional sample: for example, an extra blood sample, or a small bit of extra tissue. These extra samples are taken at the same time as your doctor or nurse is taking samples anyway, so they should not involve any extra pain. Nevertheless, you can say 'No' if you do not want it to happen on the day.
- Sometimes research projects require blood or urine samples on several occasions, so that the progress of your disease can be monitored. In these instances, you may be asked for a sample again. You can say 'No' if you do not want it to happen on the day.
- Information about your disease and the treatments you receive (now, and in the longer term) is also very useful for scientists. We are therefore asking you to let us to look at your health records as well.

#### Who can say 'Yes' to this?

- Legally, anyone under the age of 18 can say 'Yes' to the storage of their samples in a tissue bank, and their use in biomedical research – if the person understands what is being asked (they have been deemed 'competent'). We call this 'giving consent'.
- If you are under 16, we will usually ask for your consent, and for the consent of your parent(s) or the person who looks after you (your 'guardian'). This is because younger people sometimes have trouble understanding this information sheet, especially if it is coming at a difficult time for them. Or it may be that they simply prefer their parent(s)/guardian to give consent on their behalf.
- If you are 16 or 17, you can decide whether you would like to give your own consent, or whether you would like your parent(s)/guardian to consent for you. It's your choice.

#### What will happen if consent is given?

- You will be given a copy of this information sheet and the consent form to keep.
- When your sample arrives at the HBRC, we will give it a special code. We will be able to link the sample to you, but the actual scientists will not be allowed to know who you are.
- We may release samples straightaway to scientists, or we may store them in the HBRC until required.
- We may release samples for research that looks at your genes, but only to projects aimed at providing clues to the nature of disease, or if it is already known that genes are important.

- Samples may also be used to support research which uses animals, but only when this is absolutely necessary and experiments cannot be performed in any other way. Animal models can be very useful for understanding diseases in this way – but you do not have to allow it.
- Sometimes scientists need to grow cells in a culture dish for a long time. Again, this type of approach can be very useful for biomedical research.
- Mostly, samples will be used by scientists in Birmingham. Sometimes, they may be given to scientists who work outside Birmingham, in the UK or overseas. The scientists may work in universities, hospitals or commercial companies that do biomedical research.
- All information about you will be stored in accordance with a law called the UK Data Protection Act 2018. We will never release information to an insurance company, or let it be used to sell you anything, or give it to anyone except for biomedical research.
- You (and your parent(s)/guardian) will not receive any money for your donation.
- Helping the HBRC like this is ‘enduring’, i.e. we can ask for donations from you until you withdraw. This does **NOT** mean that you must donate at every hospital visit – just that there is no need for re-consent every visit.
- However, if you lose ‘competency’ after your 16<sup>th</sup> birthday, we will expect your parents or doctor to inform us, so that you, your parents (before or after your 18<sup>th</sup> birthday), or someone else (after your 18<sup>th</sup> birthday) can advise us whether your existing samples and associated information should be destroyed or retained.

### Do you have to say ‘Yes’?

**NO, YOU DO NOT.** It is entirely up to you. You do not have to agree or give a reason for choosing not to. Whatever you decide, you will still receive the best available care and treatment. Nobody will be angry if you say ‘No’.

### What happens if you change your mind?

- Nobody will be angry if you do this. You can change your mind at any time by contacting your doctor or the HBRC (details at the end of this sheet). You do not have to give a reason why.
- If you change your mind, this will not affect your care or treatment in any way, now or in the future. Any of your samples that still exist in the HBRC will be thrown away. Similarly, any information we store about you (apart from records allowing us to trace your samples’ history) will be deleted.
- We will also contact any scientists already using your samples and ensure that they destroy any unused samples and associated information. However, if you change your mind after a long period of time, your samples and associated information may already have been used, so it will be too late for those.

### What are the benefits to you?

It is unlikely that there will be any direct benefit to you, because biomedical research takes many years. However, we hope that the research done using your samples will help patients like you in the future.

### What are the risks to you?

As far as we know there are **NO** increased risks to your health associated with donating samples to the HBRC. Samples will only be collected when it is safe to do so during your routine hospital visits. Your identity will remain confidential, and when we provide samples to scientists, they will be bound by a strict agreement to use samples only for the research they said they would.

### Can you find out the results?

- No, we do not routinely report individual research results. You can find out more generally about the types of research projects using your samples by contacting us (see our details below). You can also ask to visit us the same way, if that’s OK with your parent(s) or guardian – we will check with them first, though.
- If a research project using your samples generates clinically important information, then your doctor, or another member of your healthcare team, will contact your parents about this.

### Our contact details

The General Manager, Human Biomaterials Resource Centre, College of Medicine and Health, University of Birmingham, Edgbaston, Birmingham B15 2TT (07584 312396; [hbrc-tissuebank@contacts.bham.ac.uk](mailto:hbrc-tissuebank@contacts.bham.ac.uk)).

If you have a concern or complaint about the HBRC, please contact the Research Ethics Governance & Integrity Team, College of Medicine and Health, University of Birmingham, Birmingham B15 2TT ([researchgovernance@contacts.bham.ac.uk](mailto:researchgovernance@contacts.bham.ac.uk)).