

HUMAN BIOMATERIALS RESOURCE CENTRE

Information Sheet for Children 8-12 Years Old

Introduction

- The Human Biomaterials Resource Centre (HBRC) is a 'tissue bank' that collects samples for 'biomedical research'. The samples are usually donated by patients when they go to hospital.
- We would like to ask you to donate a small sample to the tissue bank.
- This information sheet explains what happens. It is important that you understand it, and that you are happy to let us collect, store, and use your samples.
- You can say no if you want to. If you have any worries or would like to ask questions, you can ask your doctor or nurse about it.

What is 'biomedical research'?

- 'Research' is doing something in order to find out more about it. Your teacher might ask you to do research for a school project. This usually means looking things up in books or on the internet.
- 'Biomedical research' means doing special tests in a laboratory on human samples, in order to find out new things about diseases and illnesses.

Why do we need a 'tissue bank'?

- Scientists need samples from children and grown-ups with diseases and illnesses, so that they can find out why they started, and how to make them better.
- We ask lots of children to give us small samples 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'.

What are we asking you to do?

- We are asking you to say 'Yes' or 'No' to the question: "Can we have some of your sample for scientists to do research?"
- Samples are mostly little pieces of tissue left over from when you have an operation or a hospital test. Sometimes we may ask for a little bit of extra blood – but this would be collected at the same time your doctor or nurse is taking blood anyway, so you would not have to have an extra needle or anything else. Sometimes we may ask for your wee!
- Your sample will be given a special code so that scientists do not know who you are. We will keep your name secret.
- We will also ask for some of the information that doctors know about your disease or illness.
- Saying 'Yes' to the HBRC like this is called 'enduring consent'. In other words, we can keep asking for samples until you say 'Never again'. But you do **NOT** have to give us a sample every time we ask – you can always say 'not today, thank you'.
- However, there might be situations where grown-ups need to answer for you, because it has got too hard for you to think and learn.

Why are we asking you to do this?

- Scientists are interested in finding out new things about your disease or illness, or it is because very few people have your disease or illness.

Do you have to say 'Yes'?

- **NO, YOU DO NOT.** It is entirely up to you.
- If you say 'Yes' now, but you change your mind when you're older, just tell your mum or dad, or whoever looks after you, or your doctor. You can ask them to Google us to get our phone number (or you can Google us yourself).

- Nobody will mind if you say 'Never again'. Your treatment will still be the same. Any samples that we still have will be thrown away.
- If you are not a grown-up at that time, your parents, or the people who look after you, may also need to agree.

Will it do some good if you say 'Yes'?

- We hope the research using your samples will help children like you in the future.
- When you are a grown-up, it would be a really good idea to talk to your doctor about this anyway.

What will happen if you say 'No'?

- If you say 'No', nobody will mind, and your treatment will still be the same.

What should you do now?

- Take some time to think about whether or not you want to give any samples to us for 'biomedical research'.
- It would be a good idea to talk with your mum or dad, or the person who looks after you, before you decide.
- Your doctors and nurses will be also happy to answer any questions you may have.
- If you do decide to say 'Yes', you will be asked to sign a special form. Your mum or dad (or whoever looks after you) should also sign this form.

Here is some useful information for you, in case you have questions or worries later:

My Doctor is:

Telephone Number:

My Nurse is:

Telephone Number: