Bristol Biobank
Children’s Information sheet

Help us find out more about diseases

We are a group of special doctors and scientists who have a special interest in learning more about the way our body works. We work in the Children’s Hospital and the University.

We would like to tell you about how you could help these scientists and doctors.

Please read this booklet or ask the person who looks after you to read it with you. It will help you to understand what we are doing and to decide if you would like to join in and help us.
Why me?
We ask lots of children who are in hospital to help us. Some children we ask are having operations and some are feeling really poorly and have to stay overnight for medicines. Other children regularly come to see doctors and nurses in the hospital to talk about what is making them unwell.

What is it all about?
A Biobank is a place where we can store samples from people with different illnesses. ‘Samples’ are any bits from you such as blood, spit and wee.

These samples can help doctors and scientists find out more about our bodies and what happens when they go wrong. Lots of different doctors and scientists can use the samples so as they can all work together to learn about making people better.

With your help, we can try to find out better ways to help people when they are poorly.
What might we ask you for?

When you visit hospital, doctors and nurses might need to take samples from you. Once your doctors have used the samples, we would like any of them that are left over.

Sometimes we may also ask you for an extra sample that you only give to us, and not your doctors. We will discuss this with you and your parents.

This might be:

- Some spit from your mouth. We can get this by asking you to suck on a little sponge or spit in a pot.
• Some wee. We will ask you to pee in a pot. (We don’t need to watch but your mum or dad could help if it’s tricky.)

• Some snot. We will ask to tickle the inside of your nose with a thin stick a bit like a cotton bud. This is called a swab.

• An extra small bit of blood. We will get this with a really small needle in your vein. We will either use special numbing cream to stop this hurting, or we will do it while you are asleep, if you are having an operation.
Sometimes, children need to have an operation to fix things that are causing them problems, and there are bits left over that are normally put in the bin.

- If you are having an operation, we might ask to keep any bits of tissue that are taken from you while you are having your operation. We call ‘tissue’ any part of the body that comes from you.

Sometimes, we like to be able to look at differences in the stuff you give us on different days, for example before and after you have taken some medicine. This will help us to see how well the medicine worked.

You will be able to say whether you want to give us stuff on several different days, just once, or not at all.
What will you do with my samples?

If you say yes, we will keep these ‘leftovers’ for the “finding out” work we are doing. We have some clever scientists who work with us and they use the stuff you have given us to try to find out about different illnesses. Your samples might be used straight away, or they could be kept in a big freezer and be used later.

What are the good things about helping us?

Although taking left over samples, or taking some extra ones won’t help us to make you better, the things we find out may help us to make other children better in the future or to stop other children getting ill.

Are there any bad things?

There aren’t any really bad things. Most of the samples that we can collect have already been taken from you or are planned to be taken as part of an operation.

If you are saying “yes” to a swab in your nose then this tickles a bit (feels like a tickle before a sneeze!). If you say “yes” to an extra blood test, then we will offer you the ‘magic cream’ that takes some of the pain away.

You don’t have to say “yes” if you don’t want to.
What else do you want to know about me?

We want to keep your name and how old you are. We want to know why you are in hospital and what medicines you have been given to make you better. We may need to look at the notes we have about you at the Children’s Hospital to find some of this out.

Do I have to say yes?

No, you don’t have to. If you don’t say “yes”, you don’t need to say why and nobody will be upset or disappointed. If your mum or dad, or the person who looks after you does not want you to take part, that is OK too.

What do I do next?

If you have any worries or questions, you can talk to one of the doctors or nurses if you like. You can ask your mum or dad, or the person who looks after you about it as well. Then, along with them, you can decide if you want to say “yes” and let us use your stuff to do our “finding out” work or not.

Thank you for reading this booklet.