

# Storage and use of leftover (surplus) samples and associated information for research: information for young people aged 11-18

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At Great Ormond Street Hospital (GOSH), we are developing a large collection of patient samples (a sample resource) that will be used for research. During your treatment at GOSH, we may need to take samples of blood or tissue, which are used to confirm your diagnosis or monitor your condition. Normally we would either get rid of these samples once the tests have been completed, or they may be stored as part of your patient record. Instead, we would like to ask if you would consider donating these samples instead, so that they can be stored and used for future research.

This booklet explains about the sample resource and what to consider when thinking about whether to donate your samples or not. There is a consent form at the back for either you (if you are over 16) or your family (if you are under 16) to complete when you have decided. If you have any questions about this information or the consent form, please call us on 020 7905 2700 or email [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk)

## Sample storage for research

**When you come to Great Ormond Street Hospital (GOSH), we may need to take samples of your blood, urine (wee) and faeces (poo) to test. Also, if you have an operation, the doctors might take a bit of skin or tissue to test. This is a normal part of your everyday care and helps the doctors find out what is making you ill, or checks whether treatment is making you better. Usually, when all the tests have been done, we throw away whatever is left of your sample safely. We would like to ask if you would agree to let us keep your leftover (surplus) samples so that we can use them for research.**

Samples are very helpful to people doing research – they can show how an illness starts and develops. Researchers can also compare samples from someone with an illness with someone who does not have it. They can try different treatments on the sample to see how they work. They can use the samples to invent new ways of diagnosing a condition.

### What samples do we want?

We would like all sorts of samples to help with our research, such as:

- Blood
- Urine
- Faeces

- Skin
- Tissue (such as a skin sample or biopsy, or a sample removed during an operation, for example, an appendix).

**These are the type of samples we take as part of your everyday care – you would not need to give any extra ones and we would not ask you to give samples more often.**

### **How long will you store my leftover samples and where will you store them?**

If they are suitable, we plan to store your leftover samples until they are used. They will be stored in our laboratories at GOSH for the moment but in future we might have to move them to another store outside the hospital. The samples will be stored securely in locked rooms to which only staff who need to would have access to.

### **Will anyone know which ones are my samples?**

All the samples are labelled carefully with your hospital number, your name and date of birth. If we give samples to researchers, we will take off your name and any other information, so that the other researchers won't know that the sample is from you.

### **What other information would you need?**

It is more helpful if researchers can access information from a person's medical notes to go with the sample – for instance, knowing the person's diagnosis, treatment or progress. We will ask permission to access your notes for research purposes from you (or the person giving consent) when we ask about your surplus samples.

### **Would it only be GOSH doctors doing the research?**

While the samples would be stored by GOSH, we often work together with researchers from other hospitals and universities, not just in the UK but in other countries around the world. We would share the samples with these other researchers if they can prove that their research is worthwhile and safe. We will remove any information that would identify you – such as your name or date of birth. Any information from your medical notes would also have any identifying data removed from it.

### **What kind of research could they do?**

Samples could be used in any number of ways – here are a few examples:

- Looking at the cells in the sample to work out if there have been any genetic changes that could cause your condition.
- Using the sample in animal research to find new treatments – this type of research has to be licensed by the government and carried out under very strict rules.
- Working with other scientists to develop new medicines.
- Checking how the blood from someone with an illness compares with blood from someone else to see what differences are present.

Research methods are improving all the time, so in future completely new ways of carrying out research might be possible.

### Can I say what sort of research they do?

Unfortunately we cannot guarantee when your sample will be used or in which research projects, so it will not be possible for you to specify the type of research. Sometimes a sample might not be needed currently but may be kept in case it is needed in the future. All research carried out at GOSH is checked by an independent group of people to make sure that it is safe and ethical.

### Will it make any difference to me if I say yes?

We cannot guarantee that agreeing to donate your leftover sample will help you directly, but it may help children like you in the future.

### Do I have to say yes?

No – it is totally up to you (and your family) whether you decide to allow us to keep your leftover samples. Whatever you decide, you do not have to tell us why. It will not affect how we look after you at GOSH at all, now or in the future.

### Can I change my mind?

Yes – you can change your mind at any time, even if you (or your family) have signed the consent form. However, if you are under 16 and your family have signed the form, we will **not** routinely check with you when you are older to confirm that you are still happy for us to store and use your surplus samples.

If you change your mind and want to withdraw, you just have to tell us, you do not need to give a reason why. Just send an email to [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk) and we will destroy whatever surplus samples we are storing for research. However, if your samples have already been used for a particular research project, we will not be able to destroy them. It may also not be possible to withdraw consent in some instances, such as when the data from a study has already been used.

Also, if the samples are important for your everyday care, we will still use them for this purpose but not for research.

### **What happens next?**

Once you have read this information, talk it over with your family if you want before you decide. If you have any other questions, you can always call us on 020 7905 2700 or email [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk) – we will do our best to answer you as quickly as possible.

### **Will you tell me if my samples have been used?**

No – we will not be able to tell you if your samples have been used and in which project. More information about the research we carry out at GOSH is on our website at [www.gosh.nhs.uk/research-and-innovation](http://www.gosh.nhs.uk/research-and-innovation).

### **Patient Advice and Liaison Service (Pals)**

Pals is a free and confidential service which helps patients, parents and carers with any information, concerns, or problems that they have about their NHS care/service. You can contact the Pals staff by phone (020 7829 7862), email [pals@gosh.nhs.uk](mailto:pals@gosh.nhs.uk) or in person (the Pals office is located in the main hospital reception, on your left as you come through the entrance).

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Compiled by the Research and Innovation team in collaboration with the Child and Family Information Group