

# Storage and use of leftover (surplus) samples and associated information for research: information for families

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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 child's treatment at GOSH, we may need to take samples of blood or tissue, which are used to confirm their diagnosis or monitor their condition. Normally these samples may either be disposed of once the tests have been completed, or stored as part of their patient record. Instead, we would like to ask if your child 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 child's samples or not. There are different leaflets aimed at children of different ages, plus a consent form at the back for you 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 your child is having treatment at Great Ormond Street Hospital (GOSH), we may need to take samples as part of their everyday care. These samples, which may include blood, urine or tissue, are tested to confirm your child's diagnosis or monitor their treatment. Normally the samples may either be disposed of once the tests have been completed or stored as part of your child's patient record. Instead, we would like to ask you and your child to consider donating any leftover samples so we can store them and use them for research now and in the future.**

We carry out a great deal of research at GOSH and could make great use of these samples. Researchers could use them to discover why diseases start, how they differ from person to person and find out new forms of treatment.

The samples we are asking you to donate are ones taken as part of everyday care – **your child will not have to have larger samples taken or have samples taken more frequently** – it is only the leftover samples we would like.

Along with the samples, it would be helpful to access your child's medical notes to find more information about their condition, what treatment they have had so far and their progress. By looking at this information with the sample, our researchers get a full picture of your child's condition.

### How long will you store the samples and where will you store them?

If they are suitable, we intend to store the samples until they are used. The samples would be stored at GOSH initially, but may have to be moved offsite to a specialist storage facility in the future. Only authorised people would be able to access the samples, wherever they are stored.

### **General Data Protection Regulation (GDPR)**

As an NHS organisation, we use personally-identifiable information to conduct research to improve health, care and services. To enable individuals to better control their personal data, the General Data Protection Regulation (GDPR) came into force on 25<sup>th</sup> May 2018. More information on GDPR and research can be found on our website;

<https://www.gosh.nhs.uk/our-research/our-research-infrastructure/joint-rd-office/gdpr-and-research>

Great Ormond Street Hospital will manage this study based in the United Kingdom. We will be using information from your child's medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your child's information and using it properly. Great Ormond Street Hospital will keep identifiable information about your child for up to 30 years after any individual research study that is accessing the samples and associated data have finished.

Your rights to access, change or move your child's information are limited, as we need to manage your child's information in specific ways in order for the research to be reliable and accurate. If your child withdraws from the study, we will keep the information about your child that we have already obtained. To safeguard your child's rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk). Our Data Protection Officer is Anna Ferrant and you can contact her at [your.data@gosh.nhs.uk](mailto:your.data@gosh.nhs.uk)

### **Would the samples only be used for research at GOSH?**

While your child is a patient at GOSH, we work with doctors from other hospitals and universities, all over the UK and worldwide. We intend to share the samples with other researchers so long as they can prove that the research they are carrying out is ethical and safe and has been checked by an independent group of people to agree this. When we share the sample and your child's information, anything identifying them (such as their name and date of birth) will be removed. Researchers will not be able to trace the sample back to your child.

### **What kind of research will be done?**

Samples could be used in any number of ways – some examples include:

- Carrying out genetic testing on the samples to identify any faulty genes present that might contribute to a specific condition.
- Using the sample in animal research to carry out initial safety checks before moving onto clinical research with volunteer humans.
- Working with drug companies to develop new medicines.
- Comparing tissue and blood from someone with a condition to that from someone without it to identify the differences.

All around the world, new ways of carrying out research are being developed so it is possible that your child's samples could be used in a completely different way at some point in the future.

### Can I specify what sort of research is done with the samples?

Unfortunately we cannot guarantee what sort of research is carried out using your child's sample or in which projects so it will not be possible for you to specify the type of research. Sometimes a sample might not be needed at the moment but may be kept in case it is needed in future. All research carried out at GOSH is subject to strict rules and is checked by an independent group of people to make sure it is safe and ethical.

### Will the research help my child?

It is unlikely that your child will benefit directly from any research carried out on their samples, but it may help other children in the future.

### Do I have to say yes?

Depending on your child's age and maturity, they may be asked to decide whether or not to give permission for their leftover samples to be stored and used. If you think that your child is not old enough or is unable to make this decision, you can decide on their behalf. If you are at all unsure about your child's samples being used for research in the future, you should say no. Whatever you decide, we do not need to know your reasons and your decision will not affect your child's care at GOSH now or in the future.

### Can I change my mind?

Yes – you (or your child) can change your mind at any point, even after you have signed the consent form. Just send an email to [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk), you do not need to give us your reasons. If you have signed the consent form on behalf of your child, we will **not** routinely contact them when they are older to make sure that they are still happy for their samples to be stored and used.

When you have told us you have changed your mind, we will destroy any leftover samples still in storage and remove your child's information – however, we will not be able to destroy any samples that have already been used in research projects. It may also not be possible to withdraw consent in some instances, such as when samples have been pooled. Equally, if the samples are important for your child's everyday care, we will still continue to use them for this purpose but not for research.

### **What happens next?**

Depending on your child's age and their level of understanding, we would like you to read the relevant booklet or leaflet with them and talk to them about what they think. If you have any questions, you can call us on 020 7905 2700 or email [samplebank@gosh.nhs.uk](mailto:samplebank@gosh.nhs.uk) – we will try to answer as quickly as possible.

If you agree that your child's leftover samples can be stored and used, you should find the right consent form (depending on your child's age), fill it in as completely as you can and return it to us. As soon as your child's medical notes have been updated, we will start to store and use any leftover samples.

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

No it will not be possible to inform you when and how your child's samples have been used. If you want to find out more about research at GOSH in general, please visit our website at <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