

Information Leaflet

For the collection and storage of post-mortem tissue for research.

We are very sorry to hear that your child is dying or has recently died, and offer you our deepest condolences.

We understand that you may be considering donating a sample from your child's tumour for research. We would be grateful if you could take the time to read the following information and decide whether you would like to consent for small samples of your child's tissue to be stored in VIVO Biobank to help support research. This could help diagnosis and treatment of children with cancer in the future.

We do understand that this is a very difficult time for you and are very grateful to you for considering our request.

About VIVO Biobank

VIVO Biobank is the UK's only national biobank dedicated to cancer research in children and young people.

What are we asking you to consider?

We are asking you to give a sample of your child's tumour, bone marrow, blood or other tissue to be stored in the VIVO Biobank. Samples may be used in approved research in the future.



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What will happen if you say yes?

First of all, we will ask you to give your written consent by signing the biobank consent form for the sampling and storage of post-mortem tissue along with a hospital post-mortem consent form.

If your child does not require a full hospital post-mortem examination, you could still consent to a limited hospital post-mortem exam, to permit the pathologist to obtain a tumour sample. Please keep this information sheet to remind you of what you were asked to do.

What information is stored and used?

We ask that you allow the doctors and nurses who looked after your child to send information from their medical records to our secure database. This information will be used with the samples to perform research into childhood cancer.

The Biobank keeps the highest level of security. Scientists cannot find out your child's name or personal details.

Why do you need access to my child's personal details?

Your child's information may be used by the Biobank team to help retrieve additional NHS data related to their diagnosis and treatment. This may include:

- Electronic copies of your child's health records from the NHS, this may include their GP or from other organisations such as NHS England, Public Health Scotland and GIG Cymru/NHS Wales.
- Information about any illnesses or stays in hospital.
- Information about your child's DNA ("genome") held by organisations such as Genomics England and NHS England.

To do this we may share a very limited dataset including your child's date of birth and NHS number. This information is processed by a restricted number of staff, all of whom are trained in confidentiality procedures.

If you agree to take part, we will assign your child's sample and data a unique identifier. This will be used to anonymously link your child's information from their medical records and samples. This means no

personal data will be shared with researchers who will be unable to trace or identify your child from the information we share.

All information provided is confidential and kept in accordance with data protection regulations. More detail is given in our privacy statement available on our website.

What will happen if you say no?

You can say no – the choice is yours. Any samples left over after standard tests will be disposed of according to your wishes and arrangements with the hospital. They will not be used for research.

What happens if you change your mind?

You can change your mind about donating your child's samples at any time. You do not need to say why. Just let us know using the details at the end of this leaflet.

If you tell us that you have changed your mind, all samples in storage and all data held for research purposes will be sensitively disposed of.

If you change your mind after a long time the samples and data may already have been used for research. VIVO Biobank cannot recall samples or medical information from researchers once they have been used. We will arrange for the sensitive disposal of any samples left over from the research. Your child's samples and information will not be used in any further research.

The use of animals in scientific research

Researchers aim to improve our understanding and knowledge of childhood cancers. They use different methods to study childhood cancers which help increase our knowledge, improve outcomes and may develop new therapies to treat these diseases.

Studying cancer cells in test tubes has significant drawbacks because the cells are growing outside a living body. A more reliable method is to grow cancer cells in a living animal (usually a mouse). This approach mimics the way cancer cells divide and grow in people. It allows researchers to increase the number of cancer cells in a consistent and reliable way.

Research involving animals is always subject to rigorous ethical approvals and animals are only used if there's no other way to carry out the research.

Some people are happy for the tissue they donate to be used for research involving animals whilst others are not. This is the reason why the consent forms have the option to opt in or out of research involving animals. There is no right or wrong answer – the choice remains with you. VIVO biobank will respect your wishes and, if needed, will ensure samples are not released for specific projects.

Other things you should know

Your child's samples will be used only for medical research related to cancer and not for any other purpose. All requests for samples are carefully considered by a group of doctors and scientists to decide if the research is good quality and has ethical approval.

The samples and information you give will be made available to researchers who may be in the UK or overseas and therefore samples may be sent abroad for research. They may work in universities, hospitals or in private/commercial companies that do medical research. VIVO Biobank may ask researchers to pay towards some of its costs but your child's samples will never be sold for profit.

The samples may be used for genetic research (about diseases that relate to cancer that are passed on in families) but the results of this genetic research will NOT be sent to you or your child's medical team.

The results of studies which have used VIVO Biobank samples are likely to be published (including on the web) but your child's identity will never be revealed. You will not receive any payment for making a donation. If you have any questions or concerns about the samples and the bank, please ask the person from the medical team asking for your consent.

For more information, please contact us:

Email: enquiries@VIVOBiobank.org

Freephone: 0800 328 0655

Website: VIVOBiobank.org

