Parent / Guardian

Information Leaflet

Thank you for considering donating your child's samples to VIVO Biobank.

About VIVO Biobank

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

Samples from biobanks are very useful for scientists to study new ways to diagnose, treat and prevent cancer. VIVO Biobank is funded by Cancer Research UK and Blood Cancer UK.

VIVO Biobank is formed from a merger of two previous national biobanks, the CCLG Tissue Bank and the Childhood Leukaemia CellBank. If you previously consented to your child's samples being sent to either of these biobanks, these samples will now be part of the new VIVO biobank.

Funded by: CANCER RESEARCH UK for Children & Young People; Blood cancer UK

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 then be used in approved research studies in the future. These samples will be taken at the same time as samples taken for normal diagnosis or treatment purposes, no additional tests or procedures will be necessary.

It is important that you talk to your child about biobanking and, if they are old enough to understand, they too can give assent for their samples to be stored and used for research studies, although parental consent is also required if they are younger than 16.

Why has my child been invited?

All children and young people in the UK who are having tests for cancer are being asked if they would give some samples to VIVO Biobank.

What will happen if you say yes?

The first thing we will ask you to do is give your written consent by signing the biobank consent form. Please keep this information sheet to remind you of what you were asked to do.

During your child's treatment, they will have (or may already have had) samples taken for standard tests to help make a diagnosis and to monitor their disease during treatment. Any samples left over from these tests will, with your permission, be given to the VIVO Biobank.

With your permission, a small amount of extra sample may be taken at the same time to be stored in the biobank and used in medical research. This will not involve an additional procedure. The extra amount would be about a teaspoon sized amount of blood or bone marrow, and/or other tissues.

No extra tests will be carried out just for research, except occasionally a saliva sample if your child is not having blood taken for other reasons.

If you agree to give your child's samples, these will help research which could benefit future children with cancer. Samples donated by previous patients will have contributed towards your child's current treatment plan.

What information is stored and used?

We ask that you allow the doctors and nurses looking after your child to send information from your child's medical records to our secure database. Some of this information will be used by scientists along with the samples to undertake new research and all research requesting use of the samples will be subject to ethical approval. The Biobank stores all information in line with current data protection legislation. The 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, treatment and what happens next to your child in terms of their health in the long-term. This may include:

- Electronic copies of your child’s health records from the NHS; this may include from 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, NHS England and similar organisations

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 give your child a study number. 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 totally confidential and kept in accordance with data protection regulations - more information is given in our privacy statement, available on our website (see back page).

What will happen if you say no?

You can say no – the choice is yours. It will NOT affect the care your child will receive now or in the future. If you say no, any samples left over after standard tests will not be used for research by VIVO Biobank.

What happens if you change your mind?

You can change your mind about donating your child's samples at any time, just by letting us know. You do not need to say why and it will not affect your child's treatment. Our contact details are at the end of this leaflet. If you tell us that you have changed your mind, all samples in storage and all data held by VIVO Biobank for research purposes will be destroyed.

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

If your child is too young, you should let them know when they are old enough (aged 16+) so that they can withdraw their consent if they wish.

What are the benefits to your child?

Your child is unlikely to directly benefit from the research because it usually takes many years for research to produce new ways to diagnose, treat or prevent cancer. Samples donated by previous patients will have contributed towards your child's current treatment plan.

The research results will not be put in your child's health records, or shared directly with you or your child's medical team. However, their doctor would be notified by VIVO Biobank of any relevant findings.

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. An alternative and 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 patients. This method 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 whether to opt in or opt out remains with you. VIVO biobank will respect your wishes whatever the answer and, if needed, 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 research and has ethical approval.

The samples and information you and your child give will be made available to researchers who may be in the UK or overseas; therefore, samples may be sent abroad for research. They may work in universities, hospitals or in private/commercial companies that undertake medical research.

VIVO Biobank may ask researchers to pay towards some of its running costs, but your child's samples will never be sold for profit.

The samples may be used for genetic research but the results of this research will NOT be sent to you or your child's medical team except in extremely rare instances where it could have a direct clinical impact.

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 or your child will not receive any payment for making your donation.

If you have any questions or concerns about the samples and the bank, please talk to the person from the medical team who is asking for your consent

Thank you for reading this leaflet

For more information, please contact us:

Email: enquiries@VIVOBiobank.org

Freephone: 0800 3280655

Website: VIVOBiobank.org

If you want to receive updates and newsletters, please register for this on our website.

VIVO biobank

Funded by:

CANCER RESEARCH UK for Children & Young People

Blood cancer UK