

**16 and
over**

Information Leaflet

Thank you for considering donating your 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. A biobank is a collection of tissue samples and medical data donated for research.

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 samples being sent to either of these biobanks, they will now be part of VIVO Biobank.



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What are we inviting you to consider?

We are asking you to give a sample of your tumour, bone marrow, blood or other tissue, to be stored in the VIVO Biobank.

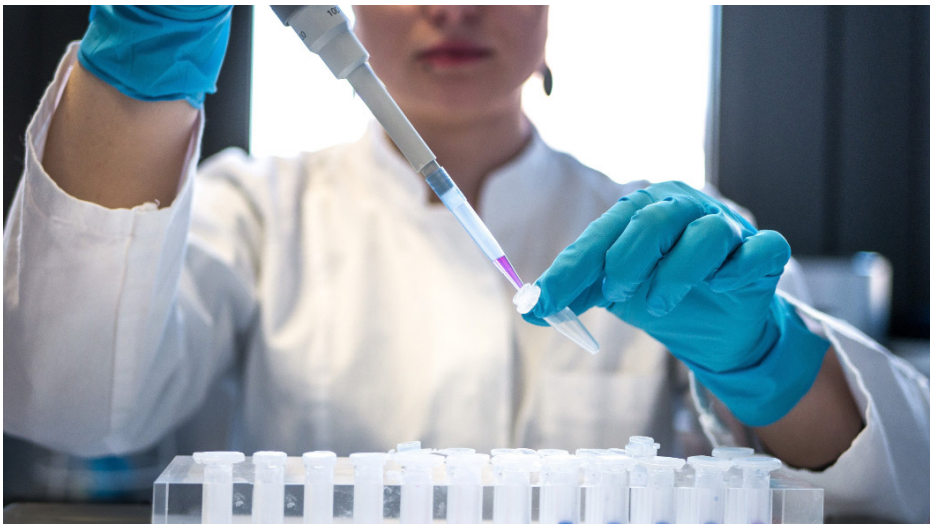
You will not need to have any extra procedures.

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.

If you agree to donate, your samples will help research which could improve the diagnosis treatments and outcomes for young people with cancer.

Why have I been invited?

All 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 treatment, you will have (or may already have had) samples taken for standard tests to help make a diagnosis and to monitor your 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 given to the Biobank and used in medical research. This will not involve an additional procedure. The extra amount would be about a teaspoon 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 you are not having blood taken for other reasons.

If you agree to give your samples, these will help research which could benefit future young people with cancer.

What information is stored and used?

We ask that you allow the doctors and nurses looking after you to send information from your medical records to our secure database. This information will be used with the samples to perform research into cancer and all research is subject to stringent ethical approvals.

The Biobank keeps this information in line with current data protection legislation. Scientists cannot find out your name or personal details.

Why do you need access to my personal details?

Your information may be used by the Biobank team to help retrieve additional NHS data related to your diagnosis, treatment and what happens next to you in terms of your health in the long-term. This may include:

- Electronic copies of your health records from the NHS, this may include from your 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 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 date of birth and NHS number. This information is shared with a restricted number of staff, all of whom are trained in confidentiality procedures. We will not use your name. We will anonymously link your information from your medical records and samples. This means no personal data will be shared with researchers who will be unable to trace or identify you 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 the website.

What will happen if I say no?

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

What happens if you change your mind?

You can change your mind about donating your samples at any time, just let us know. You do not need to say why and it will not affect your 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 samples and information will not be used in any further research.

What are the benefits to you?

You will not necessarily benefit from the research as 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 current treatment plan.

Research results will not be put in your health records, or shared with you or your medical team. However, your doctor would be notified by VIVO of any relevant findings.

The use of animals in scientific research

Researchers aim to improve our understanding of cancers. They use different methods to study 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. It allows researchers to increase the number of cancer cells in a consistent and reliable way.

Medical 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 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 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 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 through families) but the results of this genetic research will NOT be sent to you or your medical team.

The results of studies which have used VIVO Biobank samples may be published (including on the web) but your identity will never be revealed. You 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 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.



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