

**12-15
years**

Information Leaflet

Thank you for considering donating your samples to VIVO Biobank.

What is VIVO Biobank?

VIVO Biobank is the UK's only national collection of samples from children and young people with cancer.

Samples from patients are very useful for doctors and scientists who are studying why children and young people get cancer. It helps them to develop better treatments.



Funded by:



**CANCER
RESEARCH UK**
for Children &
Young People 



What are you asking me to consider?

As part of your diagnosis and treatment you will be having samples of tumour, blood, bone marrow or other tissues taken for tests. We are asking if we may take a little bit more when you have samples taken.

You will not need to have any extra procedures to do this.

The amount we are asking for is about the size of a teaspoon for blood or bone marrow or a few drops of spinal fluid or a small piece of your tumour. We are also asking if we may save any samples left over after the usual tests.

These samples will be sent to VIVO Biobank and given to scientists and doctors for research into cancer. DNA (genetic material) will be separated from the samples and stored for research only. The research may include genetic tests.

We are also asking you to allow the doctor or nurse looking after you to send some of your medical records, about your illness and treatment, to the VIVO Biobank database.

This information is really useful to researchers investigating cancer. However, we always make sure that they do not know your name or any of your personal details.

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.

Why do you want to take extra samples?

We want to take these extra samples for research. They may



help research scientists find out why children and young people get cancer and help improve the diagnosis and treatment.

Why do you need my medical details?

We need to know about your illness and any other treatment you may have had. This will help find out more about why children and young people get cancer.

This information will be stored safely in our secure database and kept confidential. Your samples will be given a number so that nobody will know the information is about you.

What will happen if I say yes?

The first thing that will happen is that you and your parents or carer will be asked to give written permission by signing the VIVO Biobank consent form.

Your samples will be sent to VIVO Biobank where they will be safely stored before being sent for research.

All researchers wanting to use your samples must ask permission from experts who check it is good research, which could help children with cancer in the future.

Research may be carried out at your hospital, at another hospital or University in this country or another country, or by private scientific companies.

There may be times when samples could be used in research involving animals (usually mice). This research would only be for the benefit of patients with cancer. You have the choice whether to allow your sample to be used in animal research or not.

What will happen if I say no?

It is up to you and your parents or carer whether you want to take part. It will not affect your treatment or the tests that you have – we will just not take the extra bit of sample and any samples left after your tests will not be used for research.

Why should I help?

We hope that the results of research using samples will help improve the diagnosis and treatment of children and young people with cancer in the future.

The research is unlikely to help you directly as research takes long time. It may help improve the diagnosis, treatments and outcomes of children and young people with cancer in the future. Your doctor would be told about any information that may affect your future treatment.

What happens if I change my mind?

You can change your mind at any time. Your parents or carer can just call or email us to let us know. Any samples you have given, that have not been used, will be destroyed.

What if I have questions?

If you have any questions you can ask the nurse or doctor who asks you to sign the consent form, or look at the VIVO Biobank website. You can also email or phone us, see below.

For more information, please contact us:

Email: enquiries@VIVOBiobank.org

Freephone: 0800 328 0655

Website: VIVOBiobank.org

