



# Biological Studies and Tumour Banking

FREQUENTLY ASKED QUESTIONS FOR PARENTS AND YOUNG ADULTS

*“What is it all about  
and how can we help?”*



# FREQUENTLY ASKED QUESTIONS

## Why are biological studies important?

Great advances have been made in the treatment of children with cancer over the last 30 to 40 years. Much of this progress has been due to improvements in diagnosis and the use of chemotherapy. Advances in science are giving us a better understanding of how cancer cells behave. But we still need to understand why cancers happen in children, to identify the differences in those who respond to treatment and discover why treatment sometimes fails. We hope to improve cure rates and develop treatments with fewer side effects.

Scientists and doctors now believe that the next major advances will come from a better understanding of the biology of different cancers. The results of this research will allow future treatment to be 'tailored' to the individual cancer. This could mean more effective treatment and fewer side effects.

## Why is it important to have a tumour bank?

We need to have tumour samples for biological studies to take place. As cancer is a rare disease in children, each sample is important. No single hospital would have enough samples to carry out meaningful research, and so a bank of samples is needed. It takes many years to build up a collection of stored tumour samples and researchers need to have ready access to

as many as possible from children treated in the past.

## What and where is the tumour bank?

The tumour bank was set up in 1998. It is a nationally registered collection of blood and tissue samples from children with cancer and leukaemia. It is securely stored in the pathology department of your hospital.

## Who owns the samples?

The Children's Cancer and Leukaemia Group (CCLG) is custodian of the samples, but you retain all of your rights over the sample.

## Who is asked to take part?

All children and young adults with cancer and leukaemia should be invited to take part in contributing to the tumour bank. If you haven't been asked about taking part, you can contact your Consultant or Research Nurse.

## What procedures are needed for tumour banking?

No additional procedures are needed. Tissue containing tumour is collected at the time of diagnosis, and sometimes for routine investigations as treatment progresses. If any of this tissue is not needed for diagnosis or tests, it can go into the tumour bank, if you give your consent.



## What kind of samples are stored?

Samples of blood, tumour, bone marrow, urine, pleural fluid or cerebrospinal fluid can be stored in the tumour bank.

## How big are the samples?

Most solid tumour samples are smaller than a sugar lump. For leukaemias, just 1 to 2 teaspoons of blood or bone marrow.

## How are the samples kept?

Leukaemia, bone marrow and blood cells are either frozen or spread thinly on a glass microscope slide and dried. For solid tumours, a small sample of the tumour is either frozen or 'fixed' in a wax block. This is so that thin sections can be cut and put on a microscope slide.

## Can anyone use the material in the bank?

No, samples are only released to researchers after approval by scientific and medical experts and an ethics committee.

## Can researchers tell who the sample is from?

No, the identity of every sample in the bank is kept completely confidential.

## Who will benefit?

The results may not be of immediate direct benefit to you or your child. However, most of the treatments used today are based on the results of previous research on tumour samples. Contributing to the bank is an important thing you could do to help other children in the future. Research using samples from the tumour bank will help us to improve cure rates further and learn how to prevent cancer and leukaemia in the future.

## What if I agree at first and then change my mind?

You can ask for the samples to be removed from the bank at any time so that the samples can't be used in research. You don't have to give a reason, and your decision will not affect the care or treatment available to you.

## How long are the samples kept?

Samples are kept indefinitely and available for research unless you or your parents request for them to be destroyed.



**Thank you for taking the time to read about  
tumour banking and how you can help.**

**You do have a choice – if you say no,  
your doctor won't mind.**

**If you have any more questions,  
we would be happy to talk with you.**

## **YOU CAN CONTACT US ON:**

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**CCLG leaflets are available to download  
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