



yorkshire &
humberside
haematology
network

Information Leaflet

You are being invited to take part in a research study. Please take time to read this leaflet carefully and to discuss it with other people if you wish. The information in this leaflet is written simply as it is for children of all ages. Please contact us if there is anything that is not clear, or if you would like more information - our contact details are on the back page.

What is research?

Research means finding out more about something.

What is this research about?

We want to collect more information about why children develop certain blood diseases. This will help us find out more about these illnesses and the best treatments to use.

Why have you been chosen?

Every year some children are told they have a blood disease like leukaemia, lymphoma or a similar illness. We hope that most of these children will take part in our study.

What do you have to do?

We would like you to give us permission to do three things:

1. Look at your doctors' notes to get more information.

2. Look at any blood that is left over from the tests you have when you come to the hospital.

3. Ask you to answer some questions which we will send in the post. A grown-up can help you with this.

We will never need to meet or speak to you to do this research.

Why do we need to look at your blood?

We need to look at your blood to help find out why children get these illnesses and to improve treatment.

We will keep your blood samples for research that we may want to do in the future. We may do this research with other people, but we will not tell them who you are.

Who will look after your blood samples?

Doctors and nurses at St James's Hospital in Leeds will look after your samples. All other information will be kept at the University of York.

Why do we need to look at your doctors' notes?

We need to know about any illnesses and treatment you may have had. We hope that this will help us find out about why children get blood diseases. We may use information from your doctors' notes to check how your health is in the future.

Will the information be kept private?

All information that is collected about you during the study will be kept confidential (private).

Why should you help?

Taking part in the research may help other children with the same illness in future.

Do you have to take part?

No, it is up to you to decide if you want to take part or not. You can change your mind and stop taking part at any time. Any information you have given or blood samples we have saved will then be destroyed.

What should you do now?

If you want to help with this research then you and your parent or guardian can sign the consent form and send it back to us in the freepost envelope. Or, to consent **online** at **portal.yhnn.org**, please follow the information given in your letter.

If you don't want to take part in the research, you don't need to do anything.

Standard NHS indemnity arrangements apply to this research.

Contact us

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