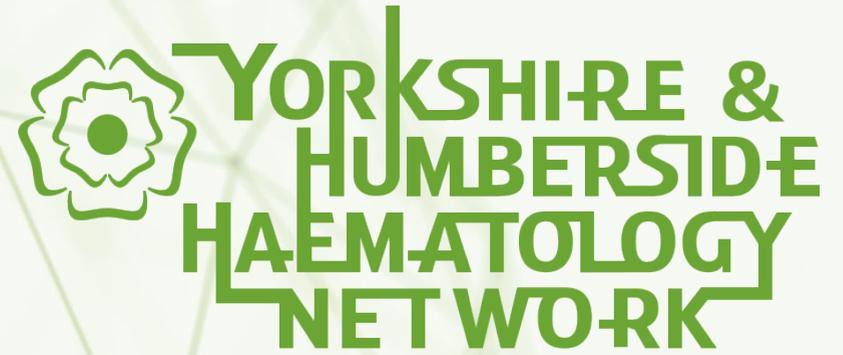
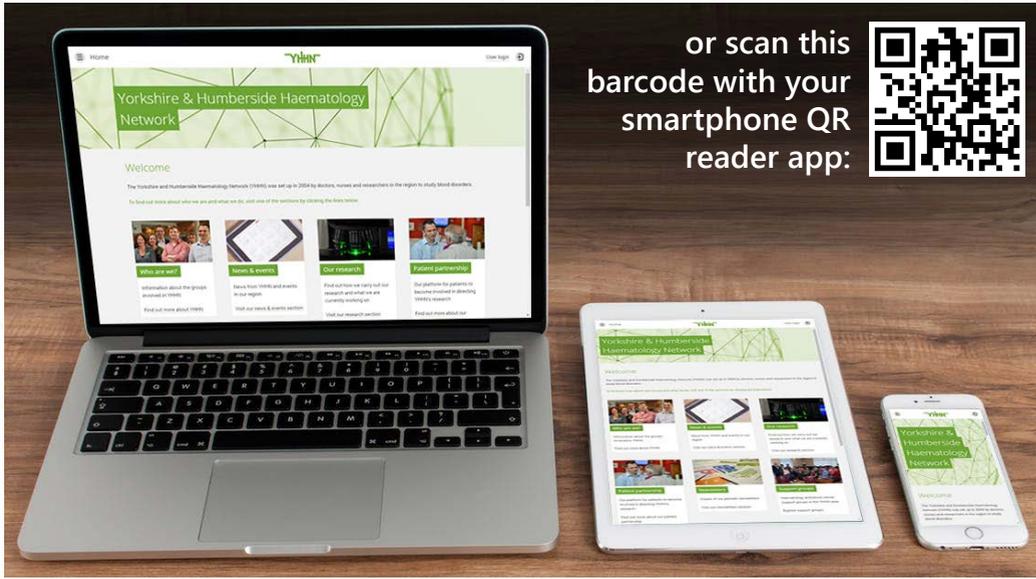


find us online at [www.YHHN.org](http://www.YHHN.org)

or scan this  
barcode with your  
smartphone QR  
reader app:



## Parent information leaflet

### Contact Us



Freephone: 0800 328 0655



Email: [enquiries@yhhn.org](mailto:enquiries@yhhn.org)



Website: [www.yhhn.org](http://www.yhhn.org)





Your child is 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.

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 the purpose of the study?

Little is known about why some people develop certain blood disorders and why people respond differently to treatment. By collecting as much information as we can from people who develop blood disorders, we hope to find out more about why these diseases occur and what determines response to treatment. This information may also help to improve the organisation of clinical services in the region.

### Who is doing the study?

The study is being organised by the Haematological Malignancy Research Network (Yorkshire & Humberside Haematology Network) - which includes the doctors and nurses responsible for your child's care - and researchers at the University of York. The study is funded by Bloodwise (formerly Leukaemia & Lymphoma Research), registered charity number 216032.

### Does my child have to take part?

It's up to you whether you would like your child to take part or not. If you decide to take part, you can withdraw your child at any time and do not have to give a reason. Your decision will not affect the standard of care your child receives or the relationship with your child's doctor.

### What should I do now?

If you would like your child to take part, please read and sign the consent form and return it in the envelope provided. If you are willing to complete a short questionnaire, please tick the box on the accompanying letter and return the slip to us with your consent form. Please ensure your correct contact details are entered on this slip. If you feel your child is unable to participate then no further action is needed.

### What studies will be done in the future?

The Yorkshire & Humberside Haematology Network is a long term research project, and with your permission we would like to use your samples and information to undertake further studies in the future. All these projects will be approved by an ethics committee. Details about these studies can be obtained by contacting us, via our newsletter or alternatively on our website [www.yhnn.org](http://www.yhnn.org).

### What if we change our mind?

You can change your mind and withdraw from the studies at any time without giving a reason. If you wish to do this, please contact us. Any information you have supplied and any samples your child has given will be destroyed. Whatever your decision, it will not affect the standard of care your child receives.

### Why do you need access to my child's health records?

We need to know about any illnesses your child may have had in the past, and any medicines and treatments they may have been prescribed. By examining the medical history of people with blood disorders, we hope to find out more about why and how these diseases develop and chart your child's response to treatment. We do this by looking at your child's medical records and by linking to computer-based records.

Identifiable information about your child may be shared with NHS Digital, including their NHS number, surname, forename, sex, date of birth and study specific identifier. This is so that NHS Digital can send us information about any hospital admissions your child may have, by linking to Hospital Episode Statistics. NHS Digital may also send us information about patient deaths and other cancers, if appropriate.

### Will the information be kept confidential?

This Network has received approval from your local research ethics committee. The members of this committee include doctors, health professionals and lay people. Any future research using information from the Registry will require further ethical approval from the committee.

All information about your child is totally confidential and kept in accordance with the Data Protection Act. Information is processed by a restricted number of staff working on the study, all of whom have been trained in confidentiality procedures.

If you agree for your child to take part, we will give them a code number. This will be used to anonymously link information from your child's questionnaire, medical records and samples. This means no one will be able to trace or identify your child from the data. Your child's samples and information will only be used for research into the causes and treatment of blood disorders.

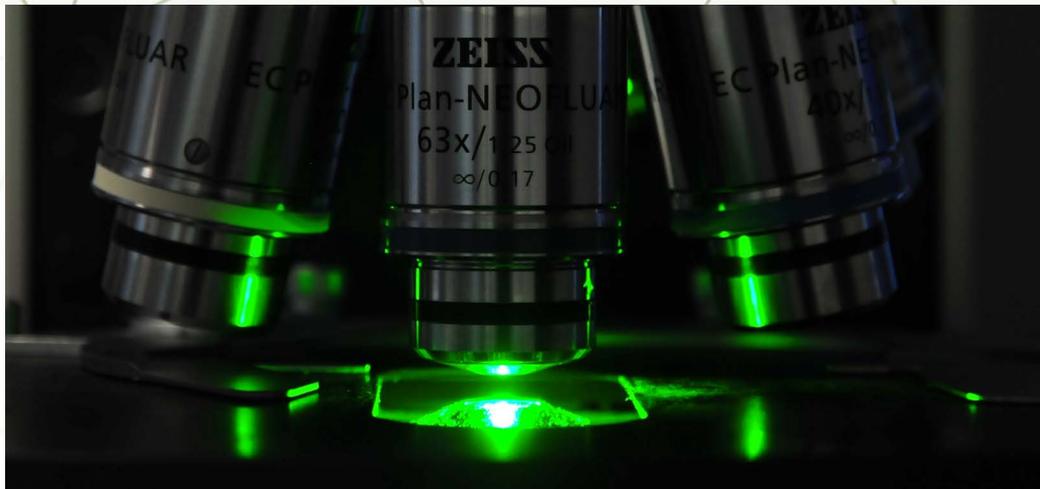
### Why was my child chosen?

In the Yorkshire & Humberside region, about 2000 people are diagnosed with a blood disorder each year. We hope that most of these people will take part in our study, which started in 2004 and will run until 2019.

### Why should we help?

Although there is no direct benefit to your child, by taking part in our study, your child could help others. Information collected from your child and other patients could lead to a greater understanding of the causes of these blood disorders and to better treatments in the future. In order for our results to be meaningful, it is very important that as many people take part in the study as possible.





### What does the study involve?

If you decide that you would like your child to take part, you should read and sign the consent form. One copy is for you to keep. With your permission, we would like to do three things:

1. Use your child's blood and tissue samples **left over from** diagnostic tests routinely carried out. These samples will be used for research purposes within ethically approved studies.
2. Look at your child's paper and computerised medical records. A research nurse will record relevant information from notes held by their hospital, local GP surgery and community nurses.
3. Send you a questionnaire which will ask about your child's background, current illness and quality of life.

On the consent form, you can give your permission for whatever parts of the study you would like to assist with. If there is any part of the study you would not like to be involved in, your wishes will be respected.

In the meantime, if you have any queries, you can contact us using the freephone number on the back page of this leaflet.

### Why do you need my child's blood and tissue samples?

These samples will allow cells and DNA to be stored and used for future research into the causes and treatment of blood disorders. Your child's samples and information may also help in the development of new treatments; this type of research may be carried out in collaboration with our academic research partners or the pharmaceutical industry. Any material shared with a commercial organisation will have all information that could identify your child removed.



### Who is responsible for the samples?

The samples will be used for research and teaching purposes only. Blood and tissue samples will be stored by the Haematological Malignancy Diagnostic Service (HMDS) at St James's Hospital, Leeds. Information relating to your sample will be stored by the Bloodwise Epidemiology Unit at the University of York.

### Will we be given any results?

Neither you nor your child's doctor will be told the results, nor will the results guide treatment decisions. If your child is asked by an insurance company if they have had any genetic tests, you can answer no because their samples will not be used for this.