



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 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 (such as leukaemias, lymphomas, myeloma and related conditions) and why people respond differently to treatment.

By collecting as much information as we can from people who develop these conditions, we hope to find out more about why they occur and what determines response to treatment. This information may also help improve the organisation of clinical services in the region.

Who is doing the study?

The Yorkshire & Humberside Haematology Network (YHHN) includes the doctors and nurses responsible for your care and researchers at the University of York.

The University of York is also the sponsor and data controller for the study alongside Hull University Teaching Hospitals NHS Trust - more information about this is given in our privacy statement, available at yhbn.org/info/data. You can also contact us for a copy to be sent to you.

The study is funded by Cancer Research UK (registered charity number 1089464) and Blood Cancer UK (registered charity number 216032).

Why was I chosen?

In the Yorkshire and Humberside region, about 2500 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 to 2029.

Why should I help?

By taking part in our study you could help other patients, although there is no direct benefit to you. Information collected from you and other patients could lead to a greater understanding of the causes of 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 as possible take part.

The Yorkshire & Humberside Haematology Network (YHHN)



What does the study involve?

If you decide to take part, with your permission, we would like to do three things:

1. Look at your paper and computerised medical records. A research nurse will record relevant information from notes held by your hospital and GP surgery.
2. Use blood and tissue samples left over from diagnostic tests routinely carried out. These samples will be used for research purposes within ethically approved studies.
3. Ask you to complete a questionnaire about your background, current illness and quality of life. You will be able to do this by **post** (on paper) or **online** at **portal.yhhn.org**

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 you would not like to be involved in, your wishes will be respected.

If you consent by post (on paper) one copy is for you to keep. If you consent online, you will also have the option to register an email address to take part in the study online.

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 access to my health records?

We need to know about illnesses you may have had in the past, and medicines and treatments you have been prescribed. We do this by looking at your medical notes and by linking to local and national computer-based records.

Identifiable information about you may be shared with NHS England (digital.nhs.uk), including your NHS number, surname, forename, sex, date of birth and study specific identifier. This is so that NHS England can send us information about any illnesses and stays in hospitals you may have, by linking to Hospital Episode Statistics. NHS England may also send us information about your health in the long-term and other cancers, if appropriate.

Why do you need my blood and tissue samples?

These samples contain cells and DNA that can be stored and used for future research into the causes and treatment of blood disorders.

Who is responsible for the samples?

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

What research might my samples and information be used for?

Your samples and information may also help in the development and approval of new treatments; this type of research may be carried out in collaboration with our academic research partners and /or the pharmaceutical industry. Any material shared with our partners will not contain any information that could identify you.

Will I be given any results?

Neither you nor your doctor will be told the results, nor will the results guide treatment decisions.

If you are asked by an insurance company if you have had any genetic tests, you can answer no because your samples will not be used for this purpose.

Will the information be kept confidential?

YHHN has been approved by your local research ethics committee. The members of this committee include doctors, health professionals and lay people. Any future research using YHHN information will require further ethical approval from the committee.

All information you provide is totally confidential and kept in accordance with data protection regulations - more information is given in our privacy statement, available at yhhn.org/info/data. Information is processed by a restricted number of staff, all of whom have been trained in confidentiality procedures.

If you agree to take part, we will give you a study number.

This will be used to anonymously link information from your questionnaire, medical records and samples. This means no one will be able to trace or identify you from the information we hold.

What studies will be done in the future?

YHHN is a long term research project, and with your permission we would like to use your samples and information to undertake studies in the future. All these projects will be approved by an ethics committee. Details about these studies can be obtained via our newsletter or on our website yhhn.org. You can also contact us using our Freephone number or email address on the back page.

Do I have to take part and can I change my mind?

It's up to you whether you take part or not - your decision will not affect the standard of care you receive or the relationship with your medical team.

You can change your mind and withdraw from the studies at any time without giving a reason and any information you have given us will be destroyed.

If you wish to withdraw, all you need to do is contact us via our Freephone number or email address - you can find these on the back page.

What should I do now?

If you would like to take part, please complete the consent form and return it in the envelope provided. Or to consent online at portal.yhhn.org, please follow the information given in your letter.

If you feel unable to participate then no further action is needed.

Standard NHS indemnity arrangements apply to this research.

Contact us

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Scan the QR code
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yhhn.org

For newsletters, our
latest research, and
more.

