

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 you provide 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 to take part, we will give you a code number. This will be used to anonymously link information from your questionnaire, medical records and your samples. This means no one will be able to trace or identify you from the data. Your samples and information will only be used for research into the causes and treatment of blood disorders and will not be passed on to anyone else.

Do I have to take part?

It's up to you whether you take part or not. If you decide to take part, you can withdraw at any time and do not have to give a reason.

Your decision will not affect the standard of care you receive or your relationship with your doctor.

What should I do now?

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

What studies will be done in the future?

The Yorkshire & Humber Network 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 by contacting us, via our newsletter or alternatively on our website www.HMRN.org.

What if I change my 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 free on 0800 3280655. Any information you have supplied and any samples you have given will be destroyed. Whatever your decision, it will not affect the standard of care you receive.

Standard NHS indemnity arrangements apply to this research.

For more information, please call the freephone number, visit our website or email at the address below:

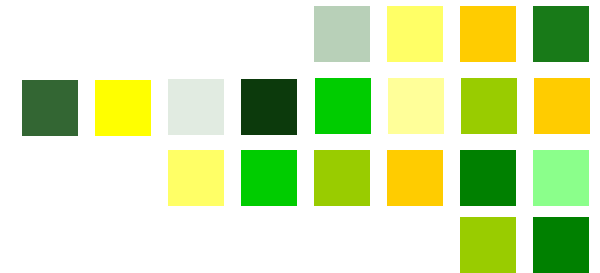
Freephone: 0800 3280655

Website: www.HMRN.org

Email: HMRN@egu.york.ac.uk



Yorkshire & Humber side Haematology Network



An investigation of
blood disorders
in the Yorkshire
& Humber
side area.

**Patient Information
Leaflet**



You are being invited to take part in a research study. Please take the 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 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 care - and researchers at the University of York. The study is funded by the Leukaemia Research Fund, registered charity number 216032.

Why was I 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 will run from 2004 to 2014.

Why should I help?

Although there is no direct benefit to you, by taking part in our study, you could help others. Information collected from yourself and others 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 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 blood and tissue samples **left over from tests routinely carried out when your condition was first diagnosed.** These samples will be used for research purposes only within an ethically approved study.
2. Look at your medical records. This will involve a research nurse recording relevant information from your hospital notes and from the notes held by your local GP surgery and community nurses.
3. Send you a questionnaire which will ask about your background and current illness.

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 of this leaflet.

Why do you need my 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. We will use the samples to make comparisons between people with different types of blood disorders and those who do not have these conditions. Your samples and information may also help in the development of new treatments. This type of research may be carried out in collaboration with the pharmaceutical industry. Any material shared with a commercial organisation will have all information that could identify you 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 Leukaemia Research Fund Epidemiology Unit at the University of York

Will I be given any results?

Neither you or your doctor will be told the results nor will the results guide treatment decisions. The samples will not be used for 'genetic tests', so if you are asked by an insurance company if you have had any genetic tests, you can answer no.

Why do you need access to my medical records?

We need to know about any illnesses you may have had in the past, and any medicines and treatments you 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 response to treatment. Information held by the NHS and records maintained by The NHS Information Centre may be used to keep in touch with you and follow up your health status.