Standard NHS indemnity arrangements apply to this research

find us online at:

YORKSHIRE & HUMBERSIDE HAEMATOLOGY NETWORK

www.yhhn.org

or scan this barcode with your smartphone QR reader app:

Contact Us

☎ Freephone: 0800 328 0655

✉ Email: enquiries@yhhn.org

Website: www.yhhn.org

NHS
National Institute for Health Research

UNIVERSITY of York

Bloodwise
Beating blood cancer since 1960

YORKSHIRE & HUMBERSIDE HAEMATOLOGY NETWORK

ipi improving patient information

Facilitating informed decision making in haemato-oncology

IRAS ID: 200556

Information Leaflet: Questionnaires

V2, May 2016

Why should I help?

The information collected will help us to understand more about people with blood disorders and the care they receive. It will help us to improve the information available, so patients are more able to make treatment choices that are right for them. It will also help us to understand if patients benefit from any changes in their care that occur as a result of the study.

What does the study involve?

The study involves filling in a questionnaire about your health on the day of your appointment, and answering questions about any treatment decisions that were made. If you wish, someone else can help you to complete the form. In the meantime, if you need any further information to help you decide whether to take part, please ask the person who gave you this form, or you can contact the study team using the details on the back page of this leaflet.

Will I be given any results?

All our study results are published in medical journals after the study is finished. They are also shown on our websites (www.yhhn.org and www.hmrn.org) and in newsletters, which are sent to patients in the study area, if they have agreed that they would like to receive this information.

Will the information be kept confidential?

Yes, any information you provide is totally confidential. If you agree to take part in the study, we will use a code number to identify you and any information you give to us. This means that no-one will be able to trace or identify you. Your details will not be passed on to anyone else.

The study has approval from a Research Ethics Committee (IRAS ID: 200556), which includes doctors, nurses, other health professionals and lay people. Any information you provide is kept in accordance with the Data Protection Act. Information is processed by dedicated staff working on the study, all of whom have been trained in confidentiality procedures.

The information you provide will be used by researchers during the course of the study and will be retained indefinitely after this. It should be noted that we may have to inform relevant professional authorities in the unlikely event you tell us that you, or anyone else, is at risk of harm.

Do I have to take part?

It is 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, or your family receive, or your relationship with the doctors and nurses caring for you.

If you lose the capacity to provide consent to take part you will be automatically withdrawn from the study. Any identifiable data you have provided would be retained and used.

What should I do now?

If you would like to take part in the study please complete the questionnaires and the consent form that are in the pack you have been given. You can do this today, and return the forms to us in the box in the clinic waiting room. If you would like more time to think about whether you would like to take part, or would like to discuss it with other people who are not with you today, please take the questionnaires with you to complete later. You can then return the questionnaires to us using the Freepost envelope in your pack.

What if I change my mind?

You can change your mind and withdraw from the study without giving a reason. If you wish to do this, please contact us on our Freephone number. Any information you have given will be destroyed. Whatever your decision, it will not affect the standard of care you and your family receive.

What if I have any queries or complaints?

You can contact us about this study using our Freephone number or email address on the back of this booklet.

If you have any other queries or complaints, the Patient Advice and Liaison Service (PALS) offers confidential advice, support and information. You can find your nearest PALS office on the NHS Choices website; and you can also ask your GP surgery, hospital or phone NHS 111 for details.

ipi
improving
patient
information

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, including the person who gave you the study pack. Please contact the study team if there is anything that is not clear, or if you would like more information. Our contact details are on the back page of this booklet.

What is the purpose of the study?

The purpose of this study is to improve the information that is available to help people with blood disorders make treatment choices. To do this we need to understand more about the health and wellbeing of patients with these diseases, and how treatment choices are made.

Who is doing the study?

The study is being organised by the Yorkshire and Humberside Haematology Network (YHHN) (also known as the Haematological Malignancy Research Network – HMRN), which includes the doctors and nurses responsible for your care and researchers at the University of York. YHHN is funded by Bloodwise (formerly Leukaemia and Lymphoma Research, registered charity number 216032) and this particular study is funded by the National Institute for Health Research.

Why was I chosen?

In the study area, over 2000 people are diagnosed with a blood disorder each year. We are inviting as many patients as possible to fill in questionnaires for us, so that we can find out as much as we can about how they are feeling and how we can improve the care they receive.