yorkshire & humberside
haematology network

NEWSLETTER ISSUE 4

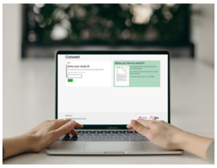
PATIENT EXPERIENCE

Researching the experiences and needs of patients with chronic blood cancers

IN THIS ISSUE

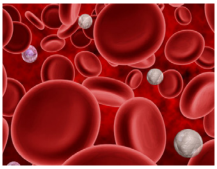
PATIENT EXPERIENCE

The experiences and needs of patients with chronic blood cancers



PATIENT PORTAL

Information on our upcoming online patient portal



CENTRE FOR BLOOD RESEARCH

Information on the University of York's new research centre

PUBLICATIONS UPDATE

Selected papers we have published since our last newsletter

WELCOME

to the fourth issue of the Yorkshire and Humberside Haematology Network (YHHN) Newsletter.

As you may know, there are many different types of blood cancer and these diseases can occur at any age, from birth through to old age. They are much more common than many people think, with over 41,000 people newly diagnosed each year in the UK.

With the aim of improving care for patients and families, researchers at the University of York, together with NHS colleagues, started a study in 2004 that included all people newly diagnosed with a blood cancer in our region. This study is called the Haematological Malignancy Research Network (www.hmrn.org); and it provides information for patients via the Yorkshire and Humberside Haematology Network website (www.yhhn.org). With funding from Cancer Research UK (CRUK) and Blood Cancer UK (BCUK), this is the only study of its kind in the world.

Since our research began, around 45,000 patients have been diagnosed with a blood cancer in the 14 hospitals in the study area. We are looking at what happens to these people over time, how their disease is managed and responds to treatment, as well as the longer-term health impacts of their condition. Part of our research involves asking about events leading up to diagnosis, and what it's like to live with these illnesses on a day to day basis.

As a result of our work, we can now provide accurate, up to date information about the number of people with blood cancer, and how treatments affect patients differently. We also know that sometimes it is difficult to get a diagnosis, and that new physical and mental health problems can occur, for example during 'Watch and Wait', or when having certain therapies.

An important part of our research involves informing people about our findings. This Newsletter describes some of our recent work on the experiences of patients with chronic blood cancers. It also provides an update on recent events and explains our new 'Patient Portal', as well as listing some recently published papers.

We very much hope you find this Newsletter interesting and would welcome any feedback you might have, which can be provided via the contact details given on the back page.

Best wishes,
The YHHN Team

PATIENT EXPERIENCE

OF CHRONIC BLOOD CANCERS

Why did we do this study?

There are many different chronic blood cancers and patients with these diseases often experience periods of 'Watch & Wait' (also known as observation, or monitoring), with treatment starting 'if' and 'when' the cancer progresses. We set up a study to explore what it is like to live with a chronic blood cancer, and how this might be improved.

What did we do?

This work was funded by the National Institute for Health and Care Research (NIHR) and had two parts. First, we interviewed patients with chronic blood cancer, sometimes with relatives, about their experiences. We looked carefully at what people said to find patterns (similarities/ differences), and how these changed over time and between people. Second, we asked people to fill in surveys about their health and wellbeing, and again looking for patterns in what people said.

What did we find?

This Newsletter shares a number of the common issues mentioned by patients, and further details can be found on our websites: (**www.york.ac.uk/healthsciences/research/ecsg/patients/** and **www.hmrn.org/publications**). By far the greatest concern was uncertainty about the future effect of the chronic blood cancer, with many people noting their information needs and views on what was good, and what could have been better (see below, with interviewee quotes given in bold).

Uncertainty and worry

People often remembered being told at diagnosis that their chronic blood cancer was: '**incurable…**' and '**hard to get rid of**', which typically led to '**shock**', especially as some people were diagnosed '**out of the blue**' after routine tests or '**didn't even know the word**' for their cancer. Other phrases recalled were '**slow growing**', '**very treatable**', '**not life-threatening**' and '**this can take months, decades to develop; go and live your life**', which were seen as '**positive**' and '**a big ray of hope**'.

Many patients were managed on Watch & Wait at first, but had expected to have treatment soon after diagnosis, as they believed this was really important for people with cancer. One said '**it's hard to understand, you have something really frightening, yet nothing happens**'. This was especially difficult for people with chronic lymphocytic leukaemia, who heard the word '**leukaemia**' and were sure they would need treatment, so didn't know why '**nothing was getting done**' until things were worse.

A lot of patients on Watch & Wait said they worried about '**if**' and '**when**' treatment might be needed. Some were told '**nothing might happen during your lifetime**'; or ‘**sometime or other, chemo will have to come in**’. After treatment, others were told ‘**you cannot predict what’s going to happen, it may never ever come back. It may come back tomorrow. It’s completely uncertain**’; or ‘**it could come back 5 or 10 years down the line, it’s a raffle, you could be lucky, or it could come back**’.

Such uncertainty had a big impact on many people, greatly affecting their lives and ability to plan for the future. Some were preoccupied, overwhelmed and distressed, which was confirmed by the questionnaire, which found high levels of anxiety and depression. One patient described it as being like ‘**Russian Roulette…a gun against my head**’. Others talked about ‘**fear of not knowing what’s going on**’ and ‘**an awful time for me**’, and said ‘**it’s just horrible being in this position**’.

Some on Watch & Wait were reassured to know their blood cancer was chronic, especially if they had been told their lifespan could be ‘**same as anybody else’s**’ and they wouldn’t need treatment at diagnosis, if ever. This group often chose not to think further about their diagnosis, largely as a way of coping and reducing worry, at least until their situation changed.

Having no visible signs of cancer, and not having treatment, made it hard to tell family and others about the diagnosis (‘**I don’t publicise it**’), mainly as they didn’t think people would understand why they weren’t being treated. Others said they didn’t understand their cancer themselves, so couldn’t explain it to others: ‘**we’ve got a son and daughter, we’ve never told them because really, we don’t know what we’re talking about**’. This meant that the support such people could have given was not available, because they did not know about the diagnosis.

Patients often saw that it was genuinely impossible for medical staff to tell them exactly what might happen in the future, because it was difficult to predict: ‘**there aren’t any answers, you’ve just got to wait and see**’; ‘**there are a lot of questions that people just don’t know the answers to**’.

Information needs

Views on information differed greatly. In terms of reducing uncertainty, some described learning more about their cancer as ‘**trying to arm ourselves with information**’, and said ‘**as much information as possible is a good thing, it’s about you and it’s important that you know’**. This group generally wanted to know as much as possible about their diagnosis, often in great detail: ‘**the first thing I did when I was told it was probably lymphoma, was go and find out as much as I could’**.

Others preferred to know only a little: ‘**I didn’t want to know for some reason**’, as a way of ‘**shutting things out**’, as ‘**ignorance is bliss**’, and as a ‘**coping mechanism**’. Such patients often relied on medical experts: ‘**I put**

my absolute trust in doctors'; or family, with one relative saying she read information for her husband, who was not '**desperate**' to see it. Needs varied within families, and some relatives wanted information for themselves, for example, about sources of support.

Patients said the information received from medical staff was generally very good. Sometimes it was felt to have been given too early, when patients were still in '**shock**' and '**so emotional**' they couldn't absorb what they had been told, or process it: '**I can't read any of this stuff**', '**I could hardly bear to look at it really**'. Sometimes patients said '**technical jargon**' was used that they couldn't follow; yet others liked to see complex graphs of their test results and data relating to them as individuals.

Information needs varied over time. One patient said that at diagnosis: '**you want to know all about it, then you don't want to know any more, you just get on with it**'. Others reached a point when they stopped seeking information: '**I know as much as I can, but I don't want to get too obsessed. I don't really look, I've got enough now**'. Some had not looked for new material for '**a good few years**'.

Additional information was needed at cancer progression; with one patient searching the internet '**more often since I came out of remission**'. This was common if a treatment decision was needed: '**before, I didn't have any choice about treatment; this time (post-relapse) I have options, and I'm going to find that really hard because I've got to find out all about it and do the research**'.

Preferences about prognosis (survival) seemed to change over time and as more was learnt about the cancer. After reading '**you can live with this for 10, 15, 20 years**' one person decided to '**put the booklet away**' and only read it again if the cancer progressed. Another told medical staff: '**I don't want to know any more**' after hearing she would '**have a normal lifespan'**. Others were afraid to know this information, in case: '**it turns out to be bad'**.

To manage uncertainty and avoid worry, people often wanted information about the present, but not the future. One patient said that although not '**blinkered**' she only wanted to know more at progression '**I'd rather think about it when it happens and if it happens**'. Another wanted information '**stage by stage, as needed, without overloading you, as too much detail of what was down the line would be too much to take on**'.

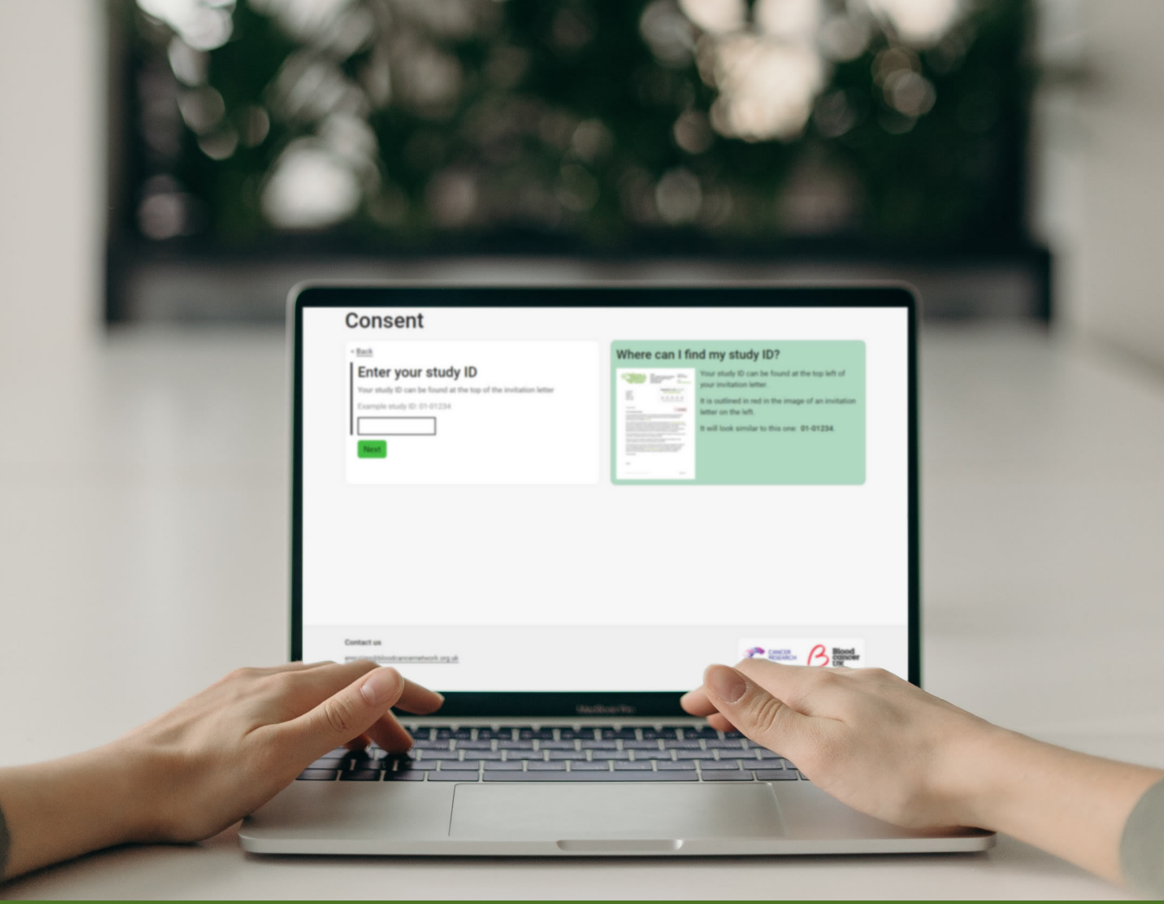
Information was obtained from clinical staff, the internet, charity booklets, websites/forums, and online/face-to-face support groups. Some preferred verbal information: '**somebody to talk to me, face to face**', or written material '**I can always go back to it, refer to it**', or a mixture of both. Booklets were said to help with the more common blood cancers, but not rare types and it was suggested that '**reliable**' online material could be better signposted by hospital staff.

What do our findings mean?

Some patients with chronic blood cancers experience long-term anxiety and distress due to their diagnosis. Our work raises awareness about these issues and could lead to changes that may prevent such problems. Patients (and family members) should ask their doctors and nurses about support (e.g. counselling) if they think this would help them. Differing information needs mean it is important that patients tell NHS staff their preferences, so that these are more likely to be met.

Final note

We are extremely grateful to the people who gave up their time to tell us about their experiences and their health, during both the interviews and by completing surveys for us in clinic.



Your study ID can be found at the top of the invitation letter

Example study ID: 01-01234

Your study ID can be found at the top left of your invitation letter.

It is outlined in red in the image of an invitation letter on the left.

It will look similar to this one: **01-01234**

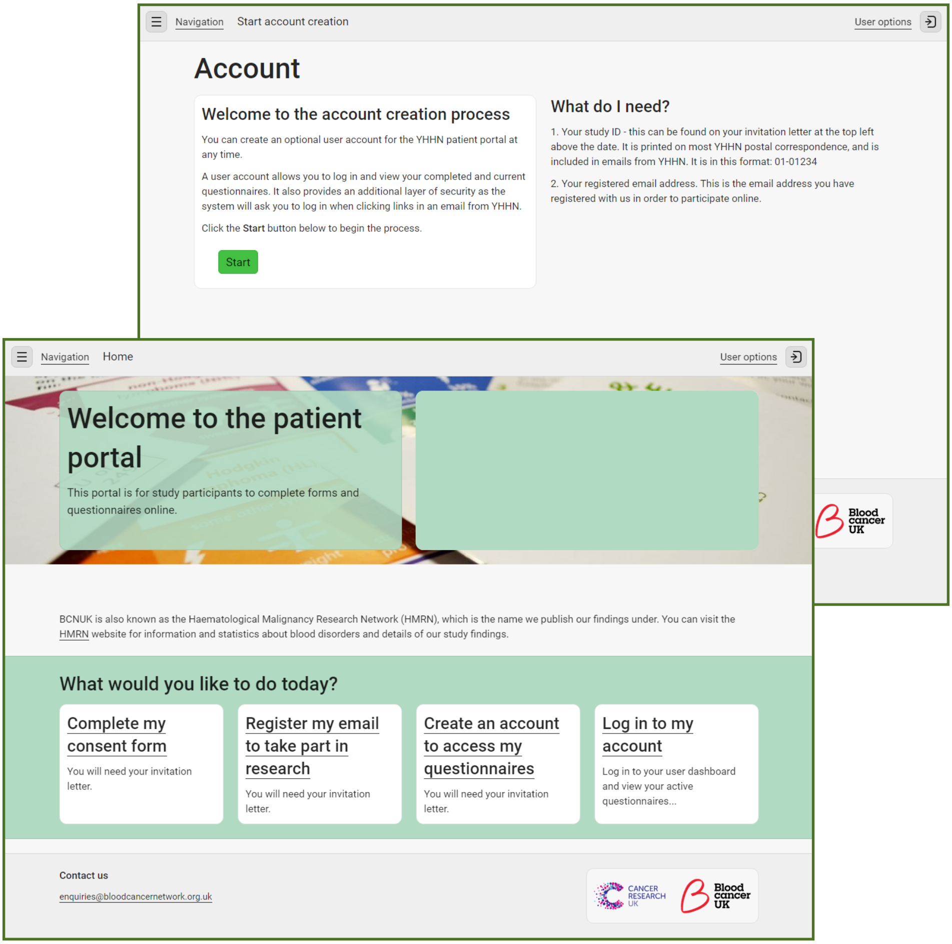
PATIENT PORTAL

INFORMATION ON OUR UPCOMING ONLINE PATIENT PORTAL

In recent years, patients have asked if they are able to take part in our research online. With this in mind, we have developed an electronic 'Patient Portal', which we are currently testing and expect to become available for use in 2024.

We know that some patients would prefer to continue with paper documents sent in the post. **This is fine!**

We will initially contact all people by post, but will also give them details about registering online, if they would prefer to take part this way. The study team will be able to answer any questions that might arise as we all get used to the new system.



Account

Welcome to the account creation process

You can create an optional user account for the YHHN patient portal at any time.

A user account allows you to log in and view your completed and current questionnaires. It also provides an additional layer of security as the system will ask you to log in when clicking links in an email from YHHN.

Click the **Start** button below to begin the process.

What do I need?

1. Your study ID - this can be found on your invitation letter at the top left above the date. It is printed on most YHHN postal correspondence, and is included in emails from YHHN. It is in this format: 01-01234

2. Your registered email address. This is the email address you have registered with us in order to participate online.

Welcome to the patient portal

This portal is for study participants to complete forms and questionnaires online.

BCNUK is also known as the Haematological Malignancy Research Network (HMRN), which is the name we publish our findings under. You can visit the HMRN website for information and statistics about blood disorders and details of our study findings.

What would you like to do today?

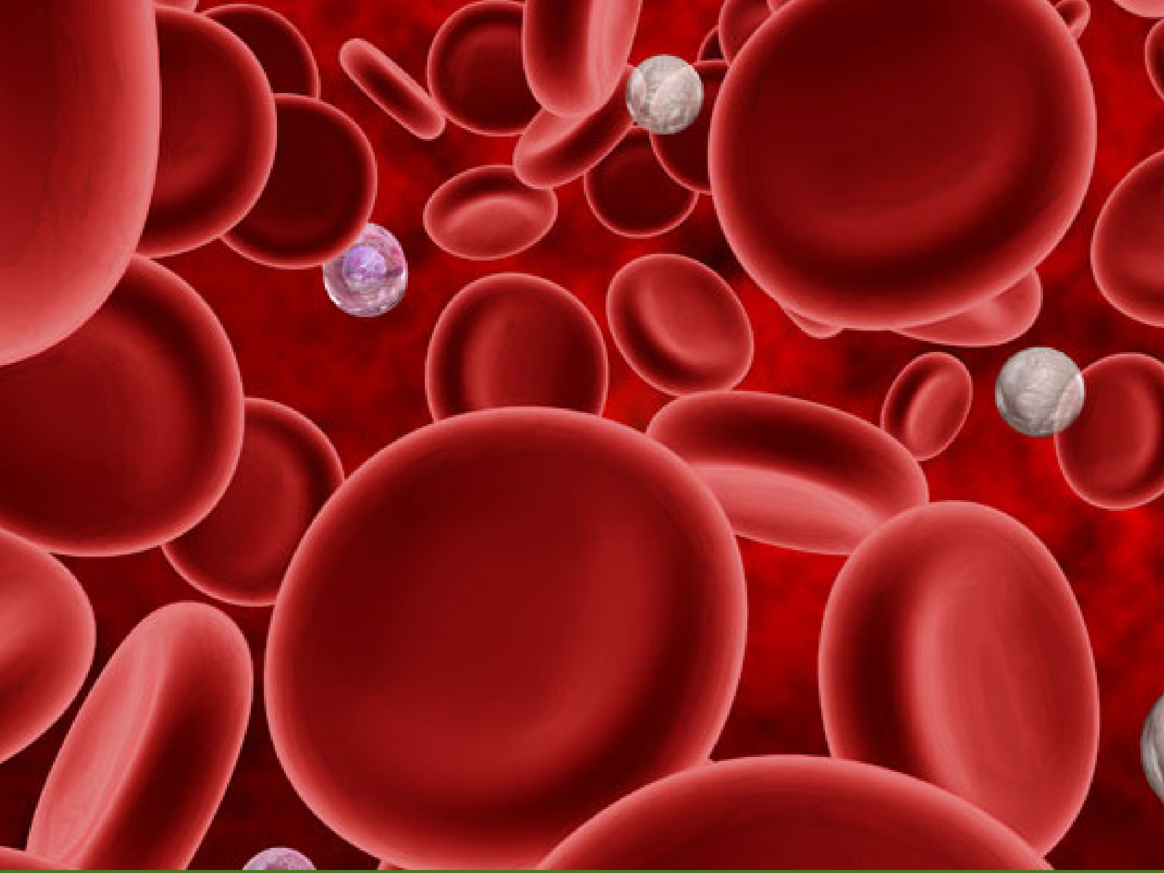
Complete my consent form
You will need your invitation letter.

Register my email to take part in research
You will need your invitation letter.

Create an account to access my questionnaires
You will need your invitation letter.

Log in to my account
Log in to your user dashboard and view your active questionnaires...

Contact us
enquiries@bloodcancernetwork.org.uk



CENTRE FOR BLOOD RESEARCH (CBR)

This year the University of York launched the Centre for Blood Research to improve understanding of blood cancer and related disorder, by learning more about their causes or finding more effective diagnostic processes and therapies. The new centre is one of the first to bring research scientists and clinical experts together in the UK and Europe. It includes York-based researchers from Biology, Health Sciences (Epidemiology & Cancer Statistics Group) and the Hull York Medical School, as well as NHS doctors and scientists. Around 15 patients and relatives attended the launch, representing people affected by blood cancer. The final session included a moving talk from Carol Miller about her experiences of acute leukaemia, followed by a discussion about the importance of having patient involvement at the heart of the CBR. Carol said "**Blood cancers are often missing from research studies, so it is absolutely great to see a whole team focusing on these diseases**".

PUBLICATIONS UPDATE

What have we published since our last newsletter?

Full copies of our publications are available to read and download/print from our study website: www.hmrn.org/publications

Multiparameter prediction of myeloid neoplasia risk (Nature Genetics)

Patient perspectives of 'Watch and Wait' for chronic haematological cancers: Findings from a qualitative study (European Journal of Oncology Nursing)

Incurable but treatable: understanding, uncertainty and impact in chronic blood cancers—A qualitative study from the UK's Haematological Malignancy Research Network (PLOS ONE)

Experiences and preferences for psychosocial support: a qualitative study exploring the views of patients with chronic haematological cancers (BMJ Open)

An economic model to establish the costs associated with routes to presentation for patients with multiple myeloma in the UK (Value in Health Regional Issues)

Molecular subclusters of follicular lymphoma: a report from the UK's Haematological Malignancy Research Network (Blood Advances)

Treatment decision making: a qualitative study exploring the perspectives of patients with chronic haematological cancers (BMJ Open)

Cohort profile update: The Haematological Malignancy Research Network (HMRN)'s UK population-based cohorts (International Journal of Epidemiology)

Chronic myeloid leukaemia: A qualitative interview study exploring disease impact from patient and practitioner perspectives (European Journal of Oncology Nursing)

Genomic and microenvironmental landscape of stage I follicular lymphoma, compared to stage III/IV (Blood Advances)

Health impact of monoclonal gammopathy of undetermined significance (MGUS) and monoclonal B-cell lymphocytosis (MBL): findings from a UK population-based cohort (BMJ Open)

Targeted sequencing in DLBCL, molecular subtypes, and outcomes: A Haematological Malignancy Research Network report (Blood)

Experiences of living with chronic myeloid leukaemia and adhering to tyrosine kinase inhibitors: A thematic synthesis of qualitative studies (European Journal of Oncology Nursing)

'Unpacking' pathways to lymphoma and myeloma diagnosis: Do experiences align with the Model of Pathways to Treatment? Findings from a UK qualitative study (BMJ Open)

Hodgkin lymphoma detection and survival: findings from the Haematological Malignancy Research Network (BJGP Open)

Risk of mature B-cell neoplasms and precursor conditions after joint replacement: a report from the Haematological Malignancy Research Network (International Journal of Cancer)

The impact of rheumatological disorders on lymphomas and myeloma: a report on risk and survival from the UK's population-based Haematological Malignancy Research Network (Cancer Epidemiology)

Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: a qualitative study (Palliative Medicine)

Disease-related factors affecting timely lymphoma diagnosis: a qualitative study exploring patient experiences (British Journal of General Practice)

Haematology nurses' perspectives of their patients' places of care and death: A UK qualitative interview study (European Journal of Oncology Nursing)

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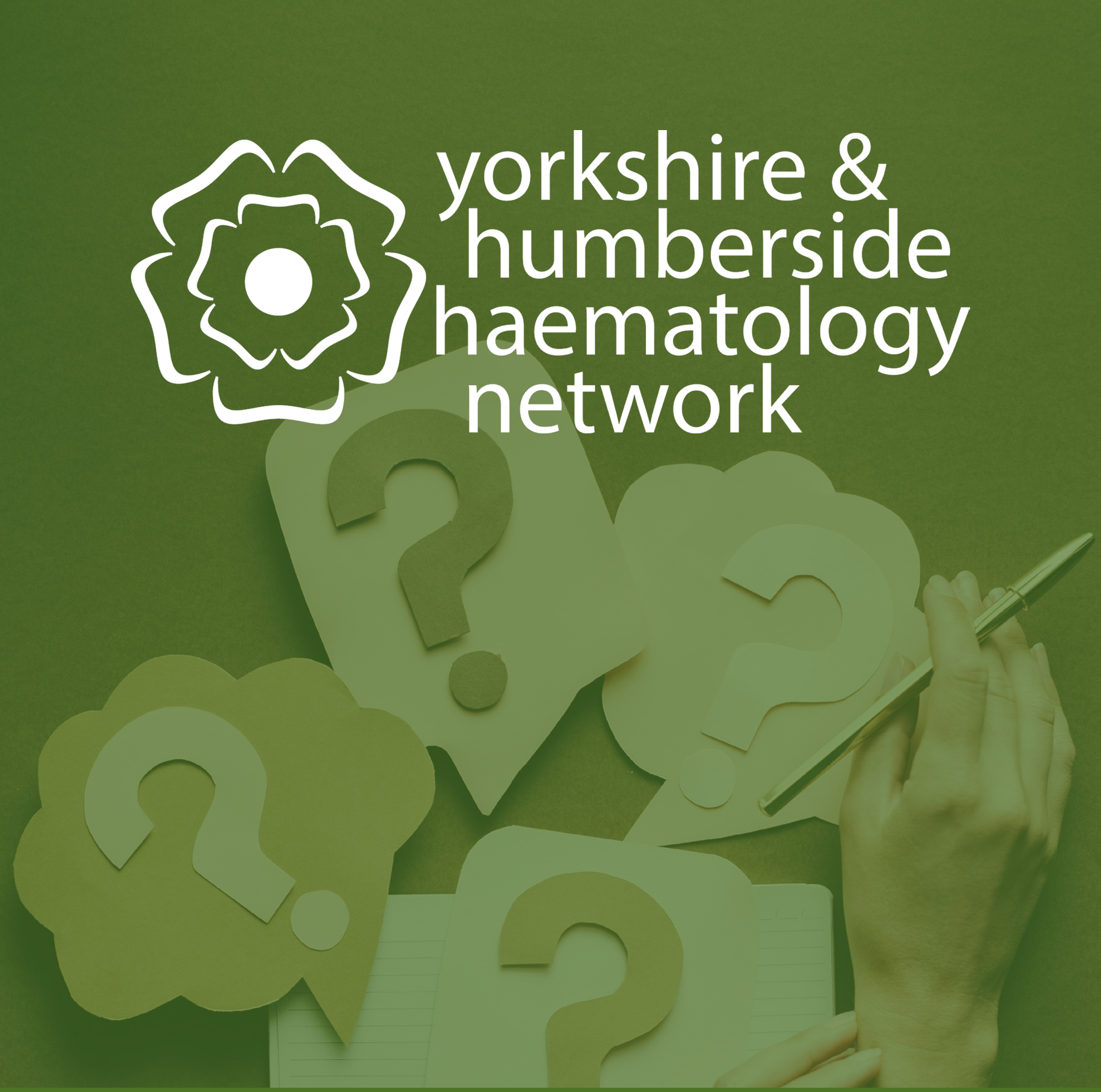

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CANCER RESEARCH UK

Blood cancer UK

NHS National Institute for Health Research

Marie Curie Cancer Care

UNIVERSITY of York
The Department of Health Sciences

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