



yorkshire & humberside
haematology network

NEWSLETTER ISSUE 3

THE PATHWAY TO DIAGNOSIS

Exploring the journey of patients with
myeloma and lymphoma

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- PATIENT EXPERIENCES
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Exploring the journey to diagnosis - YHHN findings



IMPROVING PATIENT INFORMATION

Our project to improve information for patients



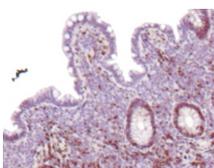
PATIENT EXPERIENCES

Your experiences of diagnosis and treatment



END OF LIFE CARE

Why do more blood cancer patients receive care in hospital rather than at home?



MANTLE CELL LYMPHOMA

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PUBLICATIONS UPDATE

Everything we have published since our last newsletter

WELCOME

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

There are many blood cancers and related disorders, some very rare and others more common. YHHN was set up to study these diseases and find the best way to manage them, with the most benefit for patients. It was started in 2004 by NHS doctors and nurses who look after people with these diseases, patients (and their families), and researchers at the University of York. With funding from the charity Bloodwise, it is the only study of its kind in the world.

Since YHHN began, more than 36,000 people have been diagnosed with a blood cancer or disorder in our study area. The experiences of these patients have really helped us to understand more about these diseases. We are now able to produce up to date information about the people affected, their treatment, how they respond to therapy, and how treatments affect people.

As well as using medical records, YHHN collects information directly from patients, often during discussions, or when they fill in surveys for us. Issues we ask about include experiences before diagnosis (such as symptoms and appointments), whilst on 'watch and wait', and during and after treatment. The YHHN team

want to ensure as much information as possible is available about these diseases, that this is accurate, up to date, and of use to patients, their families, the public, doctors, nurses, healthcare managers and policy makers.

Our newsletter is one of the ways we let people know about the work going on where they live. In this issue you will find summaries of some of our studies and a list of our recent papers.

If you'd like to know more about our studies, or to read the full publications, you can find this information at our website: www.yhhn.org.

We sincerely hope you find this newsletter interesting and welcome any feedback you may have.

Best wishes,
The YHHN Team



THE PATHWAY TO DIAGNOSIS

OF MYELOMA AND LYMPHOMA

Why did we do this study?

Every year in the UK, over 16,000 people are diagnosed with myeloma, non-Hodgkin lymphoma or Hodgkin lymphoma. There can be a lot of variation in the time it takes patients to seek medical help for the symptoms of these diseases and for a diagnosis to be made. Being diagnosed quickly is important, however, as it means the cancer may be found at an earlier stage. For some diseases, this can lead to better outcomes due to fewer complications and more treatment options. With this in mind, it is clearly important to understand exactly why delays happen, and if possible prevent them from occurring. With funding from Cancer Research UK (National Awareness and Early Diagnosis Initiative), we carried out a study within YHHN, looking at issues affecting time to diagnosis of myeloma and lymphoma.

What did we do?

We interviewed 55 people about their experiences before diagnosis, using the discussion to look at the difficulties people faced, and similarities and differences between patients.

What did we find?

We found that experiences varied, with some patients saying they were diagnosed quickly, while others said this took longer than they thought it should have, despite their

own efforts and those of their doctors and nurses. People told us about a lot of different symptoms they had experienced, which were often vague and seemed to progress gradually. With myeloma for example, many people had bone pain, felt very tired and became less and less able to carry out their usual activities (e.g. working, driving, walking around and climbing stairs). Patients with lymphoma often got swellings around their neck, which could be painless and come and go; or they might start having hot sweats. Feeling unwell but being unable to explain why, or in what way, was common.

As a result, people said they did not think their symptoms had been caused by cancer, but were due to less serious illnesses, or were a 'normal' part of the ageing process. They told us they put their problems down to 'wear and tear' or 'overdoing things' and this caused them to delay seeing their GP straight away. When they did seek help, GPs often gave similar explanations for their symptoms at first, or were also unclear about the cause. In some cases, patients said they (and their GPs) suspected that ongoing, unexplained symptoms could be due to psychological issues.

As symptoms worsened, or did not go away, people generally went back to their GP. Sometimes this happened quite a few times and led to blood tests or scans. All the people we spoke to eventually went to a GP and were seen at hospital, either after GP referral or because they decided to go to Accident and Emergency (A&E) themselves. Only a few of

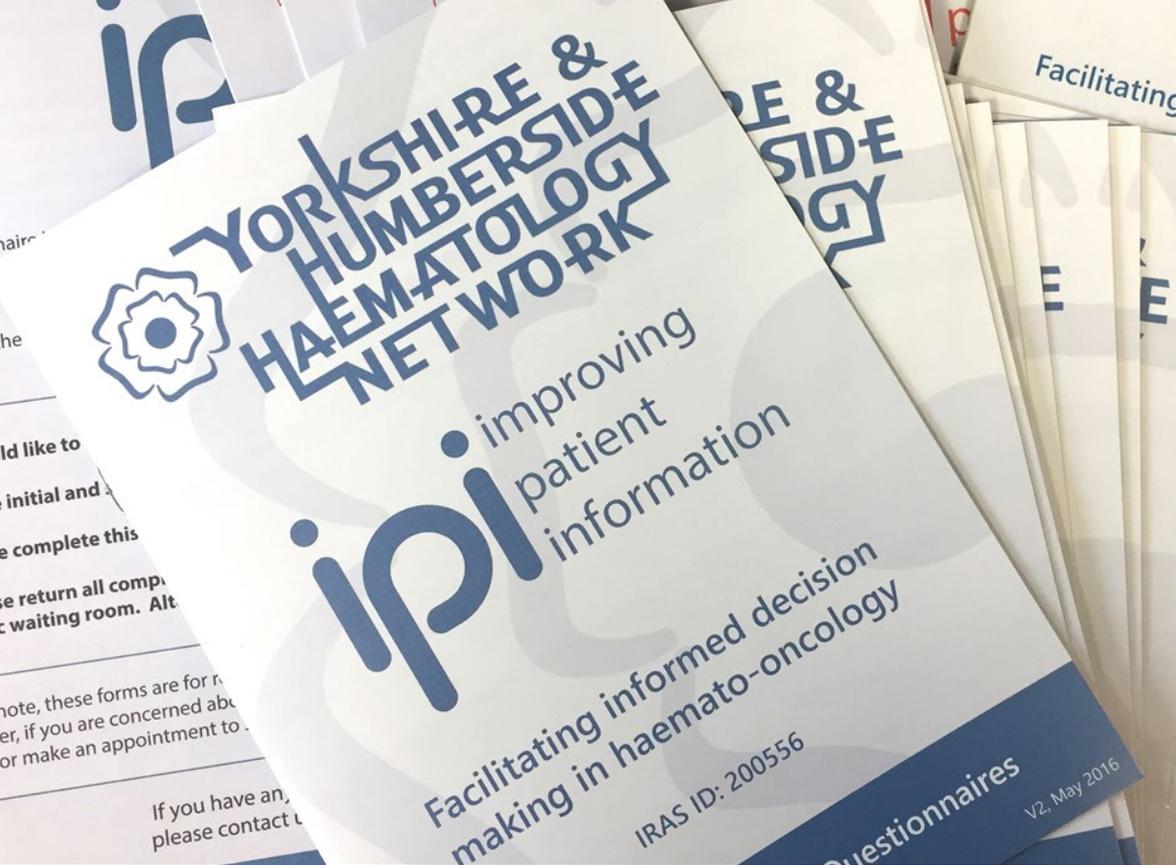
the patients who were sent to hospital went straight to a haematologist, because even at referral, symptoms were not thought to be due to a blood disorder. Once in hospital, patients said their diagnosis was usually made fairly quickly.

Patients generally thought of myeloma and lymphoma as rare diseases that could be difficult to diagnose. They said they themselves, and often their GPs, knew little about these diseases. Some said they thought their GPs would know more. With ongoing symptoms, patients thought it important that GPs consider a range of possible causes, and ask patients to return if they did not start to feel better.

What can be done?

Myeloma and lymphoma are difficult for patients and GPs to identify. These cancers do not have a screening programme; nor do they have a specific 'red-flag' symptom that would raise suspicion of cancer and could be used to improve awareness (as with breast lumps for breast cancer). It is therefore important that patients recognise what is normal for them and seek help quickly for worrying symptoms; and that GPs are supported to identify and act on unexplained and ongoing symptoms.





IMPROVING PATIENT INFORMATION

OUR PROJECT TO HELP PATIENTS MAKE INFORMED DECISIONS ABOUT THEIR CARE

Why did we do this study?

This study came about after patients with the more chronic blood cancers (such as follicular lymphoma, chronic lymphocytic leukaemia, myeloma, myeloproliferative neoplasms and some myelodysplastic syndromes), who were on 'Watch and Wait' told us of the anxiety this caused them, due to their uncertainty about the future, including their likely need for treatment. In other words, they didn't feel they had enough information about what was likely to happen next. We wanted to help with this, and so set up a programme of work within YHHN, that was funded by the National Institute for Health Research (NIHR).

Study aims

This work aimed to develop information for patients and clinicians about treatment impact (e.g. quality of life, how often people need to come to hospital, variation by treatment type etc.), outcomes and costs. In addition, it sought to develop ways of mapping this material across entire pathways.

In the final part of the programme, we wanted to explore the information needs of patients and relatives, and also their desire to be involved in treatment decisions.

Data collected

We used YHHN data on treatment, outcomes and hospital activities to assemble and model pathways, and allocate costs. This information

was supplemented by material from other sources. During 2017-18, for example, over 3,000 people in haematology outpatient clinics completed surveys for us about their health and appointments.

We also interviewed 35 patients with the diseases of interest, and 10 of their relatives, which provided us with a great amount of detailed information about their pathways and experiences, which we examined for patterns, and to look for differences over time and between different people.

We are extremely grateful to the people who gave up their time to provided us with information for this study, via both the questionnaires and the interviews.

What have we found so far?

Importantly, we showed that it is possible to produce and link information from various sources, and map these across entire patient pathways.

Patients provided a lot of useful information about their experiences in the survey. Much of this was positive, especially about the care they had received from the haematology team. They also told us a lot about their physical and mental health, and we were able to look at how this changed over time.

During the interviews, patients reported that communication with doctors and nurses was good and they knew who to talk to about

any concerns. Some people said they wanted more information about their likely prognosis (survival), quality of life, and the side effects of treatment. Specific difficulties mentioned were lack of time in busy clinics to discuss concerns, use of words they did not understand, and test results not being available at outpatient appointments.

Regarding information needs, a lot of variation was noted, ranging from patients who wanted to know everything, to others who wanted to know very little. Patients also said that their desire for information varied over time, depending where they were on the pathway,

with more material needed at relapse and before the start of treatment, for example, and less during a long period of 'Watch' and 'Wait'.

What next?

We hope that the information generated, and our methods for sharing this via pathway maps, will be further developed, for routine use in hospital settings. As blood cancer pathways are similar to many other chronic illnesses, it is likely that our findings may be useful in other conditions and healthcare settings.





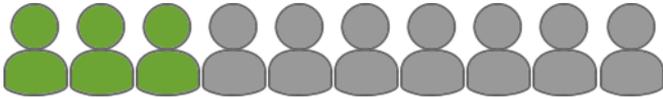
PATIENT EXPERIENCE QUESTIONNAIRE

OUR QUESTIONNAIRE TO FIND OUT MORE
ABOUT YOUR EXPERIENCES OF DIAGNOSIS AND
TREATMENT

Some time ago, we sent a questionnaire to people with blood cancers and related disorders in the YHHN area, asking them about their experiences in the time leading to diagnosis and what their hospital care was like during and after this time. More than 500 questionnaires were returned, and some of the findings are summarised below:



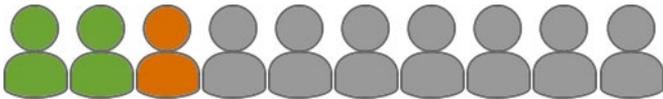
6 in 10 people had someone with them when they were given their diagnosis



3 in 10 who didn't have anyone with them, would have liked to have had someone there



9 in 10 completely understood the explanation of what was wrong with them, or some of it



2 in 10 were not given any written information and **1 in 10** found the information they were given difficult to understand



7 in 10 people said they liked to be fully involved in treatment decisions and **less than 1 in 10** wanted no involvement at all



**WHY ARE SO MANY PEOPLE
WITH BLOOD CANCERS CARED
FOR IN HOSPITAL AT THE END
OF LIFE RATHER THAN AT
HOME?**

Why did we do this study?

It is widely believed that most people would like to be cared for in their own home at the end of their life, if possible. However, many people with blood cancers die in hospital, much more so than if they have other cancers or illnesses. In this study, we explored the reasons for this.

What did we do?

We looked at medical records, interviewed doctors and nurses, and talked to the relatives of patients who had died.

What did people tell us?

During interviews, we were told that people may choose to remain in hospital at the end of their life, as this was a familiar place to them. Patients and relatives also often knew and trusted the staff, due to strong bonds that tend to develop over the course of their blood cancer. Preferences to be cared for and die at home were said to change if symptoms became too difficult to manage at home, and this was often said to lead to urgent hospital re-admission.

Many clinicians said that a lot of input was needed from nurses and GPs if patients with blood cancer who were nearing the end of life were to remain at home, but that this was not always available. Also, patients might not consider going to a hospice because they don't

know much about the care available there, or how to get a referral.

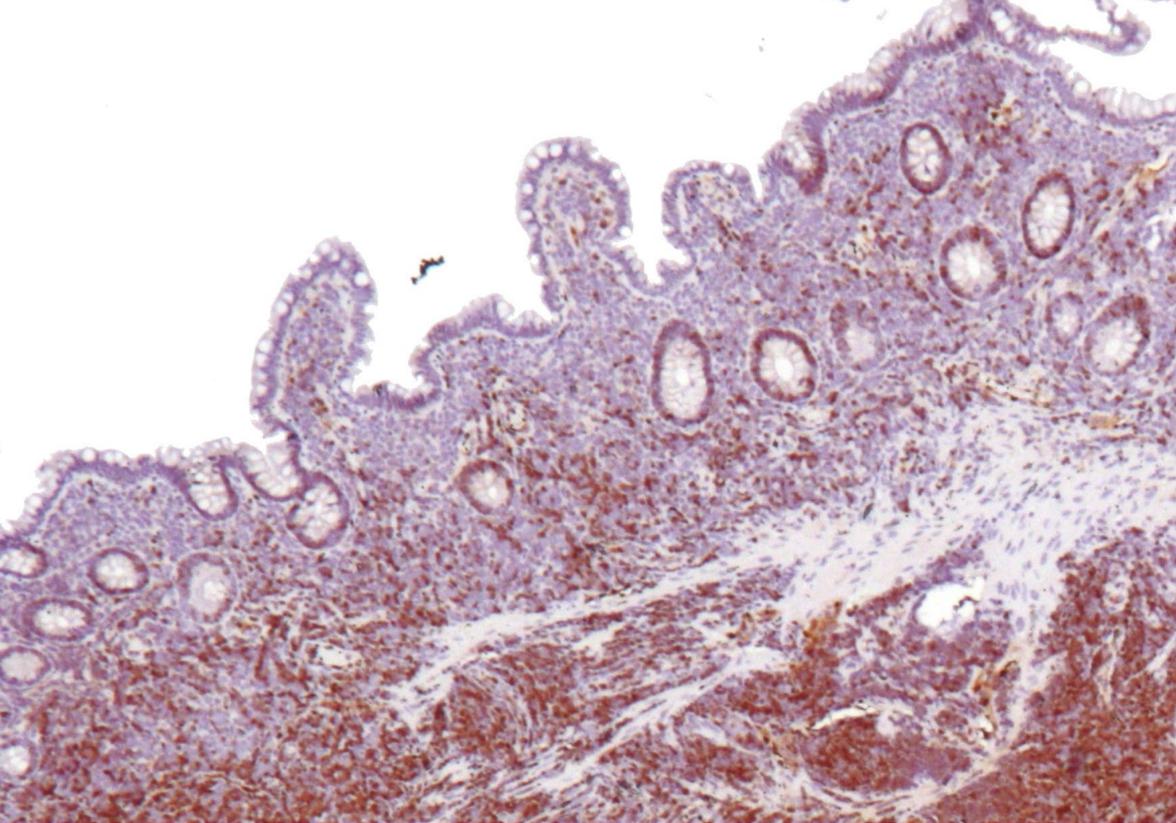
Better communication and closer working between hospital and primary care staff were suggested as ways to help patients achieve their preferences.

What did the medical records show?

The records showed that although many people discussed their end of life preferences (often more than once), some do not. They also confirmed that people change their mind over time, depending on who is involved in the discussion (patient and/or relative) and when this takes place. Home was found to be the most common first preference, although this often changed closer to the end of life, and most people died in hospital.

What happens next?

Results from the study have been published in medical journals and shared at conferences. Findings have also been shared by our charity partners, in their magazines.



MANTLE CELL LYMPHOMA

Why did we do this study?

Mantle cell lymphoma is a rare cancer, with around 450 new diagnoses in the UK each year. It is most likely to occur in people aged in their 70s and affects three times more men than women.

Most people are well enough to have chemotherapy and are given the same type of treatment, although not all people need treatment. If more chemotherapy is needed after this, it can be unclear which option is best, especially as more and more choices are becoming available.

Although clinical trials show the benefits of newer treatments, it was unclear if these improvements occurred for all patients, and this is what we wanted to find out.

What did we do?

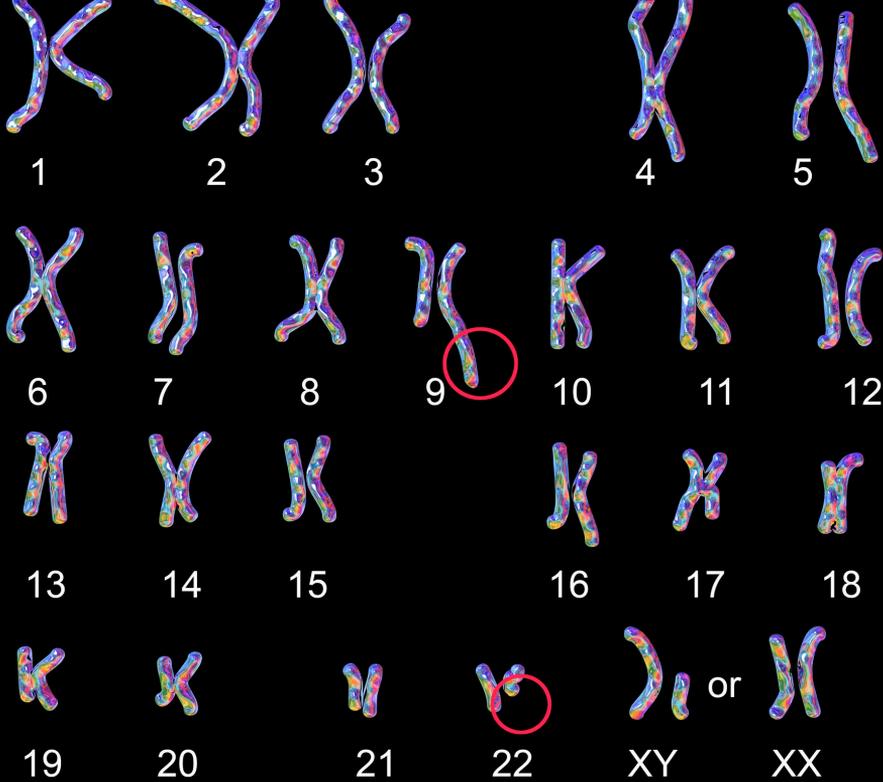
We looked at changes in treatment, and the effectiveness of new treatments over time in YHHN patients.

What did we find?

We confirmed that treatments had changed over time, and that survival was improving, particularly among older patients.

What happens next?

These findings are important because our study included people of all ages, rather than just those who take part in clinical trials, who are generally younger and fitter. Our results mean doctors are able to see how chemotherapy is likely to affect their patients, which will make sure the best treatment decisions are made for everyone.



MANAGING TREATMENT

and living with chronic myeloid leukaemia



Ann Hewison
PhD Student

In the UK 600 people are diagnosed with chronic myeloid leukaemia (CML) each year.

New treatments introduced around 20 years ago (Tyrosine Kinase Inhibitors – TKIs) mean people can now survive with this cancer as long as they would have if they didn't have it, whereas in the past it could be a rapidly fatal disease. With such improvements in survival, research is now focusing on how best to support patients to live with their CML in the longer-term. To do this it is important that any difficulties patients have are understood, so they can be supported to manage their CML like a chronic disease.

People with CML are asked to take their TKI tablets every day, but may find this difficult as some therapies are known to have side-effects. This is one of the areas I am interested in, including how often people take their medication and the factors affecting this, which I am exploring in my PhD.

As a part-time student (and full-time YHHN study nurse!), my PhD has been ongoing for around 5 years so far and is due to finish this year.

For the first part of my project, I interviewed patients, about their experiences of being diagnosed with CML and taking long-term medication, including what it is like to live with this disease, and its treatment, on a day to day basis.

For the second part of my PhD, I interviewed hospital staff (e.g. clinical nurse specialists, consultants and pharmacists), and asked how they support and monitor patients and what could be done to make their work easier.

Discussions with both groups of people were recorded and I looked at differences and similarities in the stories people told. One of the main findings was that, despite now being considered a chronic illness, CML can be difficult to live with and patients often find ways to self-manage their cancer to protect their quality of life.

The findings from my PhD will improve understanding of what it is like to live with CML, and I hope this will help doctors and nurses to provide the best care for their patients. Some of my results may also apply to other conditions needing long-term therapy, as many issues are likely to be similar.

My findings will be shown on our websites, published in medical journals and presented at conferences.

I would like to end by expressing my thanks to all the people who took part in this study, particularly the patients who talked so openly about their personal experiences of living with CML.



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

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

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

Haematology nurses' perspectives of their patients' place of care and death: a qualitative interview study ([European Journal of Oncology Nursing](#))

Impact of novel therapies for mantle cell lymphoma in the real world setting: a report from the UK's Haematological Malignancy Research Network (HMRN) ([British Journal of Haematology](#))

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](#))

Receiving treatment at a specialist centre confers an overall survival benefit for patients with mantle cell lymphoma ([British Journal of Haematology](#))

The use of targeted sequencing and flow cytometry to identify patients with a clinically significant monocytosis ([Blood](#))

Cell-of-origin in diffuse large B-cell lymphoma: findings from the UK's population-based Haematological Malignancy Research Network ([British Journal of Haematology](#))

Place of death in haematological malignancy: variations by disease subtype and time from diagnosis to death ([BMC Palliative Care](#))

Time to diagnosis and symptoms of myeloma, lymphomas and leukaemias: a report from the Haematological Malignancy Research Network ([BMC Haematology](#))

Determinants of survival in patients with chronic myeloid leukaemia treated in the new era of oral therapy: findings from a UK population-based patient cohort ([BMJ Open](#))

Determining disease prevalence from incidence and survival using simulation techniques ([Cancer Epidemiology](#))

Variations in specialist palliative care referrals: findings from a population-based patient cohort of acute myeloid leukaemia, diffuse large B-cell lymphoma and myeloma ([BMJ Supportive & Palliative Care](#))

Long-term medical costs and life expectancy of acute myeloid leukaemia: a probabilistic decision model ([Value in Health](#))

Treatment cost and life expectancy of diffuse large B-cell lymphoma (DLBCL): a patient level simulation on a UK population-based observational cohort ([Pharmacoepidemiology](#))

The prognosis of MYC translocation positive diffuse large B-cell lymphoma depends on the second hit ([Journal of Pathology: Clinical Research](#))

Lymphoma incidence, survival and prevalence 2004-14: subtype analyses from the UK's Haematological Malignancy Research Network ([British Journal of Cancer](#))

The clinical impact of staging bone marrow examination on treatment decisions and prognostic assessment of lymphoma patients ([British Journal of Haematology](#))

Preferred and actual place of death in haematological malignancy ([BMJ Supportive & Palliative Care](#))

Impact of age and socioeconomic status on treatment and survival from aggressive lymphoma: a UK population-based study of diffuse large B-cell lymphoma ([Cancer Epidemiology](#))

Risk factors and time to symptomatic presentation in leukaemia, lymphoma and myeloma ([British Journal of Cancer](#))

Targeted sequencing identifies patients with preclinical MDS at high risk of disease progression ([Blood](#))

Myeloid malignancies in the real world: Occurrence, progression and survival in the UK's population-based Haematological Malignancy Research Network 2004-15 ([Cancer Epidemiology](#))

Estimating the prevalence of haematological malignancies and precursor conditions using data from the Haematological Malignancy Research Network (HMRN) ([Cancer Causes & Control](#))

Multiple myeloma: routes to diagnosis, clinical characteristics and survival - findings from a UK population-based study ([British Journal of Haematology](#))

Treatment cost and life expectancy of diffuse large B-cell lymphoma (DLBCL): a discrete event simulation model on a UK population-based observational cohort ([The European Journal of Health Economics](#))

Emergency admission and survival from aggressive non-Hodgkin lymphoma: A report from the UK's population-based Haematological Malignancy Research Network ([European Journal of Cancer](#))

Determinants of hospital death in haematological cancers: findings from a qualitative study ([BMJ Supportive & Palliative Care](#))

Palliative care specialists' perceptions concerning referral of haematology patients to their services: findings from a qualitative study ([BMC Palliative Care](#))

Impact of novel therapies for mantle cell lymphoma in the real world setting: a report from the UK's Haematological Malignancy Research Network (HMRN) ([British Journal of Haematology](#))

Cohort Profile: The Haematological Malignancy Research Network (HMRN); a UK population-based patient cohort ([International Journal of Epidemiology](#))

Myeloma: Patient accounts of their pathways to diagnosis ([PLOS ONE](#))

A generic model for follicular lymphoma: predicting cost, life expectancy and quality-adjusted-life-year using UK population-based observational data ([Value in Health](#))



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Bloodwise
The blood cancer research charity



NHS
National Institute for
Health Research



The Department of Health Sciences