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Mapping the needs, experiences
and outcomes of people affected
by blood cancer.



Foreword



Leukaemia & Lymphoma Research began in 1960 following the tragic death of 6 year old Susan Eastwood from acute lymphoblastic leukaemia. In the 55 years since her family created our charity around a kitchen table in Middlesbrough, we have grown into a world leader in our field and have invested £500 million in beating blood cancers.

There have been many successes. The transformation in survival for the most common form of childhood leukaemia from almost zero in 1960 to 92% today; the development of the first magic bullet therapies in chronic myeloid leukaemia; the use of monoclonal antibodies in diagnosis and treatment; and the development of cell based therapies. Many lives have been saved but there is still a long way to go.

Our research has contributed to the unprecedented understanding of blood cancer and over time we have evolved from a purely academic research charity to a charity with the patient at the heart of all that we do.

We now need a plan that will put us out of business before the next 55 years are up. We need to make sure that the next £500 million that we invest addresses the needs of patients further and even faster. It's time for some more bold decisions, greater prioritisation and quicker results.

To do this we need an evidence base. Over the last two years we've conducted the largest ever blood cancer research project into Patient Need with some surprising results. Our approach is to continuously map, track and understand the needs of all blood cancer patients, and to outline the opportunities and challenges we face in beating blood cancer.

Phase one of our research has highlighted 24 key issues faced by patients across their experiences with blood cancer. They traverse the different stages: from initial awareness to diagnosis, right through to post-treatment and, for some, end of life care.

Central to our research approach is to iteratively share what we learn to continuously inform and empower the blood cancer community. From top line results to the granular detail, our findings will always be available for the benefit of everyone. This phase one report aims to bring all of the different sources of evidence together to outline the key issues facing patients. It is the first evidence report of many from this programme as we continue to explore and explain the needs of all blood cancer patients in the years to come.

Leukaemia & Lymphoma Research is committed to addressing all of the 24 key issues for patients, but we know we can't do this alone, nor can we achieve this overnight. If we collaborate, differentiate and innovate, together we can create a clearly recognised sector for blood cancer patients.

We welcome your thoughts, ideas and, of course, support.

Together we will beat blood cancers.

Cathy Gilman

A handwritten signature in white ink that reads 'Cathy Gilman'.

Chief Executive – Leukaemia & Lymphoma Research

Included in this report

The findings outlined in this report represent the evidence from the first phase of the Leukaemia & Lymphoma Patient Need research programme – conducted November 2013 to December 2014.

This includes evidence from four sources of research conducted for this study:

- quantitative research with patients, carers and the general public via two online surveys
- qualitative research with patients, carers and healthcare professionals
- analysis from national cancer datasets and patient experience research
- related literature review on blood cancer research and patient experience.

Phase one of our research has highlighted 24 key issues faced by patients across their experiences with blood cancers and related disorders as defined by the Haematological Malignancy Research Network (HMRN). See Appendix A.

This report aims to highlight all of these 24 key issues across the different stages of patient experience. Combining different sources of evidence and research to illustrate what these issues mean for patients.

The report also summarises our plan of action and our next steps for the Patient Need research within 2015/16.

All of the testimonials contained in this report came directly from participants in this research. We would like to thank everyone that has been involved in the first phase of our Patient Need study, especially patients and carers who have shared their experiences in their thousands.

We would also like to thank the following patient organisations for their support in promoting our study:

African Caribbean Leukaemia Trust, Anthony Nolan, Be Positive, Chronic Lymphocytic Leukaemia Support Association (CLLSA), CML Facebook group, Leukaemia Care, Lymphoma Association, Maggie's, MPN Voices and MDS UK.

24 areas of need for patients:

- | | | |
|--|--------------------------------|------------------------------------|
| 1 Blood cancer awareness | 9 Information and advice | 17 Watch and wait |
| 2 The biggest killers | 10 Peer-to-peer support | 18 Access to new drugs & treatment |
| 3 Early deaths | 11 Empowering patients | 19 Age and Ageing |
| 4 Pre-malignant conditions | 12 Blood cancers are different | 20 Clinical trials |
| 5 Diagnosis | 13 Role of carers | 21 Socio-economic factors |
| 6 Role of GPs | 14 Support for others | 22 Reducing secondary cancers |
| 7 Relationship with medical profession | 15 Psychological support | 23 Maintaining remission |
| 8 Clinical nurse specialists | 16 Apparent lack of provision | 24 Post-treatment |

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About Patient Need

The Leukaemia & Lymphoma Research Patient Need study is a research programme committed to understanding the needs of people affected by blood cancers.

This programme is a pioneering approach to continuously map, track and understand the needs of all blood cancer patients, and to outline the opportunities and challenges we face in beating blood cancers.



Patient Need – phase one approach

Phase one of the research programme aimed to combine the wisdom of patients, carers, health professionals, patient organisations, policy makers and researchers working at the cutting edge of blood cancer intelligence. We teamed these voices with the most comprehensive blood cancer data and research in the UK to build an evidence base to inform our decisions, now and in the future.

Starting in November 2013, the first phase of our research comprised four areas:

1. A pilot study – patients and carers:

We initiated this programme with desk based research to review and understand the different issues around blood cancer patient need, and to inform our design for a pilot study with patients and carers. This pilot study was made up of four focus groups and two in-depth patient and carer interviews. The findings from this pilot study helped inform the methodology and focus for our 2014 primary and secondary research' (Areas 2 to 4).

2. Qualitative research:

• Focus groups with patients and carers

In order to explore patients' needs and gather insights from both patients and carers we set out to hold focus groups between April and September 2014 across the UK. The aim of these focus groups was to identify areas of patient need from people affected by blood cancers across varying stages of the patient journey. This included topics such as greatest needs, identifying key information sources, key contacts and support networks, and how patient organisations can assist in helping meet patient need more effectively.

We held a total of 13 focus groups and two facilitated supporter groups with a combined total of 139 participants. Focus groups were held in Birmingham, Bristol, Cambridge, Cardiff, Colchester, Edinburgh, Liverpool, London, Manchester, Maidstone, Milton Keynes, Newcastle, Oxford and York.

These groups were voluntary and were promoted via key links to the charity such as our social media channels, patient events and regional branches, and by supporters of the charity. Other partner charities also helped promote the focus groups.

• In-depth interviews with patient and carers

In order to capture the detailed views of patients and carers we also carried out in-depth patient interviews with seven patients/carers. The aims of these interviews were the same as the focus groups and were designed to allow detailed feedback from individuals who wanted to contribute outside of a focus group session, or were unable to attend the relevant group.

These patients and carers interviews were recruited via the same methods as the focus group research. All of the in-depth interviews were conducted between April and September 2014.

• In-depth interviews with healthcare professionals

As well as capturing the needs of patients, we also wanted to gain a qualitative understanding of the perceptions of patient need and key areas for clinical practice from healthcare professionals.

We aimed to interview a range of healthcare professionals including clinical nurse specialists, clinicians, researchers, patient group representatives, and policy advisers. A total of 21 semi-structured in-depth interviews were completed from April and September 2014. The questions were focused on exploring patient need throughout the patient journey from the perspective of the relevant healthcare professional.

3. Quantitative research:

- **Online patient need survey**

To gain a larger representation of patient need and experiences we commissioned an independent market research agency (BritainThinks²), to co-develop an online patient need survey aimed at patients, carers and other people affected by blood cancer.

The overall aim of the survey was to understand patient and carer needs at four key stages (diagnosis, treatment, watch and wait/active surveillance and post-treatment), and to gain insights directly from people affected by blood cancer on how they felt needs were being met.

The survey was voluntary and promoted by Leukaemia & Lymphoma Research through via our social media channels, our monthly email newsletter and through supporters and charity connections. It was also promoted through a variety of blood cancer charities as listed previously. The survey was open from 2nd July 2014 to 1st August 2014.

We would like to state our thanks to our supporters and all these organisations for providing support in the promotion of this online survey.

The survey was completed by a total of 1,725 respondents, including 1,029 patients. The respondents were spread across age groups from 16 to 65+ years, and across a range of blood cancer conditions – see Appendix B for details

The survey contained a mix of quantitative questions and open ended questions to capture verbatim responses. The topics covered included:

- 1 Overall greatest need
- 2 Greatest needs at diagnosis, treatment, watch and wait/active surveillance and post treatment
- 3 At each stage patient respondents were then asked:
 - a to indicate the level of need they felt they had for each prompted support area (great need, some need, didn't need, don't know)
 - b for all those support areas for which respondents said they had either a 'great' or 'some' need for, they were then asked what type of assistance, if any, they had received in this area (written, face to face or via friend/family)
 - c for all those support areas for which respondents said they had received assistance, they were then asked to rate their level of satisfaction (on a scale of 1 – 5, with 1 being very unsatisfied and 5 being very satisfied)
- 4 Carers were asked what their greatest needs were and what improvements could have been made.
- 5 All respondents were asked about awareness and access to charities.

- **General public awareness research**

In August 2014, we commissioned a general public online study with YouGov³ to ascertain awareness and understanding of blood cancer conditions, and specifically the terminology used to describe them. The survey was conducted over two days, and completed by 2016 respondents, from a nationally representative sample of UK adults.

In the survey, respondents were asked about their awareness of general health conditions including certain blood cancer conditions. This prompted list of conditions included leukaemia, lymphoma, blood cancer and myeloma. Respondents who were aware of the conditions were then asked how to describe these conditions to another person through an open ended response question.

4. Secondary research – data analysis and literature review:

Complementing the primary research we also undertook parallel data analysis and literature reviews of existing sources as part of the phase one of the study. The aim of this work was to identify existing research activity around blood cancer patient need and the relevant findings.

This secondary research included a focus on the following data sources:

1. National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide partnership operated by Public Health England that coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients. NCIN gives a picture of haematological (blood) cancer statistics across the whole of the UK. This data was used to gain a national picture of blood cancers.

2. Haematological Malignancy Research Network

Set within the former adjacent UK Cancer Networks of Yorkshire and the Humber & Yorkshire Coast, the Haematological Malignancy Research Network (HMRN) was established in 2004 to provide robust generalisable data to inform clinical practice and research. It follows patients from initial diagnosis all the way through to death from any cause. HMRN can also look retrospectively from diagnosis at previous GP records. HMRN data was used to identify the survival, prevalence and incidence rates of individual blood cancers. Publications from HMRN were also used to help complement primary research findings.

3. National Cancer Patient Experience Survey

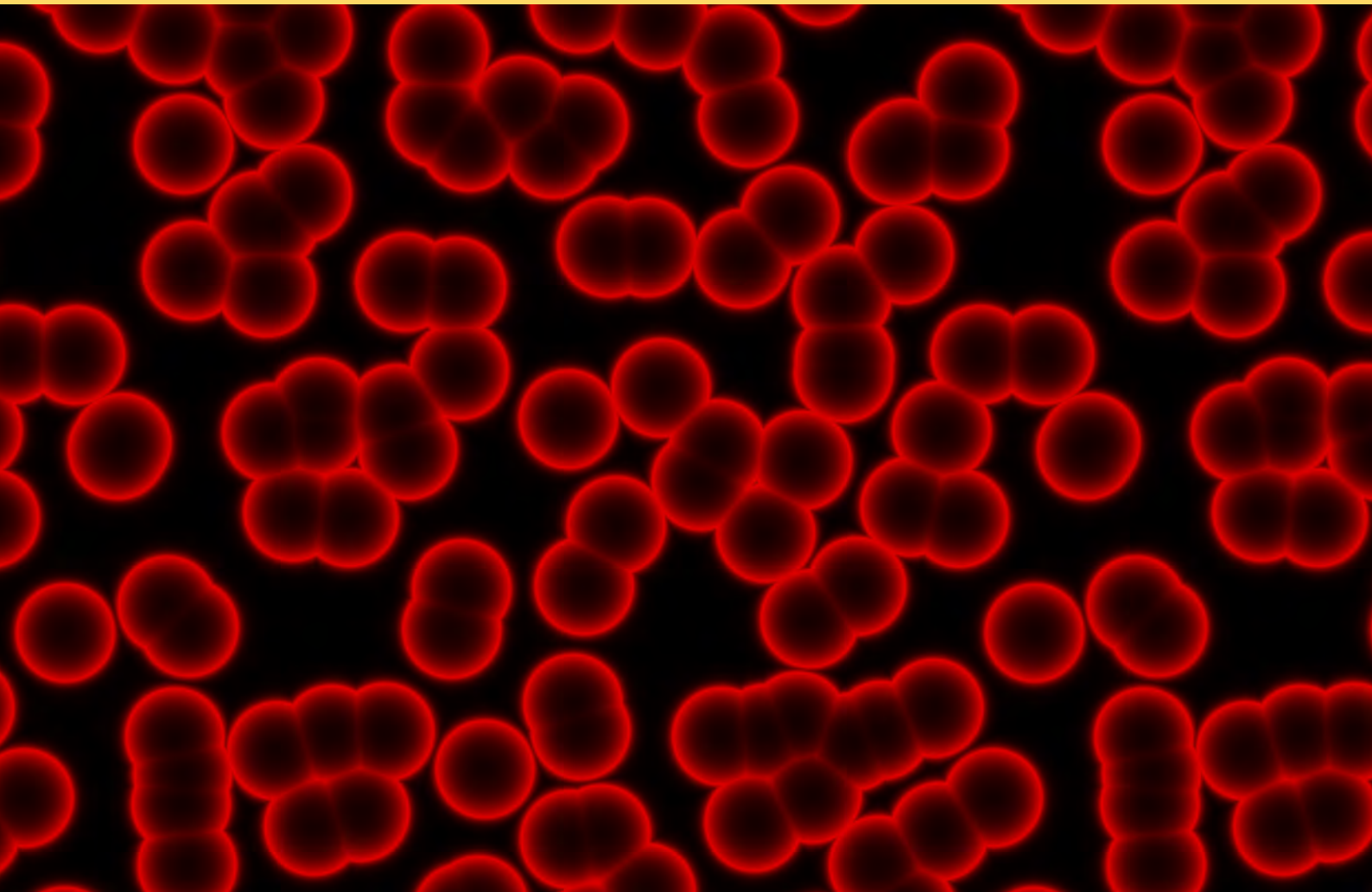
The Department of Health established a National Cancer Patient Experience Survey (NCPES) to monitor national progress and to use the findings to drive quality improvements locally. The survey is collated annually and captures patient experience for a variety of cancers, including blood cancers. We commissioned Quality Health⁴ in 2013 and 2014 to produce further analysis showing the breakdown of the NCPES questions by specific blood cancer conditions.

4. Wider literature review

This component was supported by a literature review focused on blood cancer research, current treatments, and patient experience and need assessments. It included peer reviewed journals, epidemiology trials and expert opinion articles. This element commenced in late 2013 and is an ongoing element of this research programme.

Blood cancers in the UK – a statistical overview

For this research programme we looked to use the most up-to-date and comprehensive national data available on blood cancers. We set out to give an overview of the prevalence, survival and lives lost to blood cancer conditions within the UK.



One in 10 of all new cancers diagnosed is a blood cancer

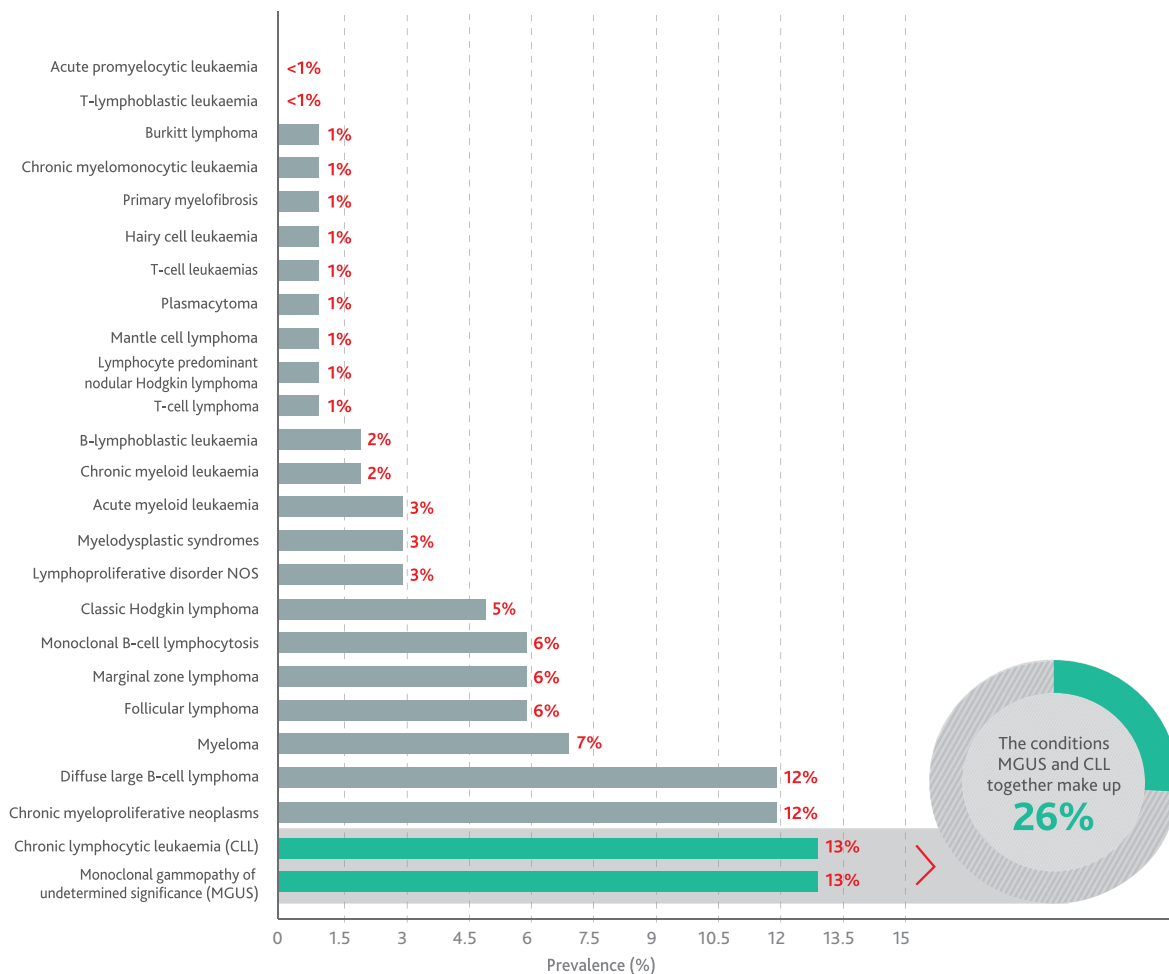
Blood cancers represent one in ten of all new cancer diagnoses each year in the UK – this means that each year 38,000⁵ people are newly diagnosed with blood cancers and closely related conditions. Tragically each year, there are also around 12,000⁶ lives lost to blood cancer.

Prevalence of blood cancers

Prevalence measures the number (or proportion) of people alive on a particular day who have had a diagnosis of the condition in question within a certain period of time – often within the last 3, 5 or 10 years. HMRN calculates 10 year prevalence (those living with a blood cancer or related condition diagnosed in the previous 10 years) as 230,000⁷ – the conditions monoclonal gammopathy of undetermined significance (MGUS) and chronic lymphocytic leukaemia together make up over a quarter of this figure (26%).

HMRN estimate that there are over 30,000 people living with MGUS diagnosed in the previous 10 years. This is likely to be an underestimate and the prevalence could be as large as 600,000⁸.

Prevalence 10 years

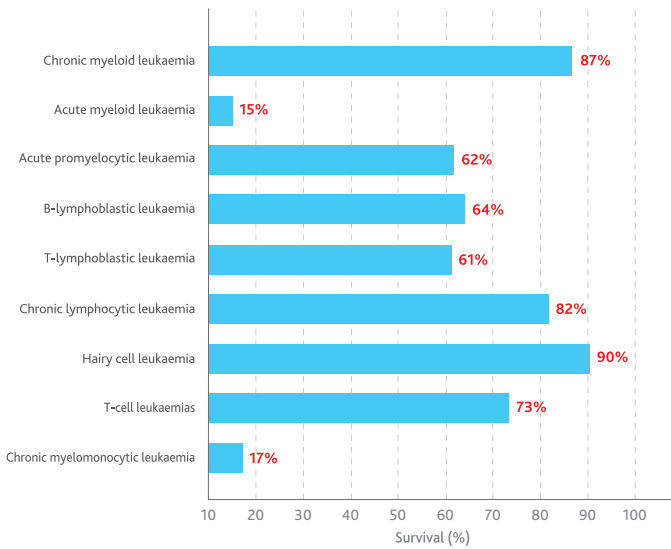


Survival rates from blood cancer

As well as prevalence we also investigated survival rates of blood cancers by condition. Relative survival rates shows whether a disease shortens a patient's lifespan or a treatment prolongs it. It takes into consideration background mortality rates. Survival rates differ depending on blood cancer type, subtypes, age and socio-economic status.

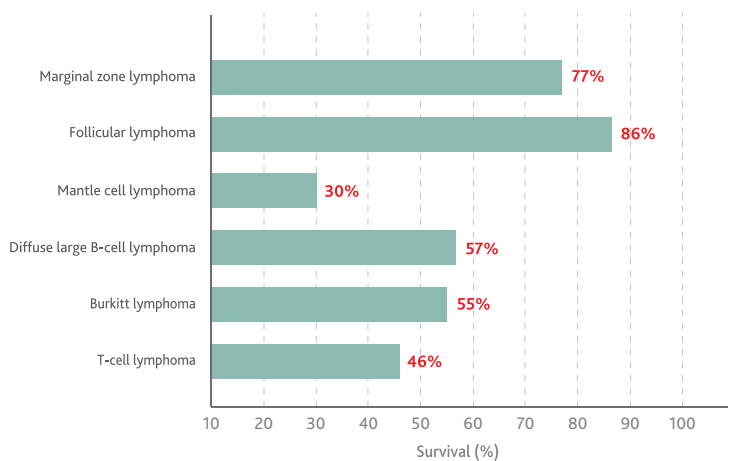
The following charts highlight the five year survival rates broken down by blood cancer type and subtype. All data and information below have been sourced from HMRN for the UK⁹.

Leukaemia – 5 year relative survival rates



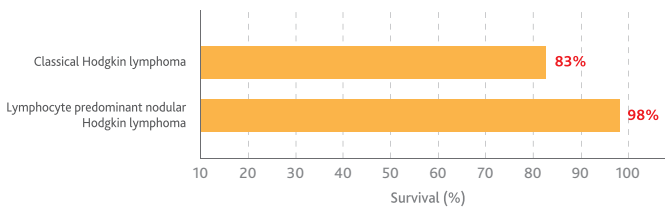
Overall the five year relative survival rate for leukaemia is 59%. Breaking this down into disease subtypes shows variation between 15% and 90%. The highest five year survival rate is for hairy cell leukaemia, a very rare form of leukaemia that accounts for 190 cases new cases a year and 2% of all leukaemias.

Non-Hodgkin Lymphoma – 5 year relative survival rates



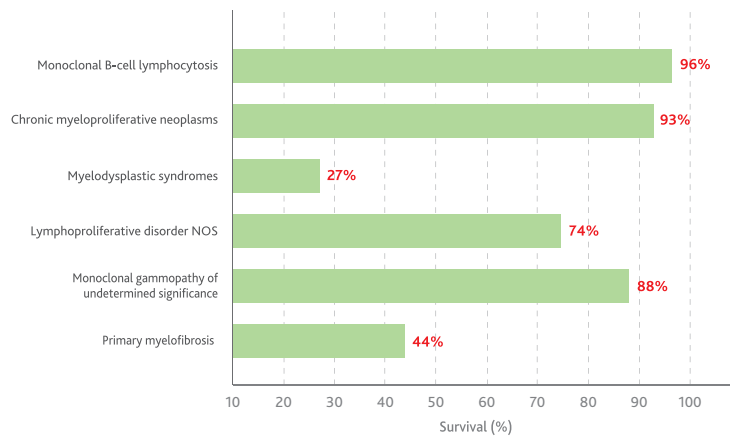
The overall five year survival rate for non-Hodgkin Lymphoma is 65%. Breaking this down into subtypes shows a variation between 30% and 87%. Follicular lymphoma has the highest survival rate (87%) followed by marginal zone lymphoma (77%).

Hodgkin Lymphoma – 5 year relative survival rates



Hodgkin lymphoma has an overall five year relative survival rate of 85%. The most common subtype of this is classical Hodgkin lymphoma accounting for 1,520 expected cases in the UK per year and has a survival rate of 83%.

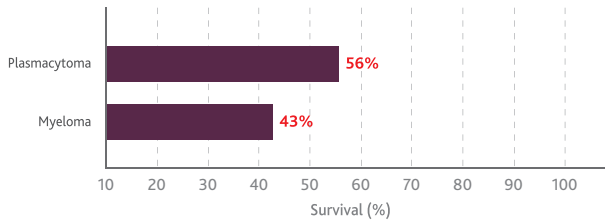
Other disorders – 5 year relative survival rates



The other classifications of blood cancer and related conditions that HMRN classify as 'other disorders' includes:

- monoclonal B-cell lymphocytosis
- chronic myeloproliferative neoplasms
- myelodysplastic syndromes (MDS)
- lymphoproliferative disorder (not otherwise specified (NOS))
- monoclonal gammopathy of undetermined significance (MGUS)
- primary myelofibrosis.

Plasma cell neoplasms – 5 year relative survival rates

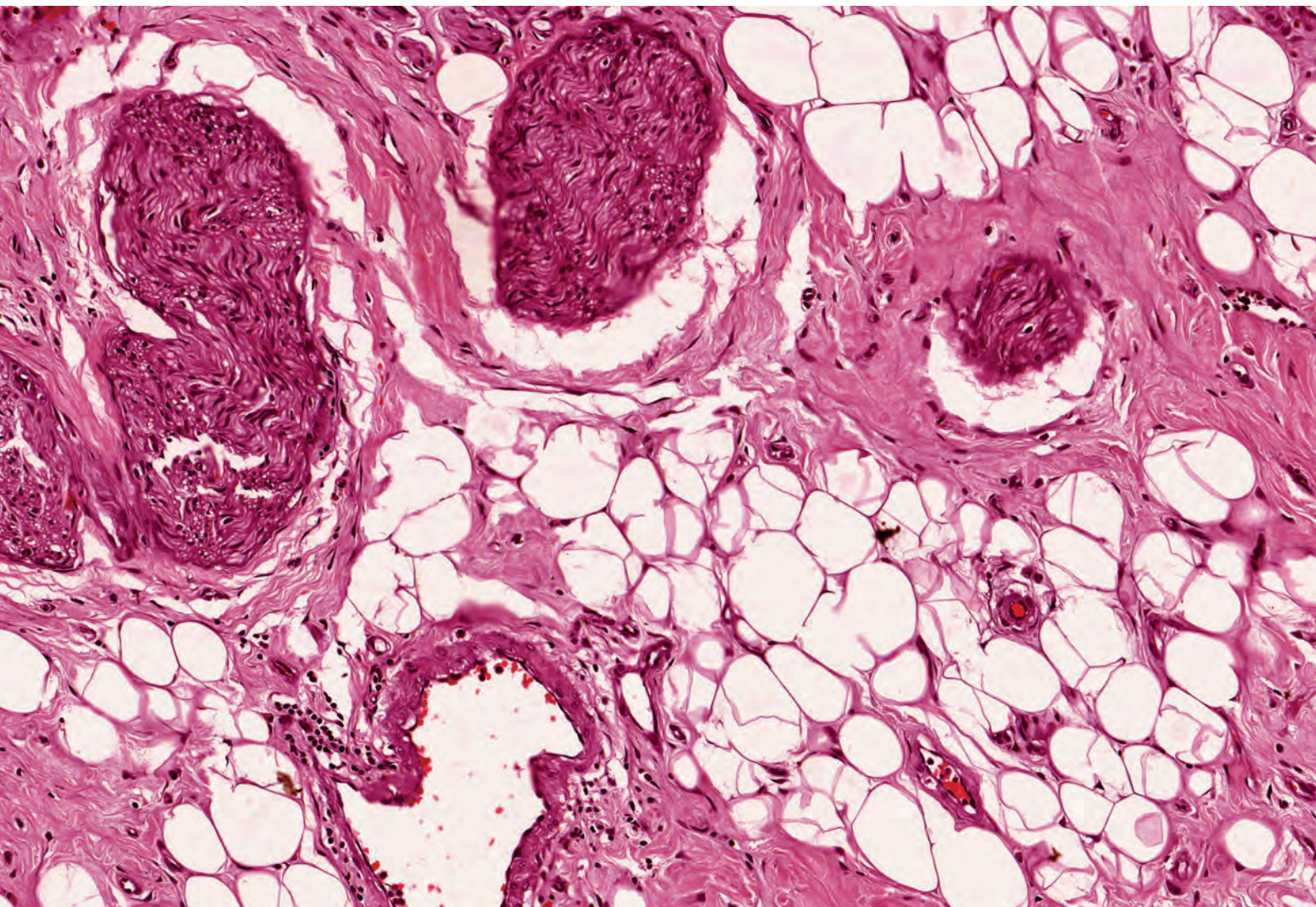


Plasma cell neoplasms include both plasmacytoma and myeloma. As its own entity, myeloma has a relatively low five year survival rate of 43%, and accounts for around 3,920 expected cases in the UK per year.

Lives lost to blood cancers – the biggest killers

To understand the different impact of each blood cancer we analysed the specific conditions that contribute the most lives lost to blood cancers, to identify the conditions that are the biggest killers.

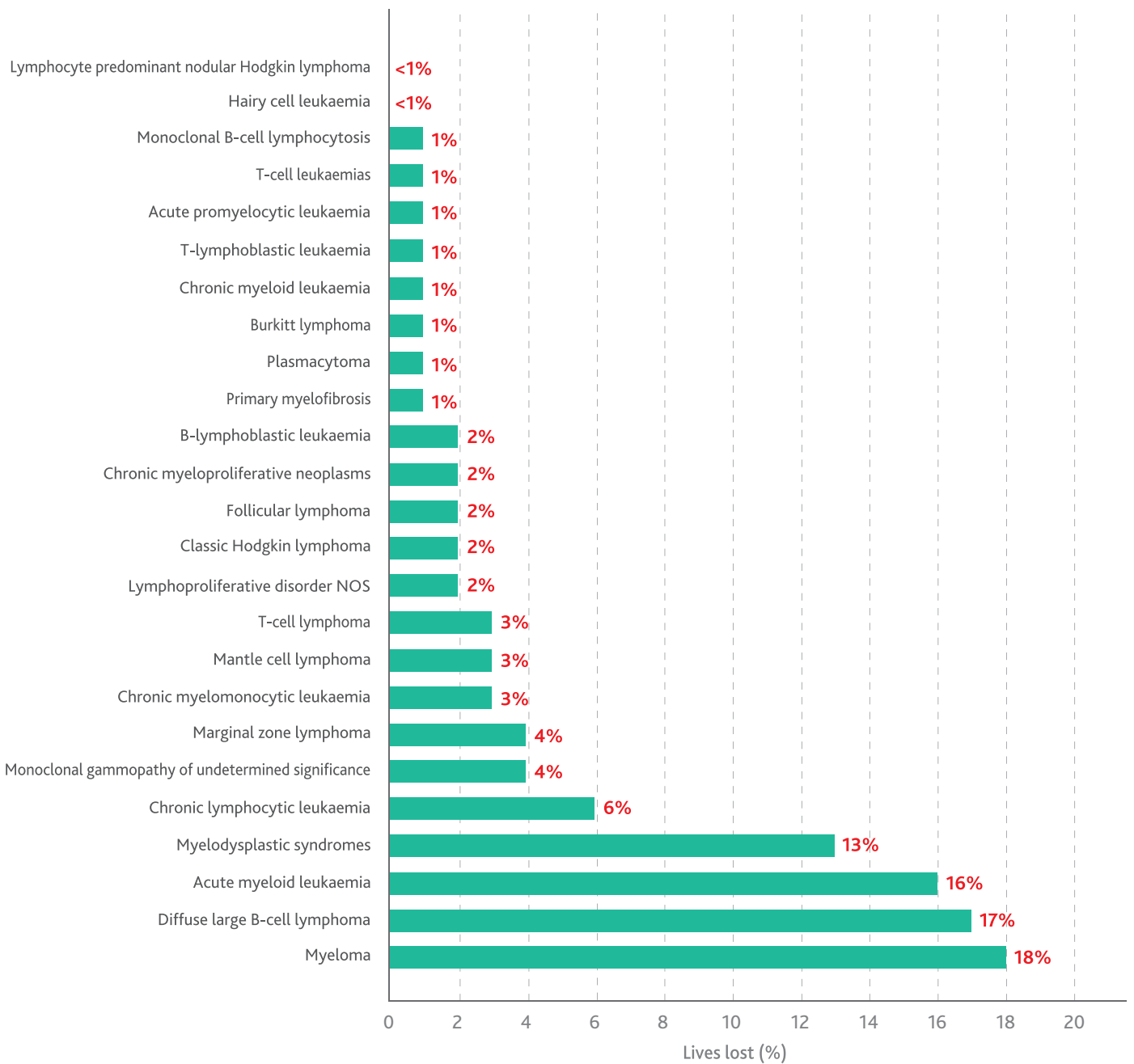
Using HMRN data, we combined expected number of cases and relative survival rates at five years post diagnosis to allow us to calculate the percentage of lives lost for specific blood cancers. The analysis has shown the impact on lives lost at five years since diagnosis across all blood cancer conditions.



Out of many different types of blood cancers, just five make up nearly 70% of total lives lost to blood cancer. The top five conditions with the highest percentage of lives lost are:

- myeloma
- diffuse large B-cell lymphoma (DLBCL)
- acute myeloid leukaemia (AML)
- myelodysplastic syndromes (MDS)
- chronic lymphocytic leukaemia (CLL).

Analysis of lives lost at 5 years post diagnosis



Impact of pre-malignant conditions

The scale of impact from these biggest killer conditions may also be larger if we include the pre-malignant conditions. There is evidence to suggest that some MDS cases will progress to AML¹⁰, and research has shown almost all cases of myeloma arise from MGUS¹¹.

Including MGUS as one of the top conditions increases the total lives lost to 74%. It also highlights that understanding and treating pre-malignant conditions in their own right may help to stop disease progression, and importantly help the successful management of these and other precursor conditions.

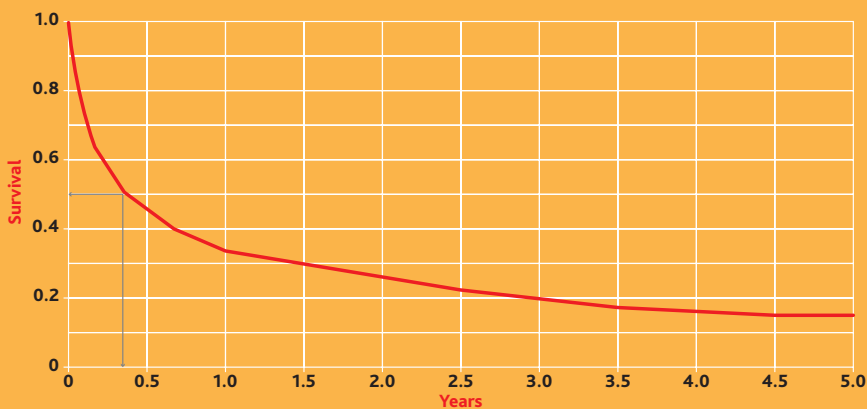


Early deaths

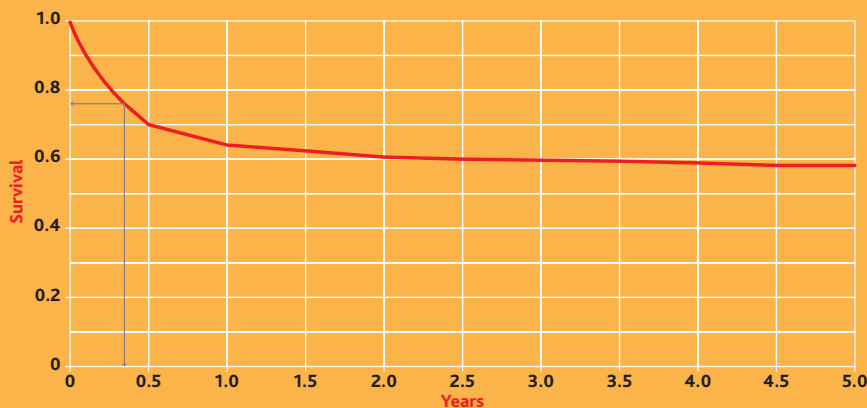
For some blood cancers a large proportion of deaths that do occur do so within the first three months post diagnosis, indicating the importance of understanding the early deaths of patients to improve overall survival rates.

As part of our on-going Patient Need research programme, Leukaemia & Lymphoma Research are working in partnership with HMRN to investigate these early death statistics. This will enable us to have a better understanding of patients who are dying early and what can be done to support patients for longer and potentially improve their survival chances.

Relative survival from AML



Relative survival from DLBCL



Survival rates as analysed by HMRN shows that there are a number of situations where as much as 50% of the disease associated deaths that occur in 5 years from diagnosis actually occur within the first three months.

Two key examples of this are diffuse large B-cell lymphoma (DLBCL) and acute myeloid leukaemia (AML).

Pre-diagnosis – blood cancer awareness and routes to diagnosis

Being aware of blood cancers and their symptoms is the very first point in the patient journey and is a central factor to improving speed and accuracy of diagnosis.

For most cancers, early diagnosis is critical to patient outcomes and survival. Early presentation of patients to primary care and timely referral into secondary care is key. Low cancer awareness can add to delay in presentation to primary care, and low recognition of cancer symptoms may in turn also lead to delay in cancer diagnosis.



Improving early diagnosis can have an impact on the potential for successful treatment. It forms part of the Department of Health's plans in *Improving Outcomes: A Strategy for Cancer*. It is an area that is being invested by the National Awareness and Early Diagnosis Initiative (NAEDI) and others.

The NHS Cancer Taskforce, established in January 2015, has identified earlier diagnosis of cancers as a leading priority. The taskforce identified that, on average, cancers are diagnosed at a more advanced stage in England compared with countries of comparable income. There are some parts of the UK where diagnosis is approaching the level of other European nations, but there is much to be done to ensure that this is the case for all cancers in all Clinical Commissioning Groups (CCGs) across England.

In NHS England's business plan for 2015/16, the target is set for CCGs, GPs and Public Health England to drive improvements in early diagnosis and one year survival rates by March 2016, and to tackle inequalities in outcomes and experience of people with cancer.

Awareness of blood cancers is low amongst the UK general public

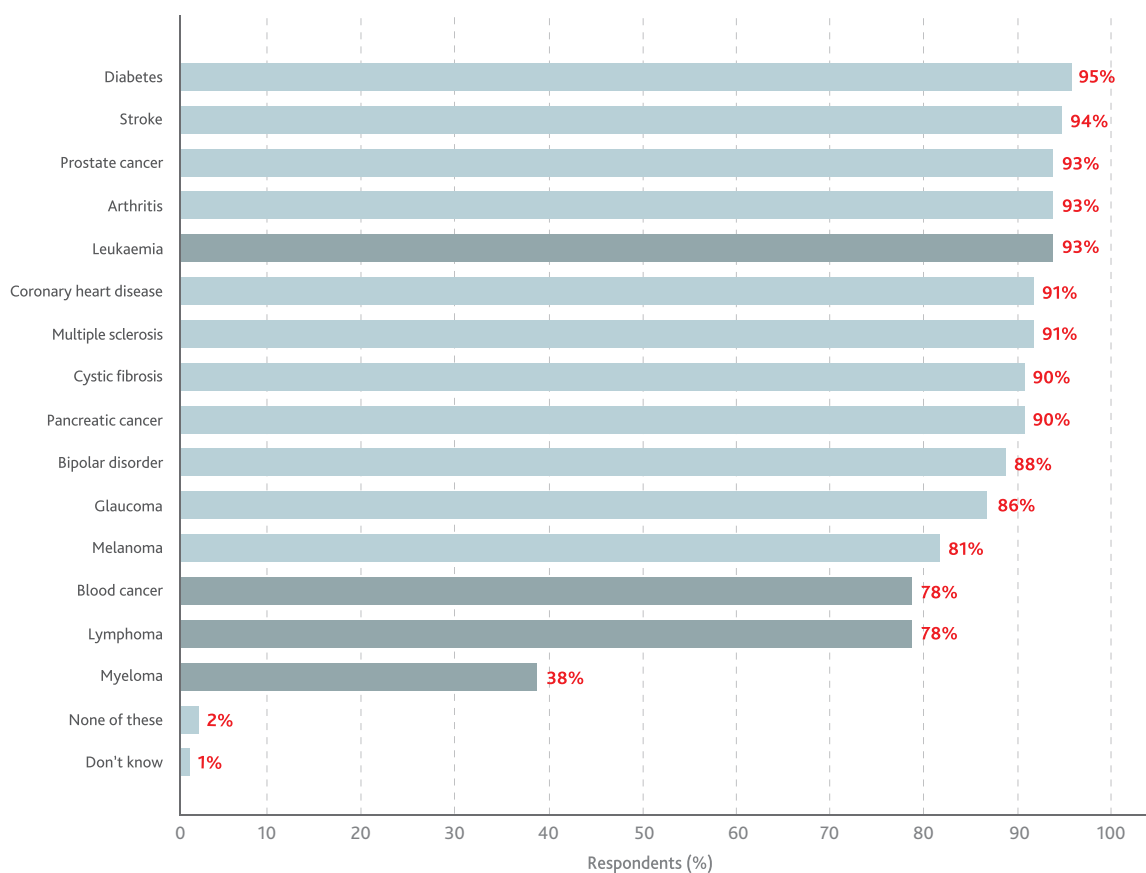
To gain a better understanding of the level of awareness of blood cancers within the UK general public, an awareness study was conducted for this Patient Need programme via a YouGov¹³ nationally representative online survey.

This study has shown that the general population of the UK know little about blood cancers, the related symptoms and how to best describe these conditions.

In the survey, respondents were asked about their awareness of general health conditions including certain blood cancer conditions. This prompted list of conditions included leukaemia, lymphoma, blood cancer and myeloma.

Over 90% of respondents had heard of the term leukaemia – this was a similar level of prompted awareness to arthritis (93%), prostate cancer (93%) and stroke (94%). There was a lower recognition of lymphoma (78%) and the term blood cancer (78%), and an even lower recognition of myeloma (38%).

Awareness of different medical conditions among the general public

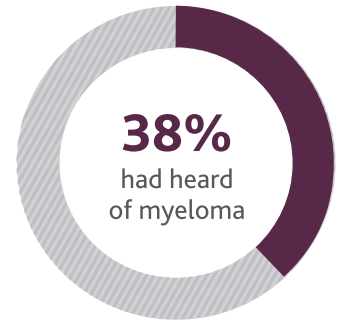
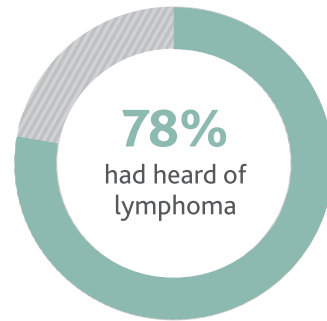
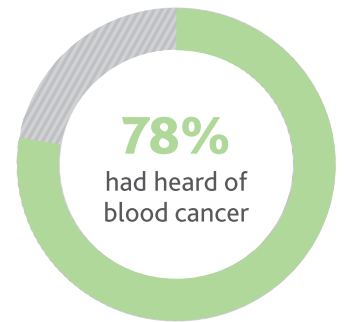
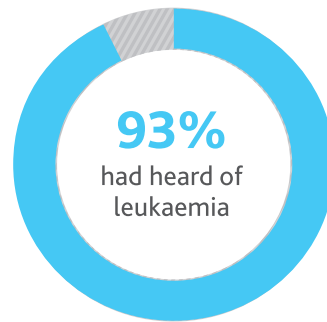


Recognising blood cancer terms

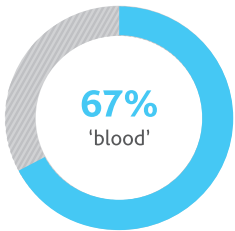
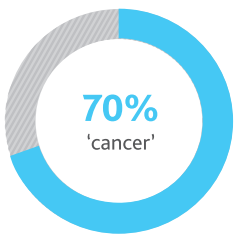
To investigate this prompted awareness further, participants who were aware of the blood cancer conditions were then asked how they would describe these terms to another person. This was completed in order to analyse the level of awareness and understanding they had of these conditions.

This highlighted that:

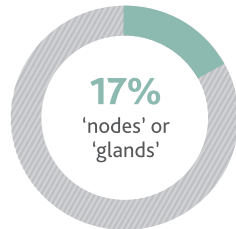
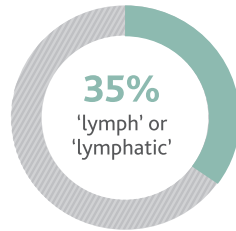
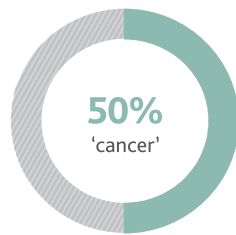
- Leukaemia had a level of awareness of 93%. It was most accurately linked to key terms, such as 'cancer' (used by 70% of respondents) and 'blood' (used by 67% respondents).
- For those who recognised the term lymphoma (78%) – 50% of these described it as a cancer. They also used terms such as 'lymph' or 'lymphatic' (35%) and 'nodes'/'glands' instead (17%).
- For those who recognised the term myeloma (38%) – 50% linked it to the word 'cancer', 16% to 'bone marrow'. Over 10% indicated the condition was related to 'skin' – confusing the term with melanoma.



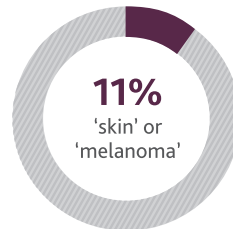
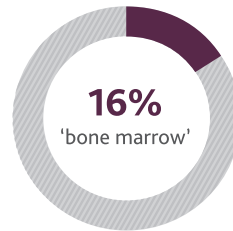
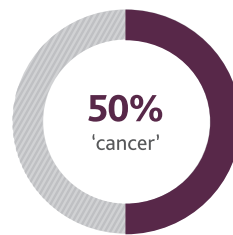
Leukaemia top terms mentioned:



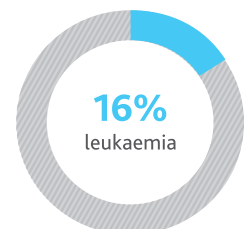
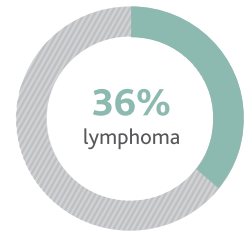
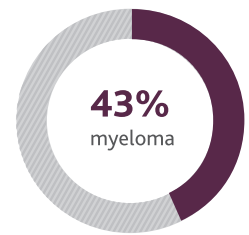
Lymphoma top terms mentioned:



Myeloma top terms mentioned:



Those who didn't know how to describe these conditions:



This study highlighted the different ways the general public described blood cancers, including many who didn't know how to describe them.

Patients also highlighted the impact of low awareness before diagnosis

This wider lack of public awareness is also reflected in patients, with many indicating during our research they hadn't heard about their condition before diagnosis. For many patients, the lack of awareness resulted in a greater need for information about the condition itself and the associated signs and symptoms.

"I'd never really heard of leukaemia before my diagnosis." – Patient

"Having never heard of myeloma a lot more information would have been useful." – Patient

For many patients this lack of awareness of their condition added to the difficulty of coming to terms with their diagnosis. Increasing awareness of blood cancers among the public is seen by many patients as important for improving the experiences of current and future patients.

"There needs to be more awareness in the general public about blood cancers. Because a lot of people think that someone with cancer would normally be having an operation or receiving chemo they don't understand conditions like mine." – Patient

Lack of awareness of blood cancers can impact early diagnosis

Symptoms of blood cancer are not always clear and therefore the patient may cause delay by not seeking out medical help, and GPs may cause delay by not spotting the symptoms as signs of blood cancer.

The non-specific nature of many blood cancer symptoms, such as night sweats, flu-like symptoms, tiredness, pain, itching and their similarities with other benign conditions, and the relative rarity of individual diseases make diagnosing blood cancer and awareness of them a challenge for patients and GPs. For many patients their condition is picked up by chance, or in the process of testing for other conditions.

"Mine was diagnosed by a routine blood test – I was feeling very, very tired it wasn't normal for me." – Patient

During our study, we asked patients to look back and think about the symptoms before they were diagnosed. They mentioned many associated symptoms but they weren't aware at the time that when put together these could be signs of blood cancer.

"It's not symptomless, there are symptoms, it's just that it's difficult to put them all together and go, 'ah'. Because there are symptoms, there's weight loss, night sweats, lumps and bumps and things, and not feeling 100%." – Patient

"I had really severe night sweats for about six to nine months before I was diagnosed. I never once mentioned them. I was confused, thinking it was something to do with the menopause." – Patient

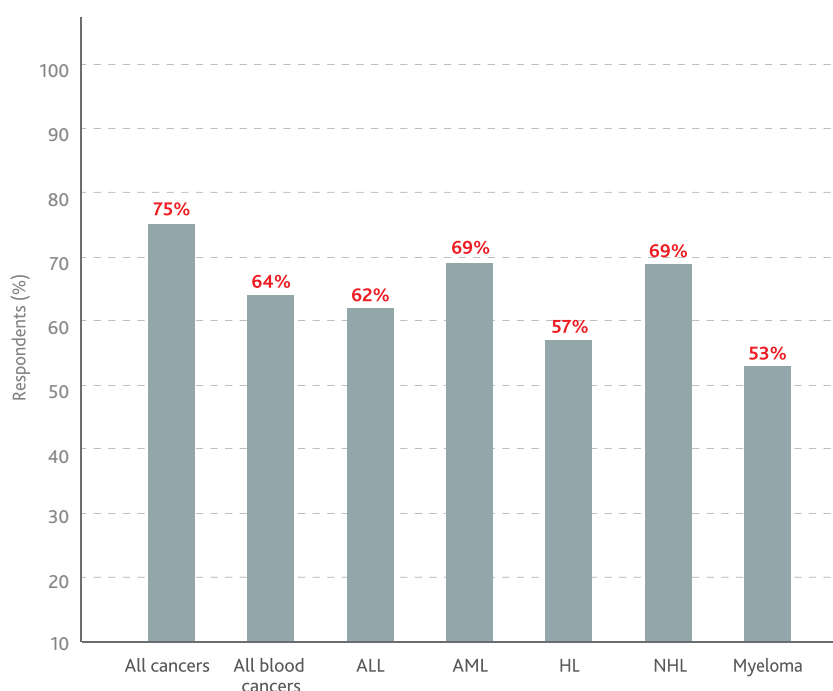
Levels of awareness in primary care

This low awareness of blood cancer symptoms may also be apparent at primary care level in GP settings. The National Cancer Patient Experience Survey (NCPES) shows that on average patients with haematological cancers have to go to their GP more times than other cancer patients before being referred to hospital. More than one in three (36%) of patients with blood cancers saw their GP three or more times, in comparison to one in four (25%) all other cancer patients.

In order to understand this issue across the different blood cancer conditions, we commissioned Quality Health¹⁴ to analyse the experience of blood cancer patients and break down the results from the 2013 and 2014 NCPES by type of blood cancer.

This analysis highlighted that over half of patients with Hodgkin's lymphoma (57%) and myeloma (53%) reported going only once or twice to their GP before being referred. These are lower proportions than across the other blood cancer conditions, indicating potential challenges around diagnosis and awareness specifically for these conditions.

Percentage of people who saw their GP once or twice before being diagnosed



Evidence suggests that delay in diagnosis may be related to UK referral guidelines

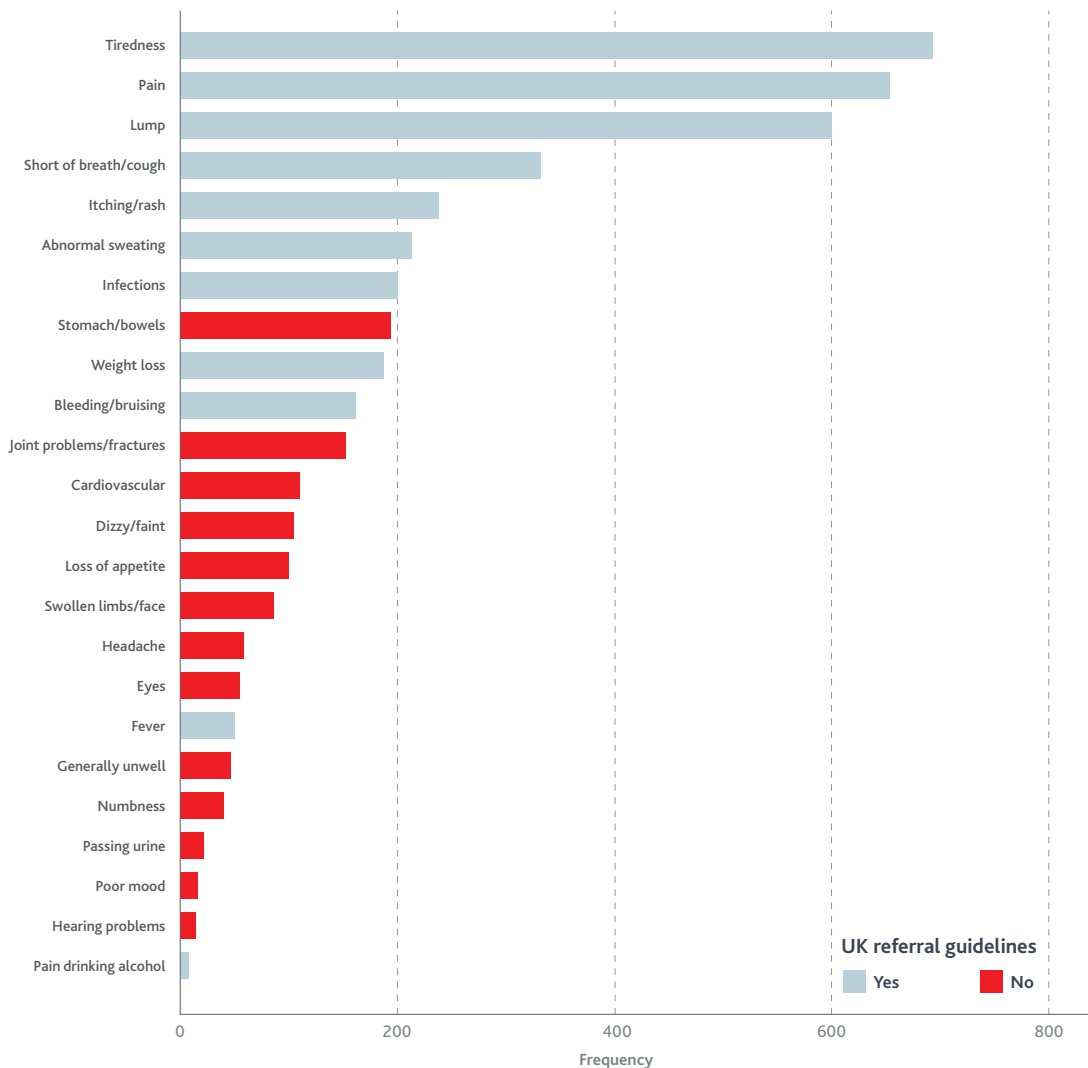
In a study¹⁵ by HMRN, information on symptoms and frequency were recorded. The results show that the National Institute for Health and Care Excellence's (NICE) UK Referral Guidelines to guide doctors and health professionals in referring suspected cancer cases to specialists may not be listing the most appropriate symptoms.

The symptoms recorded in the referral guidelines, for blood cancers, are shown by blue bars. Certain symptoms in the guidelines were mentioned in the study by patients comparatively infrequently, most notably pain when drinking alcohol, which was only reported by five patients – all with lymphoma.

By contrast, patients also identified a range of other symptoms, not listed, including stomach/bowel problems, joint problems and fractures, cardiovascular problems, dizziness and loss of appetite.

NICE has recognised there is a problem with referral guidelines and is updating their guidance to GPs on cancer symptoms, in order to speed up diagnosis. The new guidance is currently undergoing consultation and the anticipated publication date is May 2015.

Reported symptom frequency and comparison to UK Referral Guidelines



For some patients, the condition may have progressed to such an extent that they present in A&E to begin their diagnosis journey

For some blood cancer patients, the condition and related symptoms can progress rapidly and lead people into diagnosis via emergency routes. A national study by NCIN¹⁶ looked into routes to diagnosis. Routes to diagnosis is defined as the path a patient takes through the health system to the point of diagnosis.

The study looked at all cancer patients presenting via emergency routes and the effects this has on survival rates. It found that lower survival rates are linked to later stage diagnosis. It also highlighted a link between emergency presentation and later stage diagnosis, which can lead to poorer survival chances.

NCIN looked at patients diagnosed with a blood cancer from 2006 to 2008. It showed that over 50% of patients diagnosed with acute myeloid leukaemia (AML) were being diagnosed in an emergency setting. It is thought that this may be due to the acute and quick onset of this condition and potentially missed onset of symptoms.

A high proportion of patients with myeloma were being diagnosed at emergency presentation (37%) – this may be explained by broken bones being the trigger for diagnosis. However, 35% of chronic myeloid leukaemia (CML) diagnoses also happened in an emergency setting – which may be influenced by low awareness of symptoms.

Diagnosis (2006–2008)	Emergency Presentation
ALL	63%
AML	54%
Myeloma	37%
CML	35%
NHL	27%
CLL	25%
Hodgkin Lymphoma	17%

Many patients therefore are facing a blood cancer diagnosis within an emergency setting, creating different challenges and support requirements at this stage and when moving forward into their treatment.

There are significant challenges around awareness of blood cancers that are having an impact on the symptom recognition, diagnosis and experiences of blood cancer patients. For many patients and healthcare professionals this is a key issue that needs to be addressed to improve patient experience and outcomes.

Diagnosis – The beginning of the patient journey

Being diagnosed with cancer often comes as a shock. Throughout this research patients have told us with clarity and courage about the impact of their 'diagnosis moment'.

For patients, this is the start of a longer journey. It is therefore imperative that the information, advice and support given at the point of diagnosis are what patients need and want. The impact of a suspected cancer or cancer diagnosis on a patient can also be reduced with timely referral and good professional communication.



The diagnosis moment

Within our Patient Need survey, 70% of respondents felt their needs were met at diagnosis. However, when patients describe their experiences they vary enormously both in the way diagnosis is communicated and what information and support is provided.

Within the diagnosis stage, many patients felt improvements could be made around balancing the need for information and for empathy, and the communication method used to deliver the diagnosis.

- For some patients, this was focused on the tone of delivery:

"Around lunchtime, a doctor came in – I had never seen her before and I never saw her again. She walked in and spoke quickly and abruptly. I can still hear her words now." – Patient

"The diagnosis was delivered in a completely cold, calculated way. I walked out of the room and just burst into tears, it was very cold and unthinking, it was just unpleasant." – Patient

- For others, it was related to phrasing about certain blood cancers which was difficult to face in such a confusing and emotionally challenging moment:

"Great news, you may have got cancer but you've got the best one to have." – Patient

"When people tell you you're very lucky to have this cancer... There's no luck involved, I'm fortunate it's not as serious as it could have been." – Patient

"The only other thing that could have been improved was the language used. It would have been great if there was a consistent dictionary or whatever of terms." – Patient

- Our research also covered the varied methods used in diagnosis delivery. The majority of patients we spoke to were told face-to-face but some mentioned diagnosis information being given over the phone, or even via email. The method of delivery is as sensitive as the diagnosis itself, and for many patients face-to-face was the preferred option.

"The verbal communication I got on diagnosis and afterwards was fantastic, from the people I saw in person, to the treatment and service I received." – Patient

Understanding a blood cancer diagnosis

Understanding the full detail of a blood cancer diagnosis can be challenging at first and evidence suggests some patients feel less satisfied with what they hear.

The NCPES illustrates at a national level the issues for blood cancer patients at diagnosis stage. One question in the survey where blood cancer patients have a less satisfactory experience than other cancer patients is in relation to, 'completely understanding the explanation of what is wrong'. Only 58% of blood cancer patients said they completely understood in comparison to an average of 73% of cancer patients, and 79% of patients with breast cancer.

"There was a lot of confusion, and I hadn't heard of MDS before. I think the diagnosis and treatment regime could have been explained much more carefully, especially to my parents, to ensure they understood." – Carer

Information needs at diagnosis

Information delivered at diagnosis can help patients understand their condition and the next steps. Good information may improve self-management by patients, reduce inequalities in accessing care and support people in returning to as normal a life as possible following and during their cancer treatment. Information can also empower people to exercise informed choice.

Our Patient Need survey highlighted that information needs are high at this stage, with nearly all patients wanting information on:

- prognosis (95%)
- information on their specific cancer (95%)
- details of the procedures (91%).

These key areas were also accompanied by a need for more supporting information areas such as psychological support (80%), signposting (80%) and practical advice (42%).

Many healthcare professionals already recognise this high need for information at diagnosis.

"Patients need specific, good quality, accurate and up to date information about diagnosis – with different levels of complexity. Patients need a personal delivery followed up by clear, written information." – Clinical Nurse Specialist



Finding information from sources outside of the healthcare setting

The heightened need for information at diagnosis often leads both patients and carers to look in other places for support. The internet is frequently mentioned as an alternative first source outside of the healthcare setting, which depending on the website accessed may not include the most up to date information, provide information that is beneficial to patients within the UK healthcare system, and information that is found may be detrimental to the health of the patient or conflict with planned conventional treatment.

“My GP didn't know anything so I had no choice but to Google.” – Patient

“Patients are always saying we consistently need to be given accurate information. Don't let them run away to the internet. At least guide them on the internet of where to find the first place to go, go here first before you do anything else.” – Patient

In our survey, 80% of patients highlighted a need for signposting to information and support at diagnosis. Signposting to the most appropriate information is therefore a priority for patients at diagnosis.

The pivotal role of GPs in the diagnosis and referral of blood cancer patients

GPs are often the first point of contact for many patients and therefore play a pivotal role in diagnosis. From our research we have seen the challenges faced within primary care around symptom recognition and diagnosis, with many patients having a prolonged diagnosis stage which can impact their quality of health.

“I had frequent night sweats, various non-specific pains... Doctor after doctor told me it was my age or worse, in my head.” – Patient

The NCPES also asked patients if their health remained the same or got better whilst waiting to see a GP. The results show a lower proportion of blood cancer patients answered yes to this (68%) in comparison to all cancers (80%).

GPs need support in spotting blood cancers, and importantly clear and accessible referral options to reduce the delay for patients around diagnosis and accessing relevant treatment.

Treatment and clinical trials for blood cancer patients

Blood cancer can be treated in different ways depending on the type of blood cancer and how advanced the disease is at diagnosis. Treatment regimens can be as personalised to each patient as the experiences they go through.

However, patients have highlighted there are some things that contribute to a positive treatment experience including building a relationship with their medical team, having easy access to a clinical nurse specialist and access to good quality information.



Treatment is rated highly by the majority of patients and especially once they're in 'the system'

Patients have demonstrated high satisfaction with treatment and the services they receive at this stage of their journey. Just under 80% of respondents to our survey felt the needs of the patient had been met at the treatment stage – the highest level of satisfaction of any stage.

The national data from NCPES 2014 also indicates high levels of satisfaction for many blood cancer patients during treatment, with many patient's rating care as 'excellent' or 'very good' (92% for blood cancer patients in comparison to 89% for all cancer patients).

Within our qualitative research, patients and carers also highlighted elements that are key to this satisfaction, focusing on the importance of relationships they have and support they receive from their medical teams, and the information and advice they can access during treatment.

Building their relationship with medical professionals within secondary care leads to a positive experience within treatment

Once within secondary care, for many patients it will be referral to a haematologist that leads to the beginning of treatment.

This initial meeting and relationship with the consultant has been highlighted by patients we spoke to as a critical stage in preparing them for the treatment journey ahead.

"It's so important to get that initial meeting right because I think from then on it puts you in a better frame of mind." – Patient

We've heard from many patients throughout our research that during treatment especially, the medical professionals and the relationship they have built with their consultant has been remarkable.

This came across in the majority of focus groups as something that patients deemed very important and patients have been beginning to highlight to us what they really value from their doctor.

"They really are very caring, gentle and perfect, I don't know how they could be improved." – Patient

"He was lovely - I sat with him for a good half an hour and he went through it all and explained it thoroughly." – Patient

This theme has also been noted within national patient experience data, where blood cancer patients score highly when asked about their experience with medical professionals. The majority of blood cancer patients responding to the NCPES said they had confidence and trust in all doctors treating them (82%). This was similar to the percentage for all cancers (85%).

Positive impact of clinical nurse specialists

Clinical Nurse Specialists (CNSs) are critical in providing personalised support for patients throughout their cancer journey. They can help improve patient experience by acting as a patient advocate, playing a key role in patient care management, and providing a main contact for patients. CNSs often play a fundamental role in the experiences of patients with blood cancers.

At a national level, the single most important factor⁷ associated with better patient experience, in every tumour group, is the patient being given the name of a CNS in charge of their care. The NCPES showed the number of patients having a CNS has continued to increase in each year that the survey has been undertaken (up from 84% in 2010 to 89% in 2014). Haematological cancer patients reported just below the average, with 87% being given a named nurse in 2014.

Our qualitative research has backed up the importance of having this named individual to blood cancer patients. Patients highlight the benefits of this relationship and being able to easily access CNSs for support. They saw their CNS as a critical point of contact if they need information or support.

"The local consultant and specialist nurse were brilliant... We have had great support." – Patient

"I think it was the care that I received on that ward from my specialist nurse and all the other nurses that got me through it." – Patient

"(CNS told me) if there were any problems, any time, before you come back to see us, give me a ring." – Patient

However, our research also highlighted that it's not just those named as a 'clinical nurse specialist' – but also the research nurses allocated to a patient during a clinical trial that also provide vital information and support.

"I saw the research nurse, who was absolutely excellent - she went through it in a way that anybody could understand." – Patient

Accessing information and support during treatment helps improve experiences for patients

Many patients mention a need for information during treatment, particularly a clear understanding of side effects and long term effects of treatment.

Our Patient Need survey showed that nearly all patients have a need for information on side effects during treatment (97%); however, national data suggest not all patients are getting the information they require. Within NCPES, around three out of four patients with haematological cancers agreed side effects of treatment were explained to them (72%). This is a lower proportion than seen in some other cancer settings, such as breast cancer (79%).

"There are all sorts of little things that have happened because of the chemotherapy, we were never told that these things might occur... I'm still now, two years after the chemotherapy and rituximab, still having treatment for them." – Patient

Many patients said there is a high need for preparation for post treatment and helping to understand side effects may enable patients to do so. In our patient need survey, 70% of patients said they had a need for this. This was also highlighted in our qualitative research, where patients have flagged fears of relapse and the possibility of secondary cancers.

Research is needed to reduce secondary cancers and long term side effects

There have been significant advances in treatments and survival rates for many of the blood cancer conditions. However the powerful treatments that help save lives can also leave side effects and long term health problems. In some cases the treatment can cause secondary cancers.

Research to find ways to reduce the toxicity of treatment, minimising the risk of secondary cancers and long term side effects, is critical to meet these needs. Our researchers are already working towards these needs in the hope to prevent secondary cancers.

One way to vastly reduce secondary cancers is to develop targeted biological therapies – investment is needed to develop therapies that are more targeted to the cancer and less damaging to healthy tissues.

The variety of treatments for blood cancer

Treatment plans are often different depending on the specific cancer type and characteristics of the individual patient. Patients can be treated through:

- acute treatment
- watch and wait
- long-term management
- transplant.

Our study has highlighted the different patient experiences across these treatment routes.

One type of care is a period of watch and wait or active surveillance

For patients on watch and wait, this may be an incredibly distressing time. Patients at this stage have told us that more information and support is needed.

Patients will remain in this stage until tests suggest their condition is progressing or likely to do so, or symptoms become more significant. For patients, waiting to see how their condition progresses can be a very difficult time.

Our survey showed that only 61% of patients felt their needs were met at this stage, the lowest levels of satisfaction out of all the stages represented in the survey.

Being told you have cancer and being informed that it isn't going to be treated immediately can be hard for many patients to digest and understand. They have said that more information is needed to help both them and their family and friends to fully understand this approach and why they are being placed on a period of watch and wait.

"What do you mean, you've told me I've got cancer, you don't want to treat me?" – Patient

"You're telling your friends and they ask 'What treatment are you having, they're not doing anything. What do you mean they're not doing anything'. The public don't get it..." – Patient

For patients, a clear need at this stage is access to emotional and psychological support. Our survey highlighted this as the greatest patient unprompted need for people on watch and wait, mentioned by nearly one in five of patients at this stage. For some patients, living with the burden of knowing you have a cancer can be difficult to come to terms with and extra support is needed to help them through this stage, and to plan for the future.

"I didn't plan, my whole life was planned around 3 monthly check ups." – Patient

"It's one thing to hear the words and read about it, but I think emotionally and psychologically to come to terms you need support." – Patient

In addition to emotional and psychological support, patients answering our survey have also highlighted a need for information on signs and symptoms of progression (93%) as well as information about length of time on watch and wait and treatment options (93%).

Treatment outcomes may differ depending on socio-economic group

Daily treatment of the condition has become the norm for some patients – however, some patient groups may experience compliance issues and therefore further research is needed to maintain adherence.

Improvements in treatment have considerably lengthened survival times for many blood cancer patients.

For example, many people diagnosed with chronic myeloid leukaemia (CML) take a pill every day and most patients can expect close to normal life spans.

“I am very well, I have a perfectly normal life and am incredibly fortunate. The advances in CML in the last 12/13 years are just unbelievable, simple as that. I take a pill a day and that’s me sorted.” – Patient

For some, daily management of cancer as a long-term condition has become the norm which brings up other issues.

Some studies¹⁸ have shown that those living in more deprived areas tend to have poorer outcomes. A population based study looking at patients with CML showed that around 95% of patients from the most affluent groups were alive after five years, compared with just 80% of those from more deprived groups – despite having the same access to clinical care and treatment. This study suggested that this might relate to failure to adhere to the treatment regimen. Further research is therefore critical to identify if this is the cause, and to help patients in these situations.

A study published in 2012¹⁹ looked at the impact of social inequality on survival in childhood acute lymphoblastic leukaemia (cALL). The study looked at nearly 2000 children and analysed survival rates by deprivation. The results found the survival rates were different according to deprivation six to nine months after diagnosis. The study also found that differences in survival by deprivation were even starker in patients enrolled within a clinical trial setting, highlighting that the differences were not due to access to treatment.

Transplant needs

For some patients, initial rounds of treatment are not successful. Some patients may therefore need a stem cell transplant and it can be their only chance of survival.

The psychological and physical effects of a transplant can have a serious impact on the long-term quality of life patients can expect after their treatment, much in the same way as any other treatment for blood cancers. Therefore, there is a need to make sure efforts are in place to work with this group of patients to improve their quality of life, and have access to support post-transplant to ensure they are assisted with the entire range of impacts of transplant.

Our survey highlighted the needs of over 300 respondents that have had a transplant, including carers.

At treatment, most patients going through transplant needed:

- support from family and friends
- clear information about treatment and options
- reassurance that the treatment is working.

Post treatment needs of transplant patients included:

- support and advice on what to expect, the long term side effects and risk of relapse
- reassurance help was there after treatment
- post treatment follow up.

Remission

If remission is achieved, patients want to be given all the opportunities for their condition to remain that way – however, there is an underlying nervousness amongst some patients that it may come back.

“But since, I’ve had a feeling of unease because I think how can it have gone. Because they say to you, we can’t ever say you won’t get it again. It might be in another part of your system, and I think that’s what’s stayed within my mind.” – Patient

Researchers are already working towards new transplant protocols to increase the effectiveness and safety of transplant and maintaining remission by monitoring for signs of relapse. More sensitive and accurate monitoring of patients will help clinicians better understand relapse and know when the best time to resume treatment

“It’s in remission at the moment and has been for the last three years... and hopefully it will continue.” – Patient

One example is to use minimal residual disease testing – which is used in the treatment of childhood ALL. Using this test, clinicians can better gauge response to initial treatment and detect possible relapse earlier.



Different age groups of patients with blood cancer

As well as different treatment types, people of all ages go through blood cancer. A high proportion of people with blood cancer are over the age of 50 (87%) – however there are a number of younger people with blood cancer too. These two age groups often have a variety of needs.

Older patients

As society ages, the number of people affected by cancer will increase. This is relevant for blood cancers, which more often occur in older people. The average age of a patient at diagnosis with a blood cancer is 70.

Living with blood cancers is difficult at any age and the experience is particularly challenging in older patients.

Several issues have been highlighted for older patients including gaps in patient experience, particularly around information and communication available to older patients and clinical trials.

Patient experience

Older patients have specific information and practical support needs. A recent study of Patient Reported Outcome Measures (PROMS) revealed that non-Hodgkin lymphoma (NHL) patients over the age of 75 reported that they had the most difficulties with mobility, undertaking their usual activities and fulfilling domestic chores, compared to any other age group²⁰.

Clinical trials

Increased participation of older people in clinical trials may help to generate more data on the efficacy of treatments in older people and improve understanding about how cancers behave differently among this group and the impact of different treatment regimens. Many clinical trials, however, specifically exclude older patient groups. More trials are needed that focus on testing appropriate and effective treatments in these groups.

Older people report a positive experience of cancer treatment and care

Anecdotal evidence suggests that older people are more likely, than younger patients, to have confidence in doctors and nurses and feel that they were treated with dignity and respect. However, there are also areas where improvements can be made. In particular, older people are less likely to have access to a clinical nurse specialist or report being given information on side effects of treatment²¹.

As with national data, our survey highlights that at every stage, older patients (65+) were more likely to agree their needs were met in comparison to the 17-64 age group.

Understanding experience of this age group is critical to ensure support and information resources are appropriate

With a view to gaining insights into the general nature of the relationship between chronological age and treatment of blood cancers in the UK, a project by HMRN²² co-funded by Leukaemia & Lymphoma Research and The Association of the British Pharmaceutical Industry (ABPI) was established.

Whilst patients' age did not determine chemotherapy use as such, older patients were more likely to receive less intensive or attenuated doses. However, the study also found that if older patients got through the initial stages of treatment (where half of deaths occur in the first few months in some conditions) their survival curves parallel those of younger patients, indicating that they benefit just as much from existing treatments.

Younger blood cancer patients

Although the average age of blood cancer patients at diagnosis is 70, it can affect all ages.

in our qualitative focus groups, some of the younger patient groups we spoke to felt their needs were not met. It was felt that the patient literature is targeted in content and look towards much older patients and therefore younger patients can feel unsupported.

"The thing is with CML, a lot of people seem to think it's not for young people, but what you see is an awful lot of young people with it. The literature doesn't really reflect that very well, it makes the younger people feel ignored." – Patient

Younger people also flagged their needs around employment, finances, anxiety and depression²³. Evidence from this phase of research has highlighted that younger people have specific needs that we need to further evidence within phase two of this study.

Clinical trials and access to treatment

There are key issues around access to and understanding of clinical trials.

We found that 38% of blood cancer patients surveyed within the NCPES had been invited to take part in blood cancer research (in comparison to 31% of all cancers). Of those asked, 71% had elected to take part in clinical trials. This was in a comparison to an average of 63% across all cancer types.

However, when patients mentioned clinical trials in our focus groups there was a mixed reaction. Those who knew and were informed about clinical trials knew the importance of them – however, those who weren't were apprehensive and wanted more information.

"I was offered a clinical trial when I was first diagnosed, I was very nervous and scared of going onto a trial because I thought it was a new drug that was untested – I needed more information to help me decide." – Patient

An area where needs aren't always met is access to treatment and new drugs. Many patients would like to ensure that effective new drugs are made available on the NHS to all patients who will benefit from them.

Access to new medicines is a complex policy area, which brings together many issues – how to effectively assess new medicines, how drugs are priced, how are medicines developed are just some of the areas that need resolving.

"The NHS simply can't afford the expensive drugs for all blood cancer patients at the moment. These new drugs are going to cost, there's no two ways about it." – Patient

We will be working with health policy decision makers to ensure there is a long term and sustainable model for providing new drugs for all NHS patients who require them.

Support for patients and carers

For patients and carers, the need to access information, advice and support is critical at all stages of their journey. These services provide much needed guidance and knowledge as they go through the many challenges that facing cancer can create.

A key aim of our study is to highlight all the current support that is available for blood cancer patients, how they are accessing it and what is working. Our research has shown there are certain ongoing unmet needs due to lack of provision, but importantly there is also a lack of understanding of what support is available and appropriate for blood cancer patients and their families.



Access to information and advice

Patients are looking for personalised, clear and accessible information and advice on the topics most important to them – from the day of diagnosis and throughout their journey

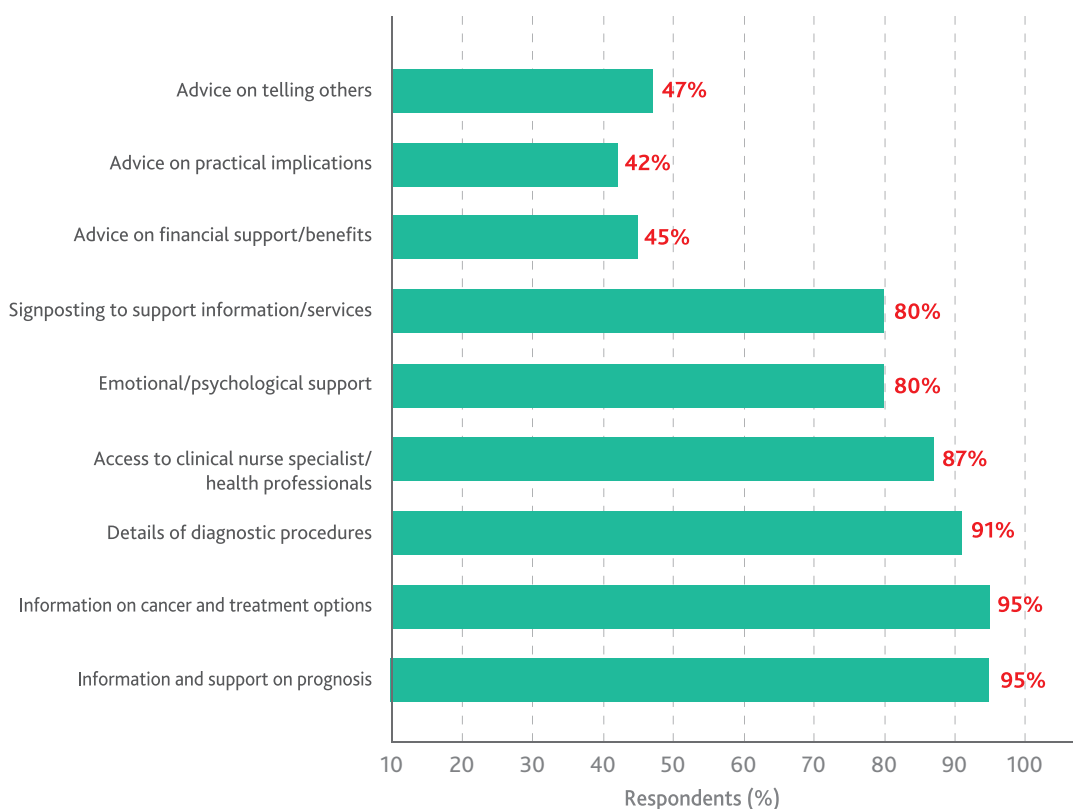
Providing clear and accessible information and advice to patients can support high quality decision-making, and is essential to ensuring patients feel empowered to access the best services, treatment and support. Many blood cancer patients we spoke to received the majority of their information at diagnosis stage, but information is essential across the patient journey. Relevant support is also required throughout to ensure that patients who receive this information fully understand what it means for them and their treatment and care decisions.

A key area of support for blood cancer patients is information about the specific cancer, prognosis and treatment types available – our Patient Need survey shows that demand for this type of information is high (95% of patients indicated they had a need for this). However, alongside this condition and treatment information, the majority of patients also require information on supporting elements – such as:

- emotional support (80%)
- practical advice, such as how to tell others (47%)
- information on financial support and relevant benefits (45%).

Patients in our survey highlighted that they have lower levels of satisfaction with, or even access to, this type of supporting information. It should continue to be an area of focus across all areas of support to ensure patients receive high quality information across all of their information needs, and importantly throughout all stages of the patient journey.

Needs at diagnosis



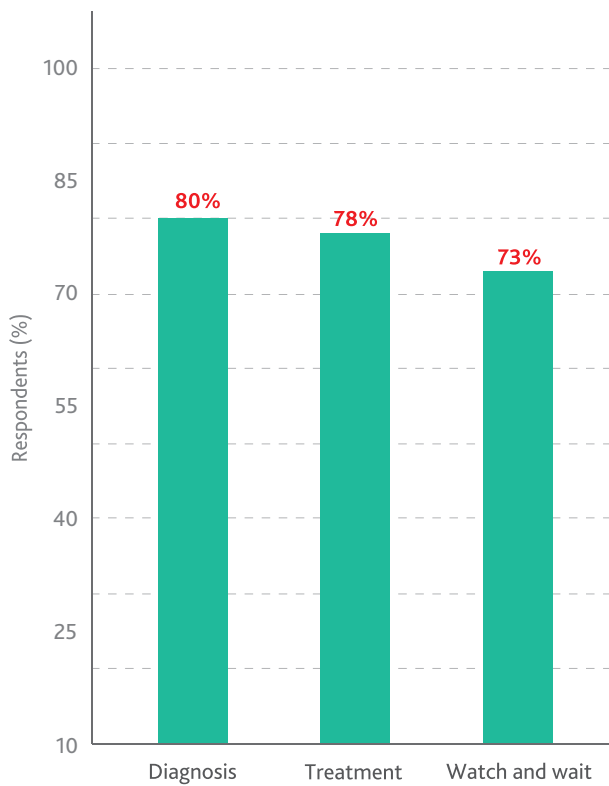
Being able to find the right information, and being signposted to the support they require, is a critical need patients want to see improved

Patients in our qualitative research told us they want help in finding the right information, through assistance and signposting by experts to the most appropriate sources for blood cancer patients.

Blood cancer patients within our survey have highlighted this need from diagnosis to post-treatment, and it is one of the key areas for improvement to enhance the experiences of blood cancer patients.

Our survey shows that improvement could be made to signposting services, as although a number of people received this service only half were satisfied with that they received.

Need for signposting (%)



Need for signposting and levels of satisfaction



Both patients and healthcare professionals indicated a need for one place to go to understand what provision is available.

"It would have been wonderful to have one person I sat down with and went over all the different options/support available." – Patient

"Someone to talk to that knows what help is available would be useful." – Patient

"[Greatest Need] Receiving professional consultancy that accurately reflected or signposted the information I have since become aware of through online support blogs." – Patient

Peer to peer support plays an important role

Patients also want information and support from their peers – online communities, buddy schemes and support groups play an important role.

Patients have also told us that it's been beneficial to meet and talk with others in similar situations at all stages of the patient journey. They find it helpful to share experiences and exchange information. Many patients have said that they can't imagine their journey without their support networks and the benefits they provide them.

"I found also once you're diagnosed and you're into treatment, you're meeting other patients going through the same stuff, you're in a network of exchange of information and a sort of camaraderie that you build up can also be helpful to you." – Patient

"He'd been on watch and wait for 20 years and if I hadn't have met him at a support day I wouldn't have known how somebody could still be really fighting fit after 20 years." – Patient

"I think what would it be like if I was going through all that treatment without somewhere like this [support group], and I would say that that would be pretty bleak." – Patient

Some blood cancers are very rare forms of cancers and therefore facilities to allow individuals affected by these conditions to connect to each other are imperative

For patients with rarer blood cancers (such as Burkitt lymphoma where there are only 210 expected cases a year in the UK) the ability to find people that have been in similar positions can be immensely supportive. Enabling this opportunity allows patients to increase their understanding and knowledge of experiences faced by people with a similar diagnosis. Helping people to connect via online and offline support allows people affected by these rare cancers to spend time with others who can share and understand their experiences.

"Overall I think my greatest need was to talk to someone who had actually had the same illness as myself... I was told that my cancer was very rare and that I would probably never meet anyone who had the same strain. I felt very isolated because of this." – Patient

Blood cancer patients feel that their experience is different in terms of awareness, care, experience and available provision

In fact, for some patients the need for support is driven by this feeling of being different.

Throughout our study, patients and carers have mentioned that at times they feel blood cancers differ to other cancers. This could be in relation to the perceived services available to blood cancer patients, the treatments and care they receive through haematology units rather than oncology, or the initial awareness and understanding within the primary care setting. For many patients their experiences can feel unique to blood cancers.

"[Related to lack of support for patients]...Is it just blood cancer? Someone I know had breast cancer operation. She's having yoga, massages you name it she's having it!" – Patient

"I may be being naïve here, but a Macmillan nurse, is that just for different kind of cancers, whereas we don't really have a nurse?" – Patient

For watch and wait patients particularly, this feeling of unique experiences is even greater because of the perceptions of others towards cancer patients in general.

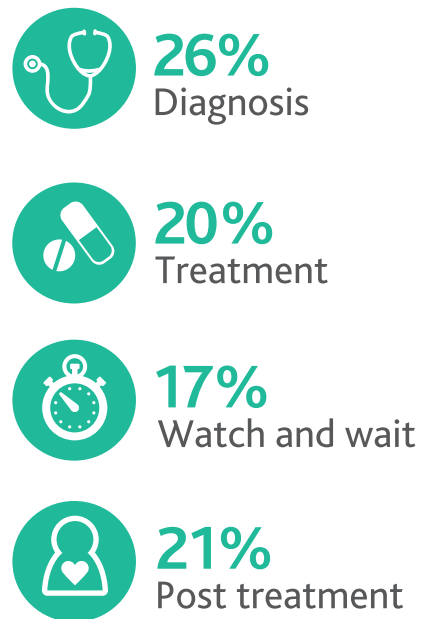
"I often feel like a fake – after all I haven't gone through chemotherapy yet, or had disfiguring surgery yet there is this stigma about the word cancer and because I don't look as people expect a cancer patient to look I don't fit-in." – Patient

Emotional and psychological support is one of the greatest needs for blood cancer patients

Across all cancers, newly diagnosed patients can experience levels of stress, anxiety and depression that adversely affect their quality of life. In fact, for many patients the highest unmet needs highlighted are psychological needs and fear of recurrence²⁴.

For blood cancer patients, emotional and psychological support is critical during and after treatment. Many patients need significant support particularly when trying to get back to normal, or finding the 'new normal' after treatment for blood cancers. Our research has shown it is one of the greatest unprompted needs as highlighted by blood cancer patients across the patient pathway.

Greatest needs (unprompted needs)



Patients in our patient need survey have highlighted this as an area where they feel there is a lack of professional provision and support they can access. Many feel they currently receive support via family and friends; however, they are looking for professional support to assist them and enable them to cope better with the impacts of blood cancer.



Need for psychological support and where assistance was received at treatment



Our research has shown that the opportunity to access professional support wasn't necessarily offered at the right time for patients, or even offered at all.

"The emotional shock was life changing and not dealt with very well. After treatment there was a huge black hole with no support, counselling or help. The cancer care and treatment was first class but after treatment... Nothing." – Patient

"I think that the emotional side of being young with cancer was overlooked. It was a year after treatment that I was offered any support from a counsellor etc." – Patient

"I did see a counsellor for one session when I was first diagnosed, but it was throughout treatment and more importantly once I was given the all clear, I really needed help." – Patient

Although required at all stages of the journey, there was a specific need for emotional and psychological support highlighted by patients after their treatment had finished.

"It was not until it was over that I took a step back and thought 'wow! What just happened there? How did I get through that?!' And I needed someone to talk to." – Patient

"Then you come through the other end and everybody expects you to be over the moon because you're all clear or in remission, and I think most people aren't, they're kind of left 'now what? At that point it all hits you what you've been through, so you get post-traumatic stress kind of stuff coming up." – Patient

Related to this lack of provision for emotional support, some patients actually felt that not all consultants and healthcare professionals truly understood the impact a blood cancer diagnosis could have on someone emotionally. For some, their requests for help were not fully considered.

"I asked if I could see a counsellor and get some psychological input. The nurse 'Well, if it gets bad enough we can refer you to a counsellor'. I was like, if it gets bad enough? I've just been told I've got cancer." – Patient

Practical assistance and advice is also needed throughout the patient pathway

At every stage we asked patients if they had a need for advice on practical matters, for example work, education, finance and benefits.

Levels of need for practical assistance ranged from 38% to 50%:

Stage	Need
Diagnosis	
Advice on telling others	47%
Advice on practical Implications	42%
Advice on financial support and benefits	45%
Treatment	
Advice regarding financial support and benefits	50%
Advice regarding practical implications	38%
Advice on work/employment rights	47%
Watch and Wait	
Advice on work/employment rights	39%
Advice on financial support/benefits	37%
Post Treatment	
Advice on work/employment rights	41%
Advice regarding financial support/benefits	48%

Although this proportion was not as high as emotional and psychological support, it was met with fewer numbers of people receiving assistance for these areas and lower satisfaction levels.

Many patients become an expert and feel empowered to make informed choices

Importantly, for many patients who did access support services and networks, they felt they became an expert in blood cancer.

Many patients talk about becoming an 'expert in blood cancers' through the experiences they face, with many indicating that it enables them to make decisions that improve the quality and understanding of their healthcare. For patients, empowerment includes:

- being armed with key practical knowledge
- armed with knowledge to challenge and ask questions of healthcare professionals
- an understanding of how they can proactively help themselves during treatment and beyond
- feeling empowered to be involved in decision making about their healthcare.

"I thought leukaemia was leukaemia. I'd never even heard of acute lymphoblastic leukaemia, I'd never heard of myeloid leukaemia. Then you suddenly become an expert in all things relating to blood cancers." – Patient

"I can look at things and look at it in a measured way now, I don't give myself negative thoughts or anything... I do want to know things, because knowledge is power and I just feel empowered." – Patient

"I've had one treatment of this drug, it's a cycle of eight, which I had initially a really bad reaction to but was absolutely determined because all my reading and research led me to believe this is really the wonder drug." – Patient

Throughout our study, we also found patients who felt like 'the true experts' were in many cases very willing to share their knowledge with other patients. All efforts should be made to support this endeavour from patients to collectively inform and empower future blood cancer patients.

Support for people looking after someone with cancer

Family, friends and other carers provide a great deal of support for patients with blood cancers, and can often be more valuable to patients than formal avenues of support. Providing care and support can come in many forms, from providing transport, assisting with personal care, to giving emotional support and encouragement. Looking after someone with blood cancers can completely change normal life, and can impact emotionally, physically and financially. We know therefore it is vital that carers themselves can also access support.

Role of carers

Patients rely on the support of others, particularly for emotional support and practical assistance.

Support comes in many forms, but within our survey, patients highlighted that the highest proportion of support received for emotional and psychological support was from family and friends – across all stages of the journey. Although access to professional support in this area was perceived to be low, many patients also turn to family members to help meet this need.

"[Greatest need] I would say mental support. Although it was my body that was under attack, I felt that my mental state was very weak. I appreciated the efforts of all to get my mental state stable, from family, friends and the medical profession during the early days." – Patient

We also know that patients depend on family and friends to provide practical assistance in order to help them; from bringing in food, looking after children and arranging transport. The result of this support can mean significant life changes for the carers themselves.

"My mum basically cooked for me and brought food in – I think I would have starved without her." – Patient

"My husband had to cut his hours at work as I had to have chemo three times a week and we had two children to look after too." – Patient

Family and friends can also aid patients in accessing and digesting information. We already know that patients find it helpful to have a second person in the room with a consultant, but they can also help patients understand their diagnosis and find further information.

"He's the sort of person who needs to understand everything about it I'm the sort of person who doesn't want to know." – Patient

Support is needed for others

We know it's not just the patient who is affected by blood cancer, but the whole family. Therefore the whole family need access to support.

In our online survey, family and friends were asked what their greatest needs were as carers.

Many mentioned a need for emotional support specifically for them, and a need for clear and accessible information, so they feel they are up to date and as well informed as they can be to support their loved one.

"[Greatest need] Staff who know what they are talking about and want to listen to us as parents, a support network of other parents in our situation who can share information and advice, and access to counselling services for us as a family and as individuals to cope with the trauma of our situation." – Carer

"[Emotional support] I had to pay for private counselling to help me get through this. I hadn't ever seen someone so unwell before and I witnessed some terrible things. I wasn't given any support from the NHS." – Carer

Practical support was another area mentioned as a need. This covers both information on financial support they can receive, and support from their employer to be able to take time off work as and when needed.

"Time dedicated to helping me understand and digest what was happening when I was in initial shock." – Carer

"The full understanding of your employer that there will be times when you cannot come to work or get called away at short notice." – Carer

Friends and family would also like to talk to others going through the same thing to help them deal with the cancer diagnosis.

"Being able to 'talk' to others going through it to out find you were not the only one feeling this way." – Carer

"It's the point that actually families are diagnosed with cancer, not just the patient." – Carer

Post-treatment

At the end of treatment, many patients feel there is a lack of provision available at this stage. Many feel that at this point in the journey it's an emotional time and has a big psychological impact. Patients mention a need to 'get back to normal' or deal with what they have been through.



Post-treatment – getting back to normal

Our survey showed that post-treatment fewer patients felt their needs were met. Only 61% of patients who responded to the survey felt their needs were met post treatment. When asked what their greatest needs were after treatment, 21% mentioned a need for emotional or psychological support and 13% mentioned a need for advice on what happens next and how to get back to leading a normal life. Both of these responses were unprompted.

There is a common perception that there is a lack of provision post treatment. Some patients feel that the support available during treatment falls away dramatically at this stage.

After a period of intense treatment within hospital, some patients may have less and less contact with health professionals and are free to move into a more normal routine at home. Our patients have told us that they would like information on follow up and check-ups, and whilst this has been met, some patients feel there is a lack of provision for other support services once they've left hospital.

"There's nobody there for you after treatment, you feel like you're on your own." – Patient

"You feel like you've fallen off the end of a conveyor belt. And you don't know what's there to catch you." – Patient

This stage in the blood cancer journey can be a confusing time for patients. For many, it is a time to reflect and talk about what they have just been through.

Patients have said emotional and psychological support is essential

We know that being diagnosed with a blood cancer has a huge psychological impact for patients. Patients have highlighted fears of relapse and lack of understanding of side effects or future health implications as concerns that have an emotional impact.

Many feel that provision for this is unavailable, the need for psychological support being highlighted as even more imperative at the post treatment stage than at any other stage of the journey. In our survey, 80% of patients had a need for emotional and psychological support at this stage. Only 70% of patients received any assistance in this area. Out of those that did, less than half were unsatisfied with what they received.

Patients also need support in getting back to normal and lifestyle advice, to help them deal with what they have been through.

In our survey, 80% of patients said they had a need for lifestyle advice but only 66% received assistance. The need differs and is very personal, depending on the individual and the individual situation. Some patients mention problems in returning to work, others had issues in getting insurance.

"I was having a few problems at work, with work, and I got sent some booklets which put things a little bit into perspective, because I didn't even realise it was a disability until I got these booklets." – Patient

For some people, post treatment means palliative care – support and advice is needed for patients and the people around them

Palliative and end of life care is an important part of the experience for some people diagnosed with cancer. It may be a difficult and challenging time for both patients and their families.

People who have supported others going through this have told us that support is needed for patients directly and family and friends around them. Some have said they felt patients were well supported during this stage but others have said that more support is needed.

"[Greatest need] Ongoing support especially when treatment has failed – this is an extremely lonely and frightening time." – Carer

"At the end getting the right help was very difficult." – Carer

"[Greatest need] support for us after his death and now, eight months later, coming to terms with our loss is so hard." – Carer

Studies²⁵ have shown that patients with blood cancers are reported to be less likely to receive input from specialist palliative care (SPC) or hospice services than those with other cancers. It has also been highlighted that patients with blood cancer have significantly shorter intervals between referral and death compared to other cancers and are therefore more likely to die in hospital.

"When the illness recurred hospital treatment was given. In retrospect I would have liked the terminal care to have been at my home but this wasn't an option at the time." – Carer

Our plan of action for 2015/16

Leukaemia & Lymphoma Research is committed to addressing all of the 24 key issues for patients, but we know we can't do this alone, nor can we achieve this overnight.

We've used this evidence to identify priority areas we want to focus on now to enable short-, medium- and long-term benefits for patients.

Our plan of action for 2015/16 will focus on delivering three key responses for patients.

A. We will align our medical research investment to our Patient Need findings

In our most recent round of funding, we committed new investments of £6 million in the biggest killers:

- We have nine new research projects on some of the identified biggest killers: diffuse large B-cell lymphoma (DLBCL), acute myeloid leukaemia (AML), chronic lymphocytic leukaemia (CLL) and myelodysplastic syndromes (MDS).
- Two further projects are aiming to tackle graft-versus-host disease (GvHD), a life threatening complication following a stem cell transplant – a therapy option for some AML, MDS, myeloma, DLBCL and CLL patients.
- Two of our six existing AML projects are addressing both AML and MDS together, which may lead to prevention opportunities.

Rounds of funding generally occur three times a year.

These, with our other research projects ensure:

- We will continue to build on our vital biological understanding and clinical research across the biggest killers.
- We will gain further understanding about the early loss of lives in DLBCL and AML.
- We will develop a better understanding of the development of myeloma from MGUS.
- We will extend our AML research focus into a shared MDS and AML focus, and include investigation in to prevention where possible.

We will work with our expert committees and engage proactively with the research community to promote our new strategic focuses and to ensure that our research has translational potential in the short-, medium- and long-term.

B. We will set up a blood cancer signposting service

Patients, carers and health professionals have told us:

- There is a low awareness of blood cancers, symptoms and blood cancer organisations.
- Blood cancer patients see themselves as different from other blood cancer patients.
- As a consequence there is a perception of a lack of provision and support.
- Patients want support from peers and professionals and want one place to go to support them through their entire journey.

We will deliver a blood cancer signposting service.

- It will be authoritative, reliable and a comprehensive source, aggregating information from many organisations that can help patients.
- It will be more than a directory - it will reflect many of the 24 issues that our research has uncovered and will be a trustworthy place for health professionals to recommend.
- It will be largely a digital solution, but with an important human element to help patients and support navigation.
- It requires a collaborative approach to amplify all that we offer together. We are already talking to Leukaemia Care, Anthony Nolan, Lymphoma Association, Delete Blood Cancer, African Caribbean Leukaemia Trust and Maggie's – and that's just for starters.

We hope that this will be the start of a clearly defined blood cancer sector and improve the lives of patients and the effectiveness of our organisations through collaboration, differentiation and innovation.

C. We will launch a blood cancer awareness campaign

We now have the quantitative and qualitative data that leaves us in no doubt at all that there is a crisis in awareness of blood cancers and their symptoms:

- within the general public
- for patients and their families
- in primary and secondary care.

We also know there is low awareness of organisations that exist to help.

During Blood Cancer Awareness Month in September we will create a major public health campaign dedicated to raising awareness and understanding of blood cancers.

- Our Medical & Nursing Advisory Panels will advise us on messaging.
- We'll consult with patients to make sure we've got it right.
- Our volunteers, patients and health professional throughout the UK will be involved.
- Through social media we'll achieve broad reach while being cost effective.
- We'll leverage editorial and advertising space and start new conversations for all blood cancer patients and the charities that are here to help.

This year we will accelerate progress towards our charitable objective of 'public understanding' and we hope that with other charities involvement in Blood Cancer Awareness Month we can achieve more awareness than ever before.

Next steps for Patient Need

Our Patient Need study will continue to map, track and understand the needs of patients and explore the challenges and opportunities we face in beating blood cancers.

From April 2015, we move into phase two of the Patient Need research programme.

Our aim is to continue to engage with patients and carers on the 24 key issues to understand their needs in further detail, and to explore with health professionals the issues they face for patients.



Through primary research in 2015/16 we will:

- investigate the different and unique experiences faced by blood cancer patients
- map out provision that is available for people affected by blood cancer in the UK
- collaborate further with health professionals to analyse the issues around awareness, diagnosis and provision for patients
- continue to review national data and relevant literature.

For more information or to speak to a member of our team, please contact the Patient Need Study team:

E. PNstudy@beatingbloodcancers.org.uk

T. 020 7504 2264

Footnotes

- 1 Primary research is new research, carried out to answer specific issues or questions. It can involve questionnaires, surveys or interviews with individuals or small groups. Secondary research makes use of information previously researched for other purposes and publicly available. This is also known as 'desk research'.
- 2 BritainThinks a consultancy organisation, which helps put the people that matter to an organisation at the heart of its thinking. <http://britainthinks.com/>
- 3 YouGov is an international internet-based market research firm www.yougov.co.uk
- 4 Quality Health works for NHS patients in all parts of the UK, whether they are treated in NHS hospitals, community services, in primary care, by mental health services, or by independent providers. Quality Health is the largest provider of patient and staff surveys to the NHS, and also works for patients and staff in hospitals in the Middle East. Quality Health is a Care Quality Commission (CQC) approved national contractor and works for 360 Trusts throughout England on the National Patient and Staff Surveys.
- 5 www.hmrn.org Expected number of cases in UK. Date accessed January 2015.
- 6 Cancer Research UK, <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/> – data provided by Office for National Statistics, UK and international cancer registries, and published population-based studies. Date accessed March 2015.
- 7 www.hmrn.org Prevalence figures for all haematological malignancies over 10 years. Date accessed March 2015.
- 8 Population based screening studies in the US and Germany estimate the true incidence of MGUS to be 3.2-3.5% in those older than 50 (Mayo Clin Proc. 2010; 85(10): 933-942; Ann Hematol. 2012 91(2):243-8)). There are over 22.7 million people aged 50 years and over resident in the UK. (Mid-2013 Population Estimates UK Office for National Statistics, 2014). A conservative estimate of 3% MGUS incidence in this population would generate a predicted UK MGUS population of 680,000 individuals.
- 9 Source for all charts www.hmrn.org- HMRN Quick Stats table. Date accessed February 2015.
- 10 There are a variety of types of MDS, and some types of MDS have a higher risk of transforming into AML than others.
- 11 Landgren OI, et al. (2007). "Multiple myeloma, chronic lymphocytic leukaemia and associated precursor diseases." Br J Haematol. 139(5): 717-23 and Hyjek EI et al. (2011). "Myelodysplastic/myeloproliferative neoplasms" Semin Diagn Pathol. 28(4):283-97.
- 12 The National Awareness and Early Diagnosis Initiative – NAEDI – is a public sector/third sector partnership. It is led by Cancer Research UK, the Department of Health, NHS England and Public Health England. They work in partnership with other public and voluntary sector organisations to support and drive forward work on early diagnosis.
- 13 YouGov survey, 'Awareness and Terminology Study'. Question: 'For the following question, by aware we mean having previously heard about a particular condition. Which, if any, of the following conditions were you aware of before taking this survey? (Please select all that apply)'.
- 14 NCPES 2014 – Analysis by Quality Health: 'Blood cancer conditions broken down by ICD10 code'.
- 15 Howell DA, et al. (2013). "Time-to-diagnosis and symptoms of myeloma, lymphomas and leukaemias: a report from the Haematological Malignancy Research Network". BMC Hematology 13:9
- 16 Haematological SSCRG events – Sept 2012 – Routes to diagnosis in haematological cancers (Lucy Elliss-Brookes) http://www.ncin.org.uk/cancer_type_and_topic_specific_work/cancer_type_specific_work/haematological_cancers/haematological_cancers_sscrg_events
- 17 Key drivers analysis of the 2014 data from National Cancer Patient Experience Survey (NCPES).
- 18 A Smith, et al. (2014) "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 2014:4.
- 19 TJ Lightfoot et al. "Survival from childhood acute lymphoblastic leukaemia: the impact of social inequality in the United Kingdom." Eur J Cancer 48(2):263-9
- 20 Department of Health: "Quality of life of cancer survivors in England: Report on a pilot survey using Patient Reported Outcome Measures (PROMS)". December 2012.
- 21 NCIN: "Older people and cancer" 2014.
- 22 HMRN: "Patient's age and treatment for haematological malignancy: a report from the Haematological Malignancy Research Network". July 2014.
- 23 Shine Cancer Support: "Innovative Support to Young Adult Cancer Survivors." December 2013.
- 24 Armes J, et al. (2009) "Patients' supportive care needs beyond the end of treatment." JCO. 27 (36) 6172-9.
- 25 Wright B and Forbers K. (2014). Haematologists' perceptions of palliative care and specialist palliative care referral: a qualitative study. BMJ Support Palliat Care doi:10.1136/bmjspcare-2014-000689.

Appendix A – Blood cancers and related conditions

Below is a list of haematological malignancies ('blood cancers') and related disorders, as given by HMRN, which cover the range of conditions termed "blood cancers" in this report.

Leukaemia

- Chronic myeloid leukaemia
- Acute myeloid leukaemia
- Acute promyelocytic leukaemia
- B-lymphoblastic leukaemia
- T-lymphoblastic leukaemia
- Chronic lymphocytic leukaemia
- Hairy cell leukaemia
- T-cell leukaemias
- Chronic myelomonocytic leukaemia

Non-Hodgkin lymphoma

- Marginal zone lymphoma
- Follicular lymphoma
- Mantle cell lymphoma
- Diffuse large B-cell lymphoma
- Burkitt lymphoma
- T-cell lymphoma

Hodgkin lymphoma

- Classical Hodgkin lymphoma
- Lymphocyte predominant nodular Hodgkin lymphoma

Plasma cell neoplasms

- Plasmacytoma
- Myeloma

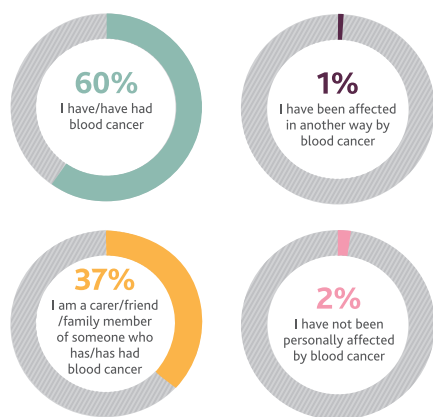
Other disorders

- Monoclonal B-cell lymphocytosis
- Chronic myeloproliferative neoplasms
- Myelodysplastic syndromes
- Lymphoproliferative disorder NOS
- Monoclonal gammopathy of undetermined significance
- Primary myelofibrosis
- Myelodysplastic/Myeloproliferative neoplasms unclassifiable

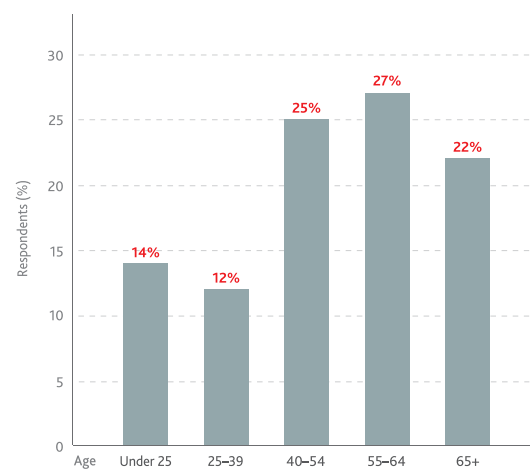
Appendix B – Survey respondent demographics

The graphs below indicate the sample of respondents to our patient need survey by type, age and blood cancers.

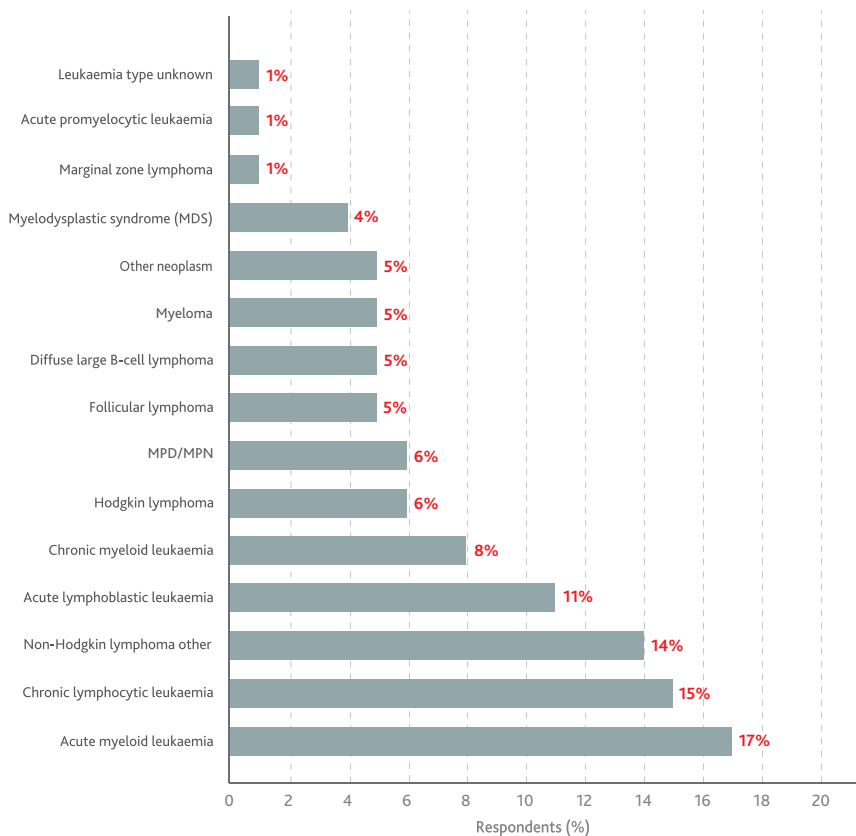
Sample of respondents by type



Sample of respondents by age



Sample of respondents by blood cancers



Patient Need

Mapping the needs, experiences
and outcomes of people affected
by blood cancer

Phase one: findings report
April 2015

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