

**LEUKAEMIA
& LYMPHOMA
RESEARCH** 

Beating Blood Cancers



PN | PATIENT NEED

IMPROVING THE EXPERIENCES
AND OUTCOMES OF PEOPLE
AFFECTED BY BLOOD CANCER

TOGETHER WE CAN

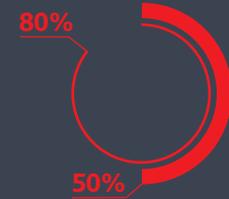
Did you know?



Every 14 minutes in the UK, someone is diagnosed with blood cancer or a related disorder. That's almost 38,000 people every year.

100

There are over 100 different types of blood cancer and related disorders, including leukaemia, lymphoma and myeloma.



80% of people with blood cancer are over 50 years old, and about 50% are over 70.

32

32 people die from blood cancer every day. 12,000 people lose their lives to blood cancer every year in the UK.



In 1960, barely 1 in 10 children survived the most common form of childhood cancer – acute lymphoblastic leukaemia. Today, thanks to research, 9 in 10 do.



Today, two thirds of everyone diagnosed with blood cancer will still be with us in five years' time. When we started, almost no one survived for this long.

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**WE'RE
HERE
WITH YOU**

Patient services

*For patients, for carers,
for anyone affected by blood cancer*

*We provide a range of patient services designed
to support and improve the lives of patients
and their families*

*For information and support, visit
leukaemia.org.uk/patient-services*

020 7054 2200

Our entrepreneurial and innovative approach has contributed to many significant developments which have been achieved by working with others; and by having the courage to make bold decisions when they were needed.

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 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. The courage of the patient stories we have heard has given us the courage to make some big plans, plans that have the best chance of success if we all work together for the benefit of patients.

In September we will be launching a new signposting service, an awareness campaign and we will be changing our name to Bloodwise – in response to the most urgent needs of patients. We are also aligning more of our research investment to the needs that we have surfaced.

From top line reports to the granular detail, our findings are available for the benefit of everyone. 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, investment. Together we will beat blood cancers.

Cathy Gilman



Chief Executive – Leukaemia & Lymphoma Research

ABOUT PATIENT NEED



About Patient Need

The Leukaemia & Lymphoma Research Patient Need study is a research programme committed to understanding the needs of people affected by blood cancer. **This is the biggest blood cancer study of its kind.**

We aimed to combine the wisdom of patients, carers, clinicians, 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 a holistic evidence base to inform our decisions, now and in the future.



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

1 A pilot study

- Desk research alongside four initial pilot focus groups and two in-depth interviews with patients and family members, involving 17 participants.

2 Quantitative research

- A Patient Need survey – completed online by 1,725 people personally affected by blood cancer, including 1,029 patients.
- A survey of the general public's awareness of blood cancer conditions – 2,000 interviews conducted online of a nationally representative sample of adults living within Great Britain.

3 Qualitative research

- 13 patient and carer focus groups and two facilitated supporter groups held across the UK (involving 139 participants), and five in-depth patient interviews.
- 21 in-depth interviews with Clinical Nurse Specialists, clinicians, researchers, patient group representatives and policy advisers.

4 Data analysis and literature review

- An analysis of key cancer data from the Haematological Malignancy Research Network (HMRN), the National Cancer Intelligence Network (NCIN) and the National Cancer Patient Experience Survey (NCPES). This was supported by an on-going literature review of blood cancer research, current treatments and patient experience studies.

In this report, you will find an overview of the key findings from this first phase of research and our response to six priority areas we have identified.

Access to all the evidence and insights from this initial research phase are available in our 'Patient Need: Phase 1 findings' report. You can find this on our website at beatingbloodcancers.org.uk/patient-need

We are deeply grateful to all those who took part in this research and to our partner organisations that have supported and promoted the programme.

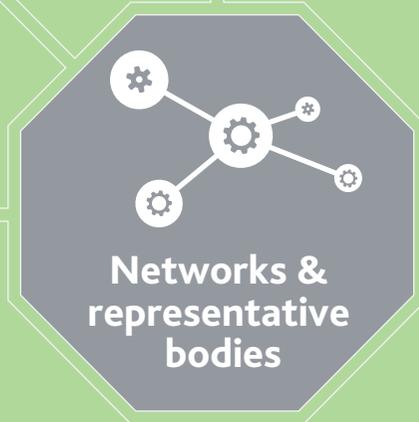


“The evidence based approach adopted in this study of patient need has revealed some startling challenges for the blood cancer community, none of which can be solved by any single organisation working in isolation.

As identified by Leukaemia & Lymphoma Research, these challenges can only be overcome by charities, the NHS, health professionals, research and industry working together in a spirit of open collaboration. I look forward to working with all these groups in the months ahead.”

Sean Duffy

National Clinical Director for Cancer, NHS England – April 2015



OUR FINDINGS



Our findings

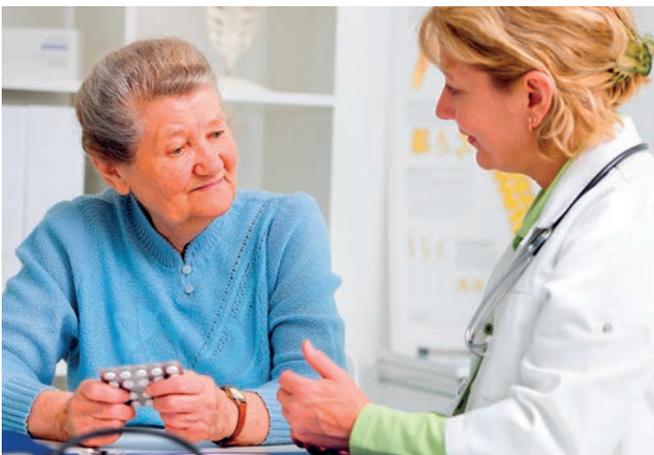
Our Patient Need research has highlighted 24 key issues faced by patients across their experiences with blood cancer.

They traverse the different stages of the patient experience: from initial awareness to diagnosis, right through to post-treatment and, for some, end of life care.

If we are to truly beat blood cancers, we need to understand all of these 24 issues from the patient perspective, and tackle them collaboratively across the blood cancer community.

- 1 Blood cancer awareness
- 2 The biggest killers
- 3 Early deaths
- 4 Pre-malignant conditions
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MEETING
PATIENT NEED:
OUR
RESPONSE



Meeting patient need: Our response

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 six priority areas we want to focus on now to enable short, medium and long-term benefits for patients.

Priority 1:

Biggest killers

Understanding what conditions have the biggest impact on lives lost is critical. The evidence has identified that just five conditions account for 69% of all lives lost within five years from diagnosis:

- Myeloma
- Diffuse Large B-cell Lymphoma (**DLBCL**)
- Acute Myeloid Leukaemia (**AML**)
- Myelodysplastic Syndromes (**MDS**)
- Chronic Lymphocytic Leukaemia (**CLL**)

Priority 2:

Pre-malignant conditions

The impact of these five conditions on lives lost maybe even larger if we include pre-malignant conditions.

Understanding and treatment of these conditions in their own right could help with successful management and may even help prevent pre-malignant conditions progressing.

Priority 3:

Early deaths

Analysing survival rates has shown us that for specific conditions, where lives are lost at 5 years, 50% of deaths occur within the first three months after diagnosis.

After this point, relative survival remains stable for many patients. Research can help us to identify which patients are at a higher risk, what's happening to them and how we can help them through these early months after diagnosis.

Priority 4:

Lack of awareness around blood cancers

Our research has shown there's low awareness of blood cancer and its symptoms amongst the general public – many patients being diagnosed with blood cancer have no pre-awareness or understanding of the disease they face.

Many patients also feel this lack of awareness exists within some primary care and secondary care settings, impacting the effectiveness of diagnosis and subsequent experience.

Priority 5:

Blood cancers are different

Patients and carers told us they feel blood cancers differ to other cancers in terms of awareness, experience, care and available provision. We need to understand this sense of difference further, whilst increasing awareness of blood cancer and of organisations that can help. The services are out there, but blood cancer patients don't know about them or see them as relevant. Many blood cancer patients are seen in a haematology unit, whereas other cancer patients will go to oncology. There is also a perception that GPs have a low awareness and understanding of blood cancer.

Priority 6:

Perceived lack of provision & need for signposting

This study has highlighted that many blood cancer patients aren't accessing the support and resources they need. Our evidence suggests this is because patients aren't clear about what's available to them as blood cancer patients, who they can contact to get guidance and signposting to services, and what organisations are out there to help them.

Key to this issue is a low awareness of blood cancer charities that are relevant to patients (including ourselves), affecting their ability to find support.

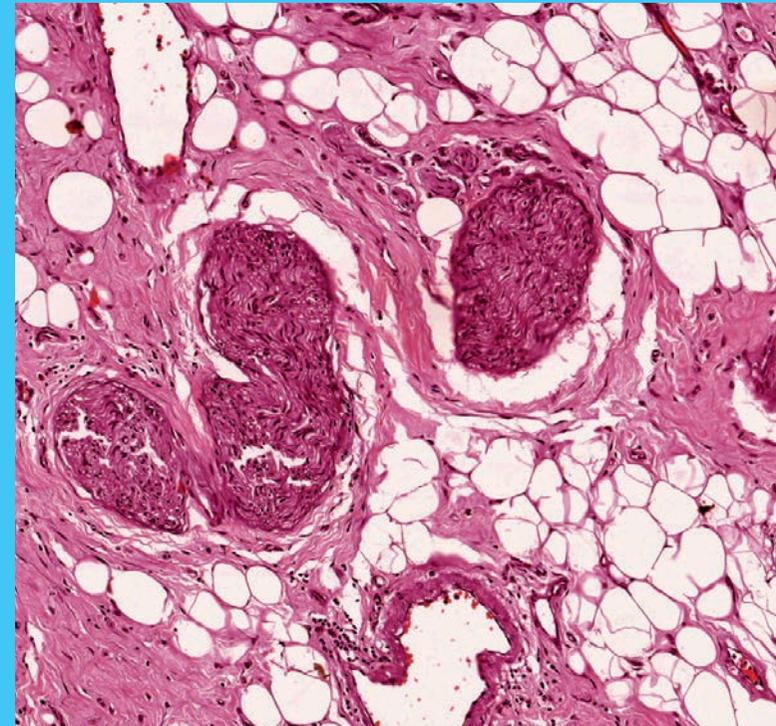
Priority 1: The biggest killers

Before we embarked on our Patient Need research programme, we already knew that:

- Blood cancers represent one in ten of all new cancer diagnoses each year in the UK – which means that each year 38,000 people are newly diagnosed with blood cancers and closely related conditions.
- 230,000 people in the UK are living with the effects of a diagnosis of blood cancer or closely related condition.
- Tragically 12,000 lives are lost to blood cancer every year.

But we wanted to interrogate patient data further, to truly understand the conditions that have the biggest impact on loss of life across blood cancers and related conditions.

To do this, we worked in partnership with the Haematological Malignancy Research Network (HMRN) to access the most up-to-date and comprehensive data on blood cancer. Using HMRN data, we combined the expected number of cases and relative survival rates to calculate the percentage of lives lost for specific blood cancer conditions at five years.



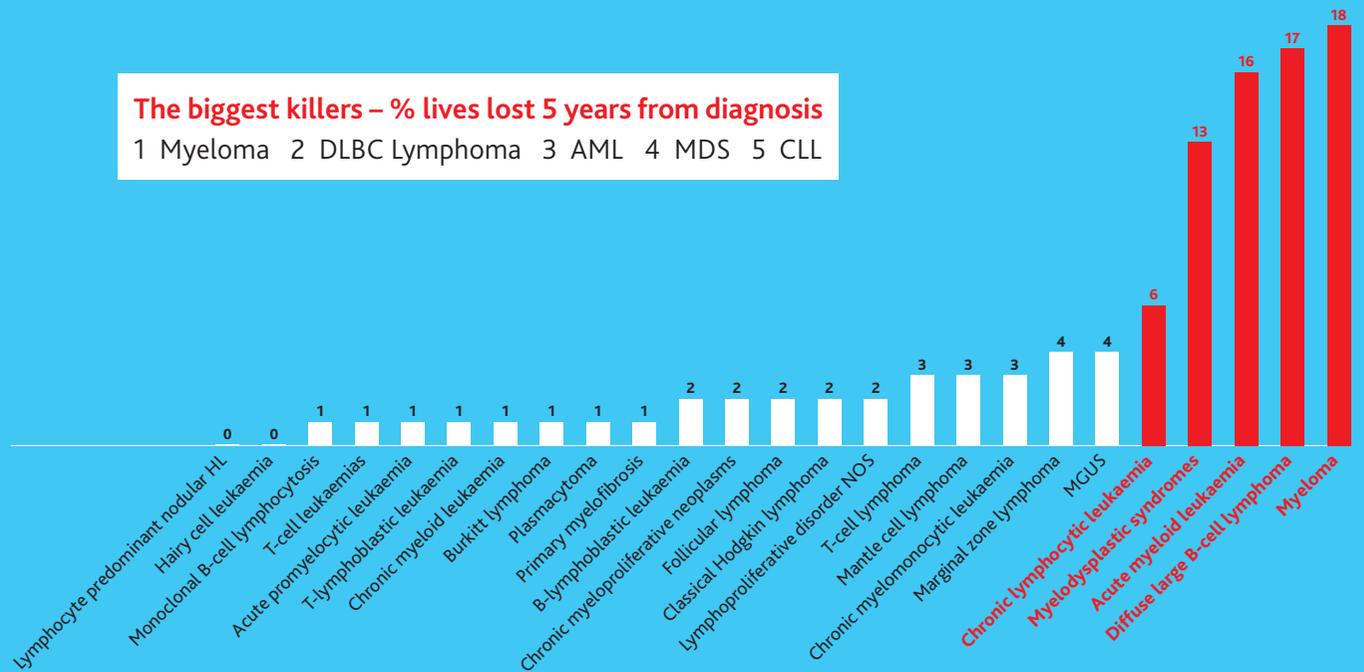
We have identified that just five conditions account for 69% of all lives lost within five years from diagnosis:

- 1 Myeloma
- 2 Diffuse large B-cell lymphoma
- 3 Acute myeloid leukaemia
- 4 Myelodysplastic syndromes
- 5 Chronic lymphocytic leukaemia

These same conditions currently account for 48% of blood cancer diagnoses each year.

The biggest killers – % lives lost 5 years from diagnosis

1 Myeloma 2 DLBC Lymphoma 3 AML 4 MDS 5 CLL



Priority 2: Pre-malignant conditions

The impact of these five conditions on lives lost may be even larger if we include the related pre-malignant conditions. The understanding and treatment of pre-malignant conditions may even help prevent such conditions progressing.

There is evidence to suggest that some MDS cases will progress to AML, and research shows that almost all cases of myeloma arise from MGUS.

If we include the pre-malignant conditions in our analysis of the biggest killers, we find that just six conditions account for 73% of total lives lost five years from diagnosis.



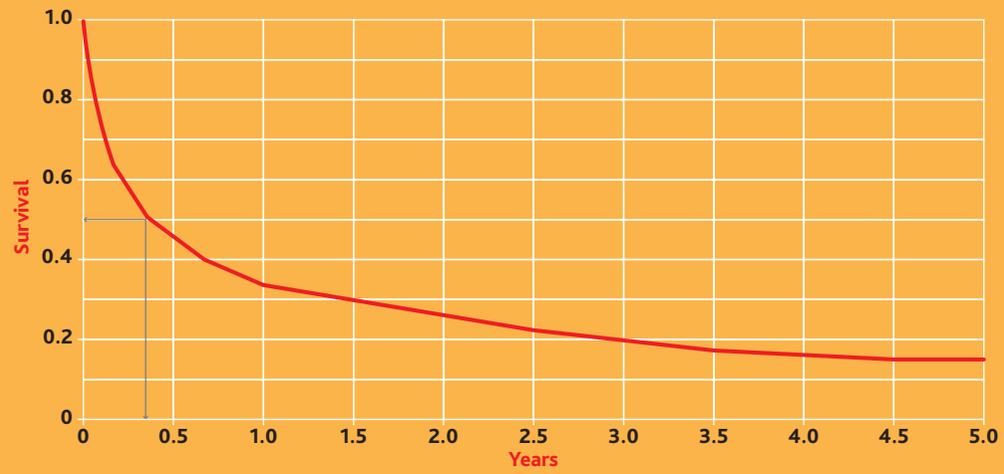
Priority 3: Early deaths

Analysing survival rates has shown us that for specific conditions, where lives are lost at five years, 50% of deaths occur within the first three months after diagnosis. After this point, relative survival rates remain stable.

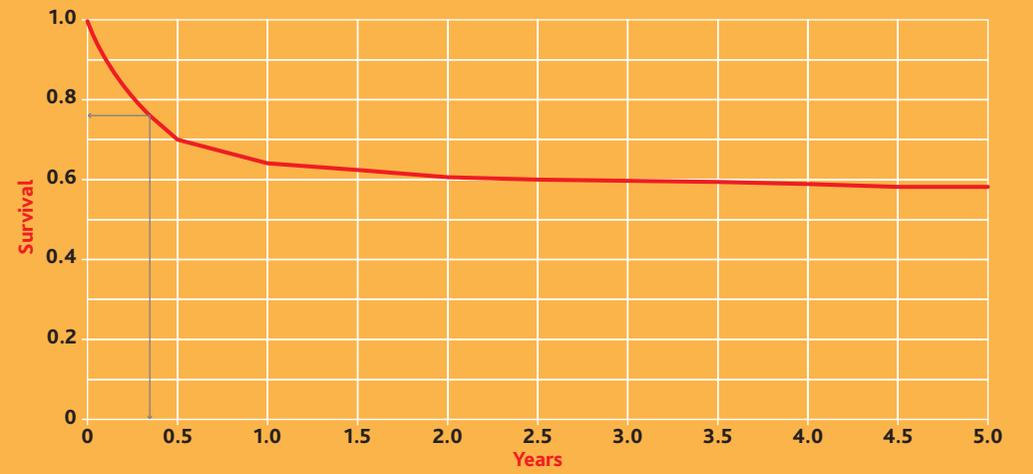
Two key examples of this are acute myeloid leukaemia (AML) and diffuse large B-cell lymphoma (DLBCL).

Research can help us to identify which patients are at a higher risk, what is happening to them and how we can help them survive these early months post-diagnosis.

Relative survival from AML



Relative survival from DLBCL



Priority 4: Lack of awareness of blood cancers

We found that people generally know little about blood cancer, the related symptoms and how to best describe them.

To gain a better understanding of the level of awareness of blood cancers within the UK general public, we commissioned YouGov to complete an awareness study. Through this nationally representative online survey, we found that awareness of different blood cancers varied enormously.

- Whilst the vast majority had heard of leukaemia and knew it to be a cancer and/or blood condition, the level of understanding beyond this varied significantly. Some believed it was a condition specifically affecting children, and some believed it was one single condition (with no idea there were many different types of leukaemia).
- Lymphoma was less well known than leukaemia and with fewer people describing it as a cancer or blood condition.
- Only 38% of people had heard of myeloma. Only half of those identified it as a cancer and could describe the condition. Many confused it with melanoma (skin cancer).

For many patients, their lack of awareness of blood cancer or related symptoms added to the difficulty of coming to terms with their diagnosis.

“There’s a staggering lack of awareness about something that’s relatively common in terms of numbers in the population.”

“Nobody had ever joined the dots. When I was diagnosed I’d never heard of lymphoma before. I didn’t get the diagnosis until I developed a lump they could biopsy.”

The signs of blood cancer are not always obvious. Typically, a GP will see only eight new cases of any type of cancer each year. Therefore, identifying the specific warning signs for blood cancer is a significant challenge.

Data from the National Cancer Patient Experience Survey (NCPES) identified just 64% of patients with haematological malignancies saw their GP only once or twice before being referred. This is in comparison to 75% for all cancers and 92% for breast cancer.

Many patients told us of an awareness crisis within the primary care environment and their frustrations at the lack of understanding of blood cancers and associated symptoms.

Increasing awareness of blood cancers within the general public and within healthcare settings is seen by many patients and health professionals as a critical step for improving the experiences of people diagnosed with blood cancer.

“As MDS is quite a rare blood cancer we’d never heard of it before. My mum says she couldn’t take any of it in, it was just lots of medical terms she and my dad just didn’t understand.”

“There needs to be more awareness among the general public. A lot of people think that someone with cancer would normally be having an operation or receiving chemotherapy. They don’t understand conditions like mine.”



Priority 5: Blood cancers are different

Patients and carers told us they feel blood cancers differ to other cancers in terms of awareness, experience, care and available provision.

This could be for a variety of reasons. The services are out there, but blood cancer patients don't know about them or see them as relevant. Many blood cancer patients are seen in a haematology unit, whereas other cancer patients will go to oncology. There is also a perception that GPs have a low awareness and understanding of blood cancer.

“He called me in and said “the bad news is you’ve got leukaemia.” He said, “I don’t know anything about it at all. I’ve referred you to the consultant. I suggest you go on the internet and find out as much as you can so you know what to ask him.”

Patients and carers noticed these differences at various points throughout their blood cancer experience:

- At diagnosis, patients feel there is a low awareness and understanding of their conditions in the primary care setting.
- After this, patients felt that they needed to quickly understand and become an expert on a potentially complex blood cancer.
- At treatment, patients needed to understand the different types of treatment for blood cancer and the specific care they could expect to receive.
- And throughout their experience, blood cancer patients and carers felt there was a lack of services relevant and available to support them.

These differences in experiences, treatment and care can leave some patients feeling isolated from certain cancer services and feeling unsure about whether such services are relevant to their needs.



“Is it just blood cancer where there’s a lack of patient support? Someone I know had a breast cancer operation. She’s having yoga, massages – you name it she’s having it.”

“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.”

“I often feel like a fake. I haven’t gone through chemotherapy yet, or had disfiguring surgery. There’s 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.”

Priority 6: Perceived lack of provision & the need for signposting

Our research has shown that many blood cancer patients aren't accessing the support and resources they need. We asked patients about their needs at each stage of their cancer experience, from diagnosis to post-treatment, and how these needs were being met.

- There was a high demand for information about the specific cancer, prognosis and treatment types – 95% of patients indicated they wanted this. Importantly, many patients were accessing support for these needs and were satisfied with this.
- However, the majority of patients also wanted information on other elements, such as emotional support (80%), practical advice such as how to tell others (47%), and information on financial support and relevant benefits (45%). For these areas of need, access to support was lower, and even when people were getting support in this area, many weren't satisfied.

Our research has highlighted that more needs to be done to meet the wide-ranging needs of blood cancer patients. Something that came up time and time again throughout our research was the idea that blood cancer patients needed better signposting towards organisations that could help support them.

“Receiving professional consultancy that accurately reflected or signposted the information I have since become aware of.”

Over 80% of patients in our survey mentioned a need for a signposting resource to help them find and access the services that are most relevant to them.

The idea about having one place to go, from which patients could be signposted towards different services, was highlighted by patients as the one thing that would make the biggest improvement in their blood cancer experience.

Patients also have a low awareness of the charities which are out there to provide support – including blood cancer charities. Patients don't know which organisations to turn to, which may stop them from accessing the services they need. Many patients simply aren't aware of the supportive blood cancer sector, or of the variety of organisations they could contact to access support.

“It would have been wonderful to have one person to sit down with and go over all the different options and support available.”



OUR PLAN OF ACTION



Our plan of action

A. We will align our medical research investment to our patient need findings

We have already made new investments of £6 million in the biggest killers

- We have nine new research projects into some of the identified biggest killers: diffuse large B-cell lymphoma, acute myeloid leukaemia, chronic lymphocytic leukaemia and myelodysplastic syndromes.
- 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.

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 diffuse large B-cell lymphoma 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.

In the last year we have invested £32 million in research and trials across all blood cancers. We are becoming ever more strategic in ensuring that our research has translational potential in the short, medium and long term. We also recognise that magic can come from blue sky thinking and keep an important element of our research spend to react to new ideas.

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 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 professionals 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.

Our plan of action continued...

D. We have changed our name

As well as studying the needs of patients we have conducted research into the market sector and into understanding our audiences better. We are committed to tackling the challenges that we've uncovered head on – building on our research work and taking on a broader role as a patient champion and provider of support.

We know that our name plays a significant role.

We need a name that shows we're here for all blood cancer patients, for their families and friends. A name that grabs the attention and signals just how important blood cancer and blood health are for everyone.

We have chosen

Bloodwise

Beating blood cancers since 1960

We chose Bloodwise because it embraces all blood cancer patients. Because it unites everything we do from our research and thought leadership to our patient support services and fundraising. Because it is simple, short and easy to remember – which is so important when you have just been diagnosed and your world has turned upside down. And because it's true to our past, right for our present and exciting for our future.



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:

- Explore the experiences of patients on watch and wait.
- 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.



And finally...
thank you

We would like to thank everyone that has been involved in the first phase of our Patient Need study, especially patients and carers that have shared their experiences in their thousands. We would also like to thank the following patient organisations for your support in promoting our study:

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

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

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**LEUKAEMIA
& LYMPHOMA
RESEARCH** 

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PN | PATIENT NEED

IMPROVING THE EXPERIENCES
AND OUTCOMES OF PEOPLE
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TOGETHER WE CAN

beatingbloodcancers.org.uk

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