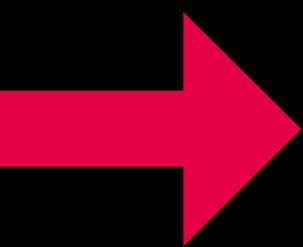


# Bloodwise

The blood cancer charity



The Current State of Blood Cancer Diagnosis in England



An End the Delays campaign report  
by **Bloodwise** | *October 2019*



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# Foreword

Receiving a cancer diagnosis is heartbreaking. But what if your journey to even getting that diagnosis had been so long and stressful that it took weeks, months or even years?

We recognise that GPs face a challenge in spotting potential symptoms of blood cancer, but we continue to hear stories from people who describe their experience of diagnosis as a 'fight' to get their GP or health professional to take their symptoms seriously. Around a third of people have had to see their GP three or more times prior to diagnosis – a figure that's remained constant over the years – and is the highest among common cancers.

These delays are having devastating impacts on people with blood cancer. It's affecting their mental health, treatment options and their chances of survival. However, people with blood cancer are more likely to survive if their journey to diagnosis is shorter. In fact, thousands of lives could be saved.

We're delighted to hear that NHS England has prioritised cancer diagnoses in their long-term plan, but as this report shows, people with blood cancer could still be left behind. This is because of the lack of comprehensive blood cancer data and the mixed knowledge of blood cancer signs and symptoms among health professionals and GPs.

We want blood cancer diagnosis rates to be as fast as other common cancers. But for that to happen, we urgently need NHS England to find new ways to measure blood cancer diagnosis rates and provide more support for GPs to help spot potential symptoms and refer for further tests.

These avoidable delays to diagnosis need to end.

**Gemma Peters**  
*Chief Executive*  
Bloodwise

**Dr Kirit Ardeshta**  
*Consultant Haematologist*  
Bloodwise Clinical Advisory Panel



Dad was 72, active and incredibly energetic. A keen runner and walker, he would often head off trekking in remote mountain ranges.

Over a space of over 18 months he experienced a series of symptoms – weight loss, a rash, a persistent cough, back pain and a lump in his groin that didn't seem connected.

As time passed and his symptoms didn't improve, he started making more and more regular trips to his GP. Nothing was diagnosed. Suddenly, he became extremely unwell, could barely speak and was in such pain that I took him to A&E. He was admitted and a CT scan was taken, but still nothing was diagnosed. He was put in a general ward, where he became critically ill and transferred to intensive care, where he was finally diagnosed with lymphoma. He never came out of hospital.

18 months after he first experienced symptoms, but only 10 days after being diagnosed with blood cancer, my dad died in great distress and leaving us traumatised.

I don't want anyone else to go through such heartbreak.

But we'll only prevent this from happening to other families if the Government intensify their efforts to shorten delays to diagnosis for people with blood cancer.

It's crucial that GPs get more support and training to help them spot common symptoms. We need a commitment at all levels, from GPs to Government, to change things for the better.

**Diana Elkins**

# Executive summary

Blood cancer can be difficult to recognise, both for people experiencing symptoms and for health professionals. However, this report shows that too many blood cancer diagnoses are still subject to lengthy, avoidable delays. These delays have harmful consequences for many people with blood cancer, in terms of their life expectancy, treatment options and overall mental health.

Analysis of publicly available routes-to-diagnosis data has shown little improvement with around 30% of cases of blood cancer diagnosed in England between 2006 and 2016 via emergency routes. However, the proportion of all cancer types diagnosed via emergency routes stood at 19% in 2016. The annual Cancer Patient Experience Survey has shown, for the third year in a row, that around a third of people with blood cancer saw their GP three or more times, before receiving a diagnosis. This is unacceptable.

Our report has also found that delays to diagnosis are having a devastating impact on the lives of people with blood cancer. Research shows that people with myeloma, Hodgkin lymphoma and DLBCL are much more likely to live more than five years if they are diagnosed at an earlier stage. This is according to data provided by the Haematological Malignancy Research Network, which is funded by Bloodwise.

As well as reduced life expectancy, people with blood cancer experience life-changing side effects from delays to diagnosis such as spinal fractures, the need for invasive surgery to remove growths and long-term pain. Furthermore, this report highlights the huge emotional and psychological impact on people with blood cancer, who in too many cases have had to fight for their diagnosis, or even been accused of hypochondria.

The picture of blood cancer diagnosis is still incomplete, with damaging consequences for blood cancer's place in the policy agenda. In too many cases the way NHS England is measuring progress in diagnosis is incomplete or inconclusive.

We welcome many of the proposals set out in the recent Long Term Plan to diagnose cancer at earlier stage, the roll-out of Rapid Diagnostic Centres and better support for the National Institute of Health and Care Excellence's (NICE) guidance on the recognition and referral of suspected cancer. However we are concerned that these proposals will not reduce delays for people with blood cancer. The lack of comprehensive data on blood cancer collected by NHS England and mixed knowledge of blood cancer symptoms among the public and health professionals are potential barriers.

## Key findings

### 1. People with blood cancer are too often being diagnosed later than they should be

- The findings of the annual Cancer Patient Experience Survey have repeatedly shown that around a third of people with blood cancer have to see their GP three or more times prior to diagnosis, more than any other type of common cancer
- Analysis of routes-to-diagnosis data shows that the proportion of blood cancer cases diagnosed via emergency routes has not significantly improved between 2006 and 2016

### 2. Delays to diagnosis are having a devastating impact on the lives of people with blood cancer

- Bloodwise research shows that more than 80% of people with myeloma and diffuse large B-cell lymphoma will survive for more than five years if diagnosed at the earliest stage, compared with just 26% and 40% if diagnosed at advanced stage, respectively
- People with blood cancer report the devastating consequences of months and even years of delays before reaching a diagnosis, including spinal injuries, the need for invasive surgery and mental health problems



### 3. There are still gaps in available data, with harmful consequences for blood cancer's place in the policy agenda

- Many blood cancers do not have staging information routinely collected, some blood cancer types such as acute myeloid leukaemia (AML) are unstageable and for others, staging data does not predict a person's survival
- This means most blood cancer types are unlikely to be included in NHS England's current proposed benchmarks towards its 75% early diagnosis ambition and so it's essential new ways are found to measure blood cancer diagnosis rates. Unless this happens, they will not receive the additional scrutiny necessary to drive improvements and address delays

### Recommendations:

We recognise the difficulties in addressing delays to diagnosis for blood cancer. This is why we are asking NHS England to commit to the following challenging ambitions, which we want to see achieved over the coming decade, with measurable progress reported on every year.

#### 1. NHS England must find new ways to measure and address delayed diagnoses of blood cancer

NHS England and Public Health England should commit to new measures of progress against reducing delays to diagnosis for blood cancer in the coming years, including:

- 1.1.** By 2024, a 10 percentage point fall in the number of people with blood cancer that require three or more GP appointments prior to diagnosis



**1.2.** Work with clinicians and Bloodwise to develop proxy measures for unstageable blood cancers, such as diagnosis via emergency routes and numbers of GP appointments prior to referral, to benchmark progress on AML and ALL diagnoses

**1.3.** The percentage of blood cancers diagnosed via emergency routes should fall from 28% at present to 19% – the current national average<sup>1</sup> – by 2028

**1.4.** NHS England issue annual progress reports against these measures, setting out activity undertaken to achieve them and drawing on the latest NCRAS data to demonstrate improvements

## **2. Better awareness of blood cancer symptoms in primary care and more support for GPs to make timely and accurate referrals**

**2.1.** NHS England should undertake an evaluation to ensure GPs are making full use of NICE guidance on referral and recognition of suspected cancer

**2.2.** NHS England's work to help GPs recognise blood cancer symptoms should particularly emphasise the use of routine blood tests to rule-out myeloma and repeat appointments to avoid delayed lymphoma diagnoses

**2.3.** In order to ensure the Rapid Diagnostic Centres are able to reduce delays to diagnosis of blood cancer, NHS England should conduct an operational review after 12 months and pilot the use of self-referral

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<sup>1</sup> With the exception of acute leukaemias

# About Bloodwise

Blood cancer is the UK's third biggest cancer killer. We're here to put an end to that.

We're a community of supporters, researchers, nurses, volunteers and campaigners, working

together to transform the lives of people affected by blood cancer.

## About blood cancer

Blood cancer is the fifth most common cancer and the third biggest cause of cancer death in the UK. In fact, it's estimated that 1:19 people will be diagnosed with blood cancer in their lifetime.

Blood cancer is the term for over 100 different types of cancer that affect the blood, bone marrow and lymphatic system. The three main types of blood cancer are leukaemia, lymphoma and myeloma.

Together, over 40,000 people are diagnosed with blood cancer every year, and there are over 250,000 people living with it.

### What are the challenges in diagnosing blood cancer?

Blood cancer can be 'vague' in isolation and it can take time for people to recognise changes in their body that indicate something is amiss. Symptoms include extreme tiredness, bruising, bleeding, lumps and swellings and unexplained weight loss.

*'I was entitled to a free health check for staff aged over 40 [through work]. It was this that showed my blood pressure was unusually high. I ended up having a blood test, almost by accident really, which showed abnormalities that were linked to pains in my back and were actually a symptom of myeloma'*

A person with myeloma

Healthcare professionals have a challenging task in separating potentially serious blood cancer related symptoms from non-threatening ones. Although myeloma can be ruled-out with a blood test<sup>2</sup> and leukaemia can also be indicated with a full blood count, there is no single diagnostic test for all blood cancers, particularly lymphomas.

It is perhaps due to the difficulty for both patients and health professionals in spotting these vague symptoms, that around a third of people with blood cancer regularly report having to see their GP three or more times before receiving a diagnosis.

# Policy context

In June 2018, the then Prime Minister Theresa May announced an additional £20bn funding for the NHS by 2023<sup>3</sup>. NHS England was asked to develop a plan which set out how this funding would be spent over the coming decade.

Launched in January 2019, the NHS Long Term Plan is an ambitious document, which sets out proposals to improve outcomes for people with blood cancer and other cancer types, including an ambition to diagnose 75% of cancers at stages one or two by 2028<sup>4</sup>.

## 75% early diagnosis ambition

However, we are concerned that many types of blood cancer will be ineligible for inclusion in the two proposed indicators to benchmark progress towards the 75% ambition. The 75% ambition is an average across all cancer types, there is no specific ambition for blood cancer.

We know, for example, that some types of blood cancer such as acute myeloid leukaemia (AML), acute promyelocytic leukaemia (APL)

and chronic myelomonocytic leukaemia are unstageable. Others, such as myeloma, currently lack enough staging information to meet the proposed threshold for inclusion. Staging is also of mixed use in some types of blood cancer, such as follicular lymphoma, where a later stage diagnosis often does not affect a person's life expectancy.

Without the inclusion of most blood cancer types in the early diagnosis ambition, we are concerned there will be no real scrutiny of delays to diagnosis, or incentive for improvement. The impact on people with blood cancer, is that they will continue to face avoidable delays to diagnosis, with consequences for their health and wellbeing.

## GP awareness

The long-term plan also made a commitment to 'ensure that all GPs are using the latest evidence-based guidance from NICE to identify children, young people and adults at risk of cancer'.<sup>6</sup>

Indicator	Description	Blood cancer types expected to be included	Numbers of diagnoses/year expected to be included	Blood cancer types not expected to be included	Numbers of diagnoses/year expected not to be included
<b>Case-mix adjusted indicator<sup>5</sup></b>	This indicator is expected to include all cancers with a staging completeness of 70% and at least 1,500 cases diagnosed annually, with outcomes reported quarterly at CCG level	Hodgkin	1,740	Leukaemia	10,250
		Non-Hodgkin lymphoma	11,970	Myeloma	4,480
				Other haematological malignancies	15,650
<b>National measure of progress against the 75% ambition</b>	This is an overall indicator, which measures progress of all stageable cancers, reported quarterly at national level	This may include most blood cancers at high-level		AML, APL, Chronic myelomonocytic leukaemia,	3,500
		Hodgkin	1,740		
		Non-Hodgkin lymphoma	11,970		
		Myeloma	4,480		



NICE published its *Suspected cancer: Recognition and Referral* guideline in June 2015. Known as 'NG12', it set out symptoms that could be caused by cancer, suitable investigations and appropriate specialists for referral, as well as helping people understand what to expect if they had symptoms that could be cancer.

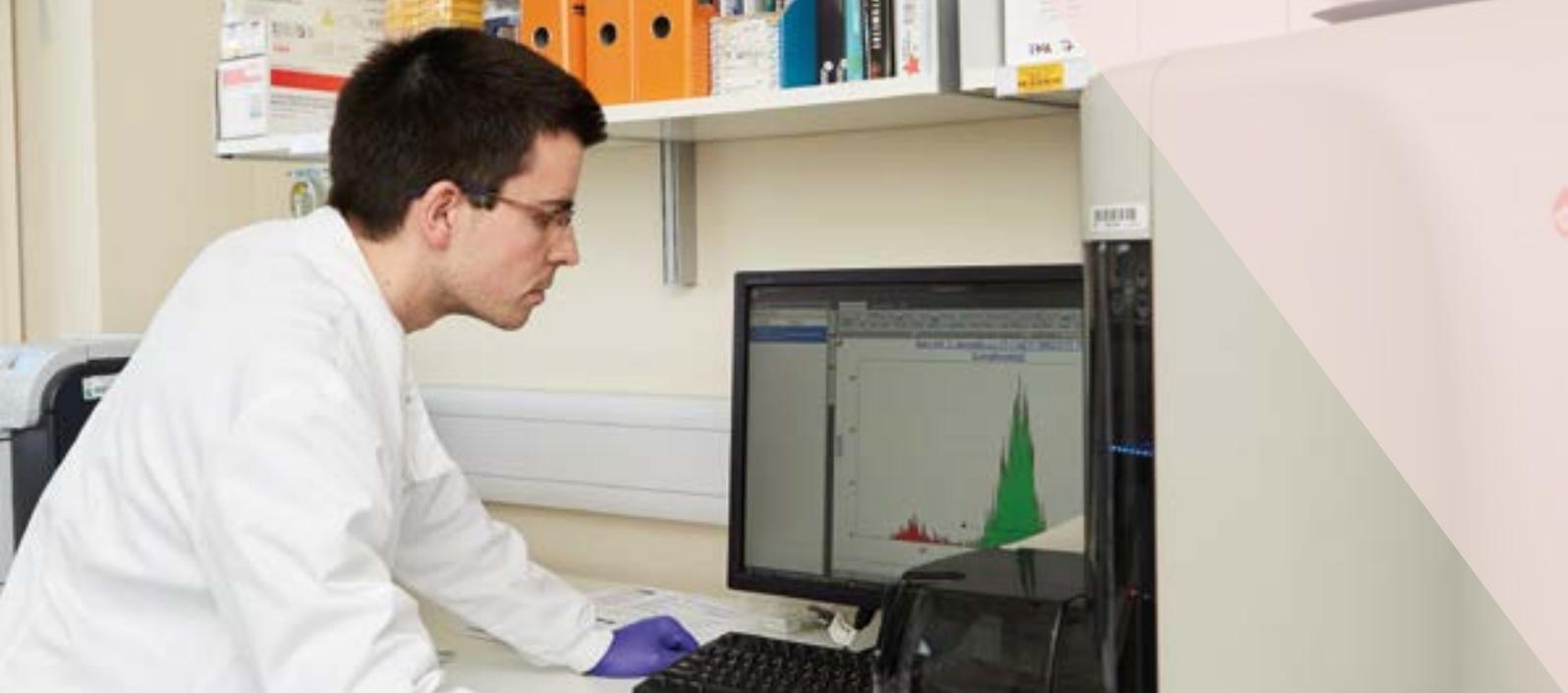
Implementation of NG12 was identified as a priority in the 2015-20 *Achieving World Class Outcomes* cancer strategy<sup>7</sup>. The Independent Cancer Taskforce recommended that NICE collaborate with cancer charities and professionals to share the referral guidelines with GP practices. It also called on NHS England to 'evaluate implementation of the new NICE referral guidelines' to 'assess impact and ensure they are deliverable'. However, it appears that this analysis has not been undertaken<sup>8</sup>.

### **Rapid Diagnostic Centres**

The Long Term Plan sets out a number of measures to achieve its 75% early diagnosis ambition, including the intention to roll out a series of Rapid Diagnostic Centres (RDCs) across Cancer Alliances in England in 2019-20.

The RDCs build on the 10 Multidisciplinary Diagnostic Centres (MDCs) which were piloted in cancer alliances in 2018. The MDCs sought to enable people with vague but concerning symptoms to receive a range of diagnostic tests, with the intention of ruling-out cancer more quickly.

The long-term plan specifies that the RDCs will, 'in time, play a role in the diagnosis of all patients with cancer, including self-referral for people with red-flag symptoms.'



Although we are hopeful that they will reduce diagnostic delay for people with blood cancer, their success will rely on:

- RDC eligibility criteria that will enable people with common blood cancer symptoms to benefit
- Prompt access to diagnostic tests following referral

Bloodwise hopes that RDCs will, in time, make a difference to speeding up diagnosis for people with suspected cancer but they will not, alone, ensure the Government meet their ambition to diagnose 75% of cancers at stage one or two.

## Workforce

We recognise the workforce challenges that are affecting diagnostic capacity in the NHS at present. We note, for example, Royal College of Pathologists research that found that only 3% of NHS histopathology departments have enough staff to meet clinical demand.

We recognise that organisations are such as Cancer Research UK and Macmillan are campaigning actively in this area and we support these efforts.

## What the data tells us

### Methodology

This report brings together a range of statistics and insights from the Office for National Statistics

and Public Health England and the findings of the Cancer Patient Experience Survey (CPES) to tell the story of blood cancer diagnoses in England.

This has been supplemented by a synthesis of research conducted by the Haematological Malignancy Research Network (HMRN), which is funded by Bloodwise and feedback from the blood cancer community via social media in June and July 2019.

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<sup>2</sup> Koshiaris et al Early detection of multiple myeloma in primary care using blood tests: a case-control study in primary care available at: <https://doi.org/10.3399/bjgp18X698357>

<sup>3</sup> BBC, NHS funding: Theresa May unveils £20bn boost, available at: <https://www.bbc.co.uk/news/health-44495598>

<sup>4</sup> NHS England, The NHS Long Term Plan, available at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

<sup>5</sup> Case-mix adjustment is a statistical technique that enables comparisons between different patient populations

<sup>6</sup> NHS England, The NHS Long-term Plan

<sup>7</sup> Independent Cancer Taskforce, Achieving World-class Cancer Outcomes, available at: [https://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

<sup>8</sup> House of Commons, written question, 259195 available at: <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2019-06-03/259195/>

# Findings

## 1. Delayed diagnosis is having a devastating impact on people with blood cancer

### Reduced survival

There is a clear survival benefit to being diagnosed with blood cancer at earlier stage. Haematological Malignancy Research Network figures show that:

- More than 8 in 10 (84%) people with **myeloma** will survive for more than 5 years if diagnosed early, compared with fewer than 2 in 10 (26%) if diagnosed at a later stage.
- More than 9 in 10 (94%) of people with **Hodgkin lymphoma** will survive for more than 5 years if diagnosed early, compared with around 7 in 10 (73%) if diagnosis comes later.
- More than 80% of people with **diffuse large B-cell lymphoma (DLBCL)** – the most common type of non-Hodgkin lymphoma – will survive for more than 5 years if diagnosed at the earliest stage, compared with just 40% if diagnosed at the most advanced stage of the disease.

Bloodwise has heard from our community of people whose symptoms were missed and subsequently passed away. The wife of a person with AML explained *'my husband visited the doctor several times and was told it was a virus. He also went to out of hours clinic at hospital where he was prescribed co-codomal. A few days later he managed to persuade doctor to arrange blood test. This was done a week later and leukaemia was diagnosed. He was admitted to hospital and had chemotherapy which was not successful, he died three months later.'*

In addition to reduced life expectancy, long delays to diagnosis narrow treatment options, can cause significant stress and anxiety and are associated with significant, long-term complications.

### Reduced treatment options and long-term side-effects

Diagnosing some types of blood cancer at later stages can lead to reduced treatment options, because delays can mean patients are less fit and are less able to tolerate aggressive treatments. HMRN research also shows that later diagnosis (and with it, more advanced disease) affects the intention of clinicians to treat a person's DLBCL with curative intent. An HMRN study found that only 71% of those diagnosed via emergency admission were treated with the intent to cure their condition, compared to 88% of those presenting via other routes<sup>9</sup>.

Delayed diagnosis and more intensive treatment regimens also have devastating long-term impacts on the lives of people with blood cancer. A person with Hodgkin lymphoma explains: *'I was told that I had an unusual presentation of Hodgkin lymphoma – a huge mass which filled my chest and was pressing on my heart. It was also attached to my lungs and blood vessels. I had part of my lung removed and repairs to my heart in order to ensure that the mass was gone. Nothing showed in my lymph glands. I was a 51-year-old woman, so I wasn't your typical Hodgkin lymphoma patient.'*

Emergency presentation of myeloma is associated with both advanced disease, poorer outcomes and a greater risk of serious side effects, such as renal failure and bone lesions<sup>10</sup>. Someone with myeloma explains the impact of late diagnosis on her condition: *'I eventually paid and saw a private neurologist and he admitted me onto his ward the next day, via NHS and had my MRI scan the day after. A large mass was found so I was then given a CT (only an hour after). I was transferred by ambulance at midnight for surgery. I was hours away from paralysis and needed decompression surgery as three of my vertebrae had been destroyed with damage to surrounding ribs.'*

*'The stage my cancer was at meant I had to undergo six months of intensive treatment including six cycles of chemotherapy. I was left feeling seriously ill and tired, with constant pain in my veins. The hair loss that followed was extremely upsetting and I decided to shave my head in an attempt to take control.'*

A person with Hodgkin lymphoma

A person with non-Hodgkin lymphoma explains:

*'I had six or seven appointments, as well as telephone appointments, told I was depressed, crippling back pain 12cm tumour caused stress fractures on my lower back, my kidney was up under my diaphragm. I paid privately for an MRI and was on chemo 24hrs later.'*

### **Mental health impacts of delayed diagnoses**

A person with follicular lymphoma explains:

*'I was told time and time again that I was fine. One GP asked "when was I going to realise that there was nothing wrong" with me. Another said I had amazing blood and I should go away. This obviously caused me to doubt myself occasionally, though I knew deep down that something wasn't right.'*

Another person with lymphoma reported similar experiences: *"Over 4-5 months I would visit the GP regularly – sometimes weekly. My GP would give*

*me antifungals as they seemed to reduce the gland swelling and had put me on antidepressants. The GP I was seeing regularly was insistent it wasn't cancer. I was looking down all routes, chronic fatigue. I genuinely thought I was going mad. I spotted my notes at the GP's had 'Cancer Phobic' written on them."*

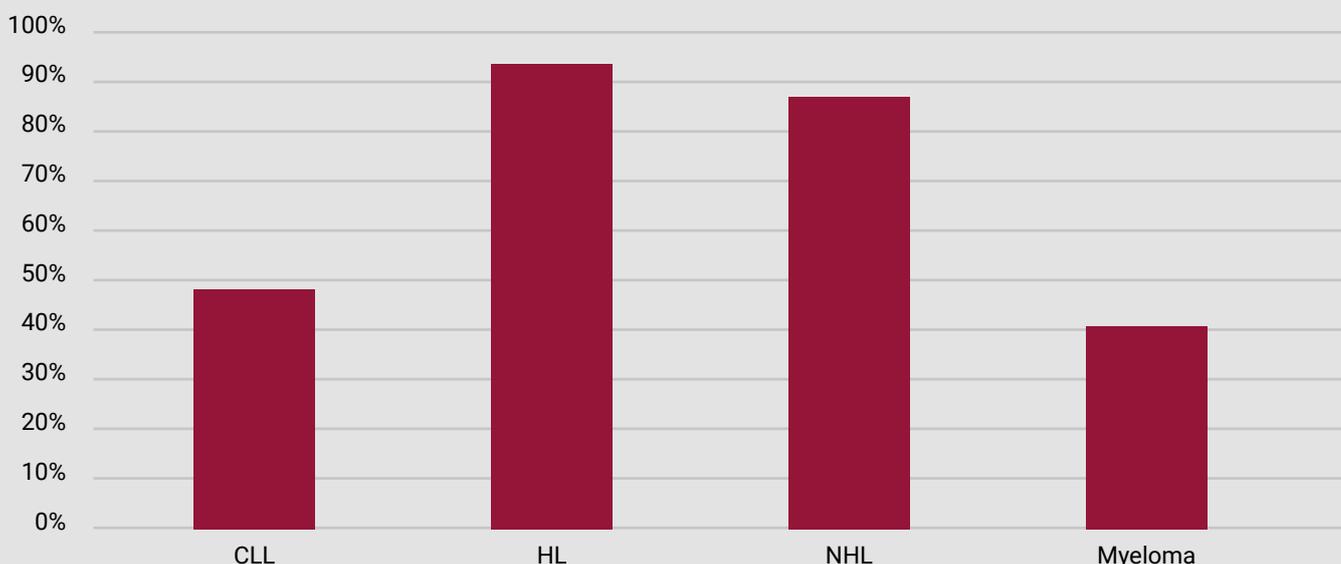
## **2. NHS blood cancer staging data is of mixed quality and predictive value**

Diagnosis by stage is the most common way of measuring how early cancer diagnoses occur. Staging is a way of quantifying the extent to which a cancer has grown or spread. However, in many solid-tumour cancers, stage refers to the size of the tumour.

Given that most blood cancers do not form tumours and spread widely through bone marrow and blood, they can, in many cases, be diagnosed at late stage by default. For example, people with follicular lymphoma are often diagnosed at stage four although many people do not require treatment.

In some cases, different sub-types of blood cancer have different staging systems. For example, chronic lymphocytic leukaemia (CLL) is staged using the Binet system, while chronic myeloid leukaemia (CML) is staged based on

### **Completeness of data by stage**



whether the cancer is in chronic, accelerated or blast phase. This means that it's not possible to group leukaemia diagnoses into overall stage. Furthermore, some types of blood cancer, such as AML, cannot be staged at all.

Even where a blood cancer such as myeloma can be staged, the data is not collected in 60% of these cases.

However, HMRN is able to provide the most complete picture of both stage at diagnosis and survival available for most types, given that it collects detailed data on blood cancer patients across Yorkshire.

The graph below shows that for myeloma, DLBCL (the most common type of non-Hodgkin lymphoma) and Hodgkin lymphoma, fewer than 45%, 30% and 36% of cases were diagnosed at stages one or two, respectively.

As noted above, stage at diagnosis does not always reliably determine a person with blood cancer's prognosis. A person with lymphoma explains: *'Following my diagnosis, I was placed on something called watch and wait – a concept and treatment plan that turns everything you think you know about cancer upside down. To be diagnosed with a stage 3 cancer and be told your treatment*

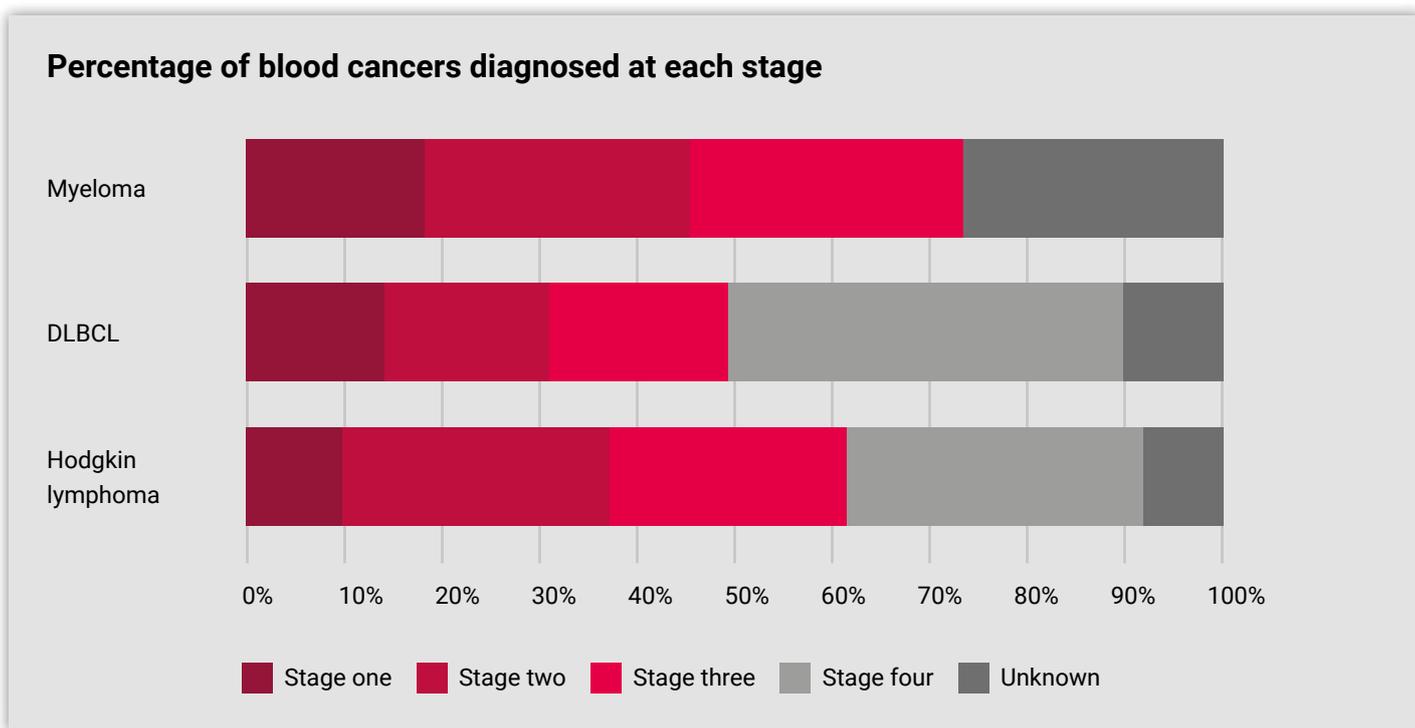
*plan is to watch the cancer and wait to treat it, is no easy concept to wrap your head around'*. In fact, in non-Hodgkin lymphoma, a person's cancer may be widespread from the outset, so a higher stage may not always reflect delays to diagnosis.

Although staging is a suitable measure of progress for most cancer types, our findings show that staging data for many blood cancers is either incomplete or inconclusive. We fear that most blood cancer types will therefore be excluded from the measures of progress against the government's 75% ambition and could be forgotten about altogether by policymakers unless more practical measures are developed.

**Recommendation: NHS England and Public Health England should commit to new measures of progress against reducing delays to diagnosis of blood cancer in the coming years**

**Recommendation: NHS England issue annual progress reports against these measures, setting out activity undertaken to achieve them and drawing on the latest NCRAS data to demonstrate improvements**

We therefore call on NHS England and Public Health England to work with Bloodwise and other



Cancer type	Percentage of all cancer cases diagnosed via emergency routes	Number diagnosed via emergency routes	Total cases per year
Blood cancer	28%	7,703	27,036
Female breast cancer	4%	1,663	45,652
Colorectal	23%	7,964	34,951
Lung	32%	12,345	38,379
Prostate	7%	2,850	40,489

charities that represent people with unstageable cancers to develop proxy measures that can enable policymakers – and people with cancer – to understand what progress has been made towards reducing delayed diagnoses for these cancer types.

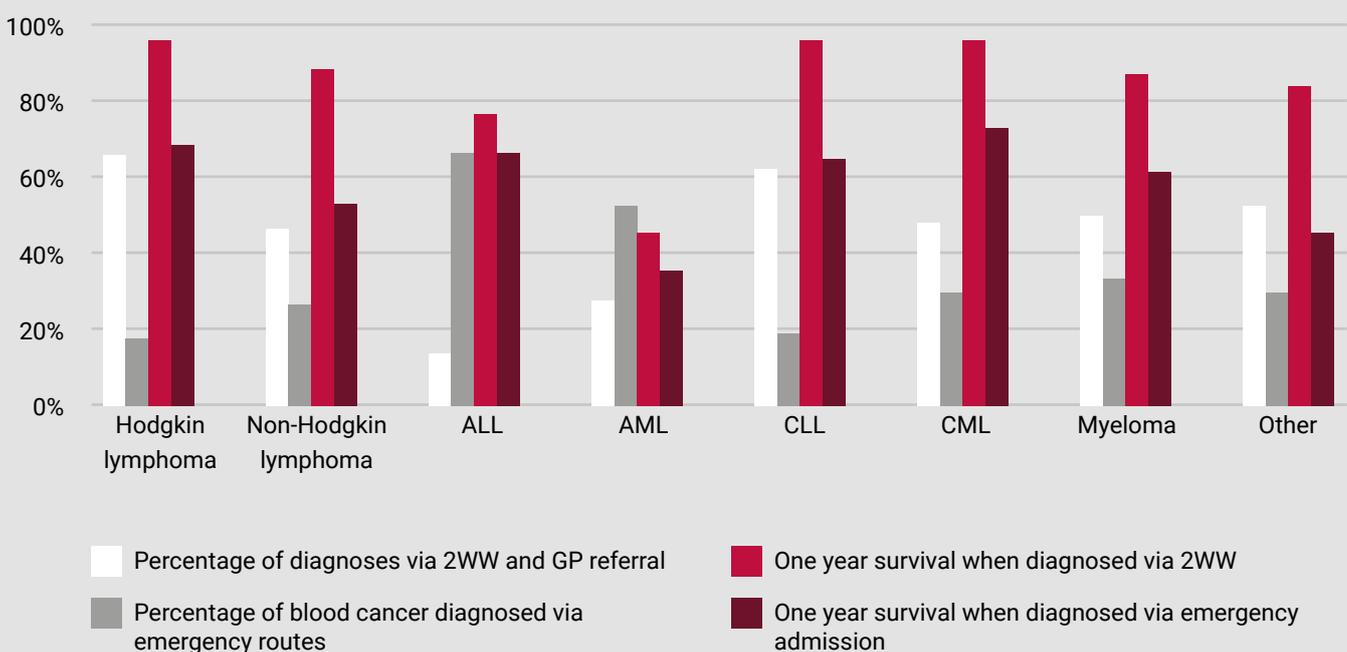
**Recommendation:** NHS England should work with clinicians and Bloodwise to develop proxy measures for unstageable blood cancers, such as diagnosis via emergency routes and numbers of GP appointments prior to referral, to benchmark progress on AML and ALL diagnoses

### 3. People with blood cancer are more likely to be diagnosed via emergency routes than many other cancer types

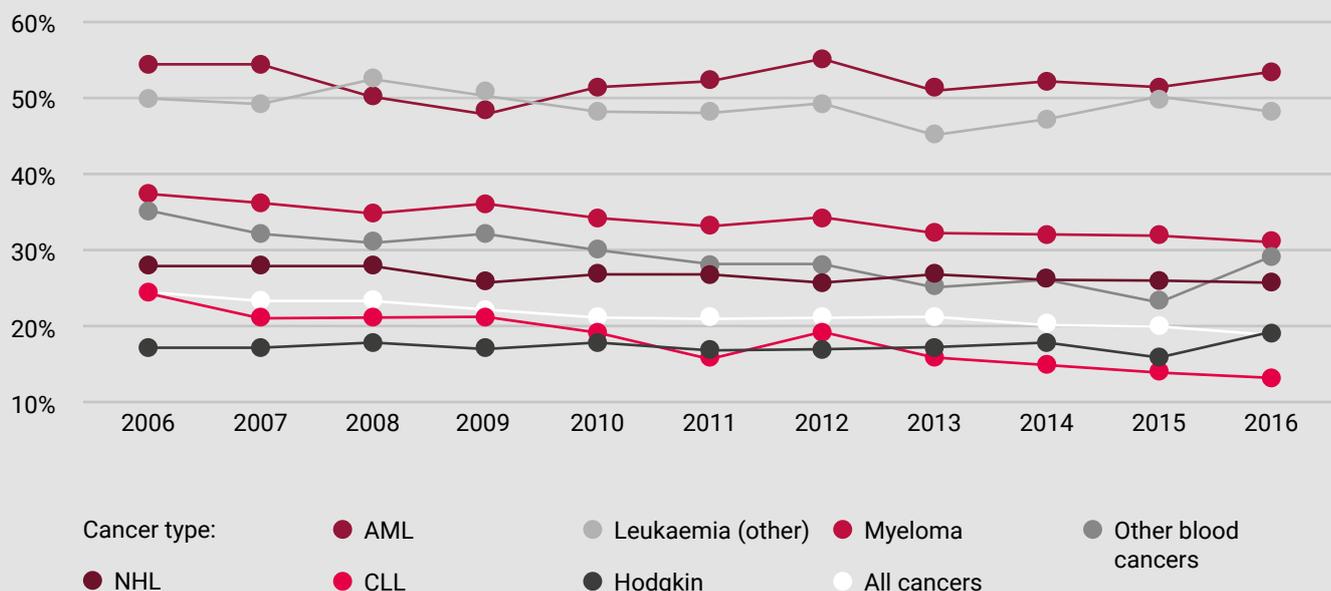
Analysis of the most recent NCRAS data available<sup>11</sup> shows that a higher proportion of people with blood cancer are diagnosed via emergency admission than most other common cancer types (see above).

Breaking down routes-to-diagnosis data by blood cancer type shows a correlation between those who are diagnosed via emergency admission and reduced one-year survival (see below).

One-year survival by 'two-week wait' and emergency admission for different blood cancer types



## The percentage of cases of blood cancer and all cancers diagnosed via emergency routes between 2006 and 2016



### 4. The proportion of diagnoses via emergency routes has not fallen significantly over the last decade

Analysis of NCRAS data shows that the proportion of blood cancers diagnosed via emergency routes has fallen 5% between 2006 and 2016. However, in 2016 this route still accounted for 28% of blood cancer diagnoses<sup>12</sup> (see above).

AML is most frequently diagnosed via emergency routes, due to the difficulty in spotting symptoms at earlier stage.

Although rates of emergency diagnoses for blood cancer are still too high, the graph above also shows that the average percentage of emergency admissions for all cancers has fallen steadily from 24% since 2006 and now stands at 19%<sup>13</sup>. Emergency diagnoses, in most blood cancer types, are associated with poorer quality-of-life, reduced treatment options and, in some cases, reduced life expectancy.

It is therefore crucial that NHS England measures progress towards reducing emergency diagnoses of blood cancer and bringing them into line with the national average by 2028.

**Recommendation:** The percentage of blood cancers diagnosed via emergency routes should fall from 28% at present to 19% – the current national average by 2028

### 5. Blood cancer referrals for diagnosis are happening more slowly than other cancer types

The findings of the annual Cancer Patient Experience Survey data continue to show that people with blood cancer face a higher number of GP appointments than other common cancers, before receiving a diagnosis<sup>14</sup>:

Cancer type	Percentage of respondents that required three or more appointments		
	2016	2017	2018
Blood	27%	27%	28%
Breast	3%	3%	4%
Bowel	20%	20%	20%
Lung	23%	24%	22%
Prostate	18%	17%	16%

Previous research conducted by HMRN has explored<sup>15</sup> delays to diagnosis of blood cancer further. Analysis of the HMRN cohort in Yorkshire found that both the time taken for a person to visit their GP to discuss symptoms ('the patient interval') and the time between first presentation at a GP and a diagnosis ('the diagnostic interval') are both significantly extended and contribute toward diagnostic delay:

Blood cancer type	Patient interval (days)	Diagnostic interval (days)
CML	33.5 days	9
CLL	22	42
AML	13	10
DLBCL	9	69
Myeloma	31	83
HL	30	67

Further HMRN research into the experiences of people with myeloma has found<sup>16</sup> that many people required multiple GP appointments before being diagnosed. In several cases, GPs mis-referred to a range of secondary care specialists, including gastroenterology and respiratory medicine before haematology.

In fact, the problem of mis-referral is not unique among people with myeloma. People with a range of blood cancer types have also shared their difficulties in having their symptoms recognised and receiving appropriate referral:

*"I was diagnosed in 2006, but looking back, it is clear now that my symptoms actually started in 2005 with intense, itchy spots as well as excess sweating. I was misdiagnosed at first with my blood tests showing anomalies which was put down to an infection. I continued to feel ill, with my symptoms not improving."*

A person with Hodgkin Lymphoma

*'In February I came down with the flu and visited my doctor only to be told to go home and rest. After nearly two weeks I still felt extremely lethargic, and generally unwell, I returned to my GP and was told that it was still the flu and that it would pass. I returned to the doctor a week later, thinking I might now have glandular fever and requested blood tests. I was booked in for*

*blood tests the following Monday morning and the following day I received an urgent phone call from my surgery telling me that I had leukaemia and had to get to the hospital immediately'*

A person with AML

*'After feeling unwell and thinking that things just weren't right- we had a series of visits to the GP, only to be told that 'they didn't know what they were looking at' but 'it was very serious and complicated'. Calls were made to local hospitals and eventually my daughter was admitted, first to a gynaecological ward, and then a teenage ward.'*

The mother of a person with Burkitt Lymphoma.

*'I knew something was wrong but for two years I was trying to get a diagnosis. My symptoms of back ache, abdominal pain and night sweats were dismissed as the menopause. I was a woman of a 'certain age'. Following a further blood test I was referred to a gynaecologist. Luckily, he took to the decision to send me to a haematologist, who discovered my lymph nodes had doubled in size over the previous year'*

A person with follicular lymphoma

**Recommendation: By 2024, a 10 percentage point fall in the number of people with blood cancer that require three or more appointments prior to diagnosis**

## Paying privately for diagnoses

Some people with blood cancer also report having to be stubborn, or even pay privately to receive a confirmed diagnosis:

A person with Waldenstrom's explains: *"In May 2016, I went to my GP having found a lump in my neck and he pretty much dismissed me. Following another appointment with a different GP. He referred me for an ultrasound. Although I was told 'everything was fine', the lump in my neck continued to grow and I was becoming more concerned. I started a new job in March 2017 and once I was eligible for private healthcare, I went to see the on-site GP. He referred me to a private ENT professor who ordered extended blood work, who also referred me to an ENT specialist who dealt with head and neck surgery. He performed the*



*lumpectomy on my neck and the biopsy sample was then sent for analysis to a private laboratory in Oxford. I was then referred to a haematologist.'*

The sister of a person with myelodysplastic syndrome said: *'My sister went to her GP, having not been in years, she had to wait a week for an appointment. When she got there, she begged for blood tests as she felt so ill. She refused to leave surgery until they agreed to have blood tests taken. A nurse eventually agreed after [she] sat for a few hours – she was in the cancer ward two hours later when the lab obviously rang due to her severely abnormal results.'*

Given that around a third of blood diagnoses consistently require multiple appointments prior to diagnosis from year to year, it is clear that improvements will not occur without greater ambition from NHS England. It is necessary to set stretching targets for reducing the number of multiple GP appointment prior to diagnosis, so that it falls within the average of all common cancers by the end of the decade.

### **Positive experiences**

However, in some cases people with blood cancer do receive prompt referral and timely diagnosis:

*"I presented to my GP with deep purple/black bruises surrounding both eyes. She didn't know what it was but referred me a local haematologist. As soon as he saw my "raccoon eyes" he was sure I had Amyloidosis, a rare incurable, life threatening disease, the rare cousin of myeloma or lymphoma."*

A person with amyloidosis

*"I had a small, painless lump on the side of my neck. No other symptoms. I saw my GP and he immediately referred me to the hospital. A needle biopsy indicated lymphoma, confirmed as mantle cell lymphoma by an excision biopsy days later. Very pleased to have been seen by a relatively newly qualified GP who spotted the signs and referred me."*

A person with mantle cell lymphoma

As we have seen, GPs have a challenging task in separating potential blood cancer cases from



routine health problems, however CPES figures continue to show that people with blood cancer routinely require multiple appointments before diagnosis. If delays to blood cancer are to be reduced, GPs require more support to help spot signs of blood cancer and make appropriate referrals and progress should be measured in this regard.

NHS England committed in the Long Term Plan to '*ensur[ing] that all GPs are using the latest evidence-based guidance from NICE to identify children, young people and adults at risk of cancer*'. It is crucial that NHS England prioritises efforts to measure awareness of crucial referral guidance and ensure that all GPs are confident to use it when necessary.

**Recommendation:** NHS England should undertake an evaluation to ensure GPs are making full use of NICE guidance on referral and recognition of suspected cancer

For both Hodgkin lymphoma and non-Hodgkin Lymphoma, HMRN research shows that 'safety-netting' (including GPs booking follow-up appointments for patients and discussing with them warning signs of deterioration) could be beneficial in reducing lymphoma delays<sup>17</sup>. Even in cases where blood cancer is not immediately suspected, routine use of safety-netting practices and blood tests could help to reduce avoidable delays for people with blood cancer.

We therefore recommend that NHS England supports GPs by encouraging practical steps that could reduce delays to diagnosis irrespective of whether they directly suspect blood cancer.

**Recommendation:** As part of its ambition to ensure GPs are using NICE guidance, NHS England should emphasise practical steps such as the importance of routine blood tests to rule-out leukaemia and myeloma and safety-netting practices, to help reduce delays to diagnosis

## Rapid Diagnostic Centres

The RDCs hold great potential in reducing extended delays to diagnosis for people with blood cancer. Evaluation of the MDC pilots conducted via the ACE programme has shown that they are effective in diagnosing a range of blood cancer types, though some of these cases were still identified at late stage.

An evaluation<sup>18</sup> of the MDC pilots published by Cancer Research UK in April 2019 found that 13% of cancer cases diagnosed were blood cancer (n=30 cases). This included types of myeloma, leukaemia and both Hodgkin and non-hodgkin lymphoma. This contrasts with around 9% of all cancer cases diagnosed in 2016 being a type of blood cancer according to NCRAS<sup>19</sup>.

However, the evaluation also shows that, in some cases, delays are still occurring. A person with blood cancer quoted in the evaluation noted that *'I had been to my GP six times with headaches and dizziness without making any progress' and that 'it was not until I passed out at home and was taken to Wythenshawe Hospital that I got a referral for the Multidisciplinary Diagnostic Centre (MDC)'*.

In order to ensure the RDCs are optimised to truly reduce delays in blood cancer diagnoses, NHS England should commit to evaluating their effectiveness after a year and prioritise ways for people to self-refer for diagnostic tests.

**Recommendation:** In order to ensure the Rapid Diagnostic Centres are able to reduce delays to diagnosis of blood cancer, NHS England should conduct an operational review after 12 months and pilot the use of self-referral

<sup>9</sup> Kane et al, Emergency admission and survival from aggressive non-Hodgkin lymphoma: A report from the UK's population-based Haematological Malignancy Research Network, available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5446261/>

<sup>10</sup> Howell et al, Multiple myeloma: routes to diagnosis, clinical characteristics and survival – findings from a UK population-based study <https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.14513>

<sup>11</sup> NCRAS, routes-to-diagnosis workbook 2006-16, available at: [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis)

<sup>12</sup> NCRAS routes-to-diagnosis workbook 2006-16

<sup>13</sup> NCRAS, routes to diagnosis workbook 2006-16

<sup>14</sup> Quality Health, National Cancer Patient Experience Survey, available at: <https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

<sup>15</sup> Howell et al, Time-to-diagnosis and symptoms of myeloma, lymphomas and leukaemias: a report from the Haematological Malignancy Research Network, available at: <https://bmchematol.biomedcentral.com/articles/10.1186/2052-1839-13-9>

<sup>16</sup> <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0194788>

<sup>17</sup> Howell et al, Disease-related factors affecting timely lymphoma diagnosis: a qualitative study exploring patient experiences, available at: <https://bjgp.org/content/69/679/e134>

<sup>18</sup> Cancer Research UK, Key messages from the evaluation of Multidisciplinary Diagnostic Centres (MDC), available at: [https://www.cancerresearchuk.org/sites/default/files/ace\\_mdc\\_report\\_may\\_2019\\_1.1.pdf](https://www.cancerresearchuk.org/sites/default/files/ace_mdc_report_may_2019_1.1.pdf)

<sup>19</sup> NCRAS, Routes to Diagnosis yearbook, available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/common-cancers-compared#heading-Zero>

# Conclusions

This report has shown that in too many cases, blood cancer diagnoses are subject to avoidable and unnecessary delay, with consequences for people's treatment options, mental health and potentially their survival.

Our analysis of study data and the feedback from people with blood cancer highlights the challenge that GPs face separating potential blood cancer cases from routine health problems. However, CPES figures continue to show that people with blood cancer routinely require multiple appointments before diagnosis. If delays to blood cancer are to be reduced, GPs require more support from NHS England to help spot signs of blood cancer and make appropriate and timely referrals.

NHS England has a crucial role to play in reducing delays to diagnosis for people with blood cancer. The Long-term Plan committed NHS England to *'ensur[ing] that all GPs are using the latest evidence-based guidance from NICE to identify children, young people and adults at risk of cancer'*. It is crucial that efforts to measure awareness of crucial referral guidance and ensure that all GPs are confident to use it when necessary are made an urgent priority.

Although staging is a suitable measure of progress for most cancer types, our findings have shown that staging data for many blood cancers is either incomplete or inconclusive. We fear that most blood cancer types will therefore be excluded from the measures of progress against the government's 75% ambition and could be forgotten about altogether by policymakers, with consequences for people's lives, unless NHS England finds new and more practical ways to measure progress towards reducing delays to diagnosis in blood cancer.

The National Cancer Patient Experience Survey (CPES) has consistently shown that around a third of people with blood cancer have to see their GP three or more times prior to diagnosis. This is more than most other common cancer types and it is unacceptable. NHS England must drive progress towards reducing the number of multiple GP appointment prior to diagnosis, so that it falls within the average of all common cancers by the end of the decade.

Our analysis has also shown that around 30% of blood cancers are diagnosed via emergency routes, according to the most recently available NCRAS data. This is far more than the average of only 19% for all cancers. Emergency diagnoses, in most blood cancer types, are associated with poorer quality-of-life, reduced treatment options and, in some cases, reduced life expectancy. It is therefore crucial that NHS England measures progress towards reducing emergency diagnoses of blood cancer and bringing them into line with the national average by 2024.

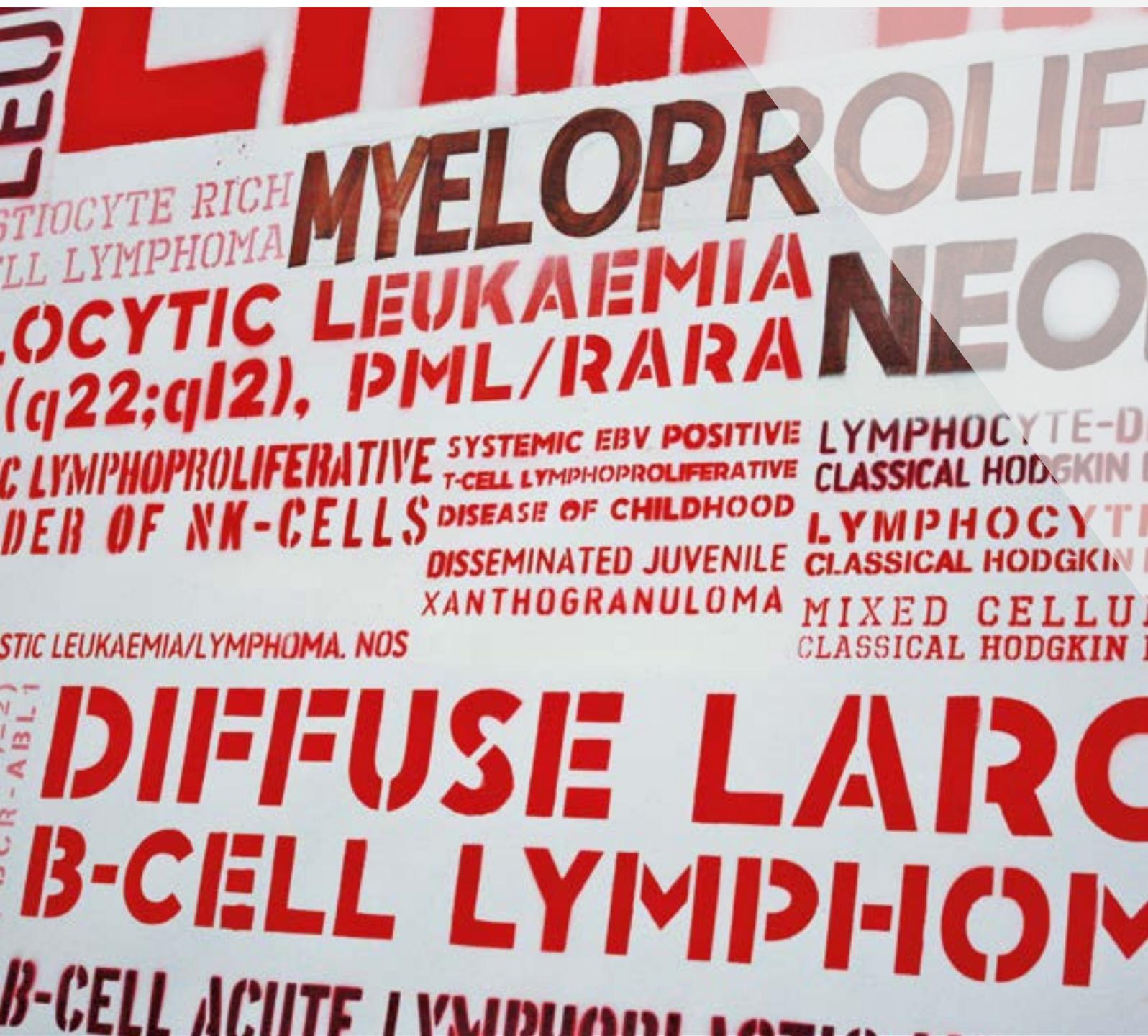
According to NHS England, some types of blood cancer, including acute and chronic myeloid leukaemia cannot be staged. This means that they will not be included in progress towards the 75% ambition whatsoever. NHS England and Public Health England should work with Bloodwise and other cancer charities to develop proxy measures that can enable policymakers – and people with cancer – to understand what progress has been made towards reducing delayed diagnoses for these cancer types.

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