

## Demanding better for those affected by leukaemia: Our priorities for the next government

Our mission at Leukaemia UK is to stop leukaemia from devastating lives. Through our manifesto, we are setting out our key priorities for the next government to drive improvements for people affected by leukaemia. These priorities were developed by listening to nearly **300 people with lived experience of leukaemia** and an extensive analysis of **national and international health policy, research and population health data**.

Leukaemia doesn't discriminate. It affects people of all ages – babies, children and adults. In the UK, almost 10,000 people are diagnosed with leukaemia every year, of whom 635 are children and young adults. Leukaemia is the most common type of cancer in children (33% of all cancers in the under 15s are leukaemia).

Despite progress in overall cancer survival, only half of leukaemia patients live longer than five years after their diagnosis. Especially for some types of leukaemia, such as acute myeloid leukaemia (AML), the five-year survival is shockingly low, at 13.6% compared to an average of 55% across all cancers in England.

Leukaemia is hard to diagnose due to non-specific symptoms, and hard to treat. Patients are mainly reliant on long-term gruelling treatments to survive as surgery is not an option due to the nature of the disease, leaving them with a weakened immune system and growing mental and physical support needs.

Currently, national plans and strategies focus on solid cancers, like those of the breast, bowel, lung and prostate, without taking into account the unique needs and different nature of the 240,000 with leukaemia and other blood cancers. A national approach is necessary if we want leukaemia to see the progress that other cancers have seen in survival and quality of life.

**The next government has a unique opportunity to address this injustice and make bold, long-term, national commitments to stop leukaemia from devastating lives, and we, at Leukaemia UK are more determined than ever to support the next government to save and improve more lives of those affected by this terrible disease.**

**We are asking the next government to publish a cancer strategy within its first year to save and improve the lives of those affected by leukaemia.**

These are the four priorities we set out for a cancer strategy that meets the needs of those with leukaemia:

- ✓ **Priority 1:**  
Investment in cutting-edge leukaemia research to benefit all patients
- ✓ **Priority 2:**  
Improvements in early diagnosis of leukaemia
- ✓ **Priority 3:**  
Access to kinder, more effective treatment and care for all leukaemia patients
- ✓ **Priority 4:**  
Publication of more and better health data and clinical audits to improve quality of diagnosis, treatment and care of leukaemia

## Our four priorities

### Priority 1: Investment in cutting-edge leukaemia research to benefit all patients

#### The challenge:

Research is making good progress in understanding the causes of leukaemia, and from this, more targeted treatments are being developed which could one day reduce the need for gruelling and toxic chemotherapy. However, there are concerns about the attractiveness and capability of the UK to deliver high-quality clinical trials to test promising new treatments, and to adopt new innovations arising from research into the NHS setting. Moreover, patient participation in clinical trials is currently low. Our survey has revealed that **four in ten people** with leukaemia were not informed about the benefits of patient participation in research, with **one in two** not offered any opportunities to participate in research.

*“If I relapse again there are no more treatments, they can give me. I got leukaemia at 13 and relapsed at 19. Patients like me, who can't handle any more intensive therapy, need new, less harmful, more effective treatments. They could well save the lives of many people.” Jake from Suffolk, 21 years old*

#### The opportunity:

Aligned with the UK's vision to become a world-leading hub for life sciences and medical research within the next decade, the next government is at a unique position to maximise opportunities from the multi-disciplinary environment that the UK offers for medical research – i.e. the NHS, universities, and industry. Currently, advances in genomic medicine have enabled personalised diagnostic and prognostic tests to guide precision treatments and this progress should continue in leukaemia. Participation in clinical trials should be an option for everyone with leukaemia, regardless of where they live in the UK.

#### Our recommendations:

The next government should:

- Transform the UK into a global hub for leukaemia research and development within the NHS. The next government should champion and support UK life science research and build on UK's strengths in research discovery, including bringing together expertise from industry, charities and academia. The next government should implement the recommendations of Lord O'Shaughnessy's 2023 review into commercial clinical trials in the UK, ensuring equity in participation of patients in research. This is key to amplifying investment into novel, more effective treatments and therapies to cure leukaemia as leukaemia patients are fully dependent on new treatments to survive the disease as surgery is not an option for them (unlike solid cancers). The UK should also learn from international initiatives to drive research breakthroughs, such as the USA Cancer Moonshot.
- Facilitate robust patient data collection and sharing for leukaemia research. With a shift towards secure data environments across the NHS, there is greater availability and accessibility of NHS healthcare data, and thus a greater appreciation of the value of data in research. The next government should enable access to real-world health patient data to facilitate novel, more personalised interventions to diagnose and treat leukaemia.

### Priority 2: Improvements in early diagnosis of leukaemia

#### The challenge:

Delays in leukaemia diagnosis pose significant risks. Diagnostic tests for many cancers require complex, high-tech equipment, while leukaemia can be diagnosed through an inexpensive full blood test. However, a survey revealed that **only one third of patients** received an urgent full blood test within the 48 hours of presenting symptoms recommended by the National Institute for Health and Care Excellence (NICE). Acute leukaemia patients reported an alarming delay of three to four months in some cases. Diagnosis through **emergency presentation** stands **at 37%** for people with leukaemia that is higher than the national average of all cancers, contributing to low survival outcomes.

*“Liz was tragically diagnosed with Acute Promyelocytic Leukaemia (APML) the day before she passed away at just 51 years old. And although she’d suffered over six months of varying symptoms leading up to her eventual hospitalisation, her diagnosis came too late.” Jonathan, Liz’s husband from Leicestershire*

## **The opportunity:**

Early diagnosis is key to saving and improving the lives of more leukaemia patients. Currently, the NHS England long-term plan has a specific focus on improving cancer early diagnosis. Some examples are the development of programmes to identify and monitor those at risk, an increase in referrals for diagnostic tests, investment in more capacity for diagnostic assessments and reduce delays through faster diagnostic pathways.

## **Our recommendations:**

The next government should:

- Develop comprehensive early detection strategies for leukaemia. The next government should invest in programmes to help us understand and identify leukaemia risk factors, populations at risk and establish proactive testing and monitoring for those people.
- Improve access to full blood tests. An inexpensive full blood test is needed to diagnose leukaemia or rule it out, and timely access is key. To address issues with GP capacity, referrals through pharmacists and dentists should be considered by the next government as recommended by Leukaemia UK and Leukaemia Care’s ‘Spot Leukaemia’ campaign. Moreover, the next government should increase phlebotomy capacity through community diagnostic centres as recommended at the All-Party Parliamentary Group for Diagnostics report.
- Develop a leukaemia faster diagnostic pathway: The next government should work with NHS to reduce delays in diagnosis of leukaemia as well as diagnosis through emergency. Faster diagnostic pathways for leukaemia should be developed and implemented, so that everyone with symptoms has faster access to full blood tests and other diagnostic investigations.
- Introduce proxy targets for non-stageable cancers. The current NHS England 75% stage 1 and stage 2 early diagnosis target is relevant to solid tumours only, excluding over 240,000 people with blood cancers such as leukaemia in benchmarking and tracking progress. This is not only an injustice for blood cancers, but it also makes it unlikely for England to meet the national target by as blood cancers are the fifth most common cancer in the UK. Therefore, a proxy measure for non-stageable cancers, like leukaemia, is crucial to current early diagnosis national targets.

## **Priority 3: Access to kinder, more effective treatment and care for all leukaemia patients**

### **The challenge:**

The treatment and care needs of each leukaemia patient differ vastly. Unlike other cancers, leukaemia patients undergo long-term gruelling treatments, resulting in growing physical and mental needs. With remission, the threat or worry of relapse is often not far away and for certain treatments good survival rates are not guaranteed. During treatment, there are many challenges facing leukaemia patients, such as hidden costs and difficulties accessing routine care, compounded by the vulnerabilities associated with having a weakened immune system. Shockingly, **only 9% of people** with leukaemia surveyed had been offered **a holistic needs assessment** to identify and address their emotional and physical needs to ensure they can tolerate long-term treatments.

*“I spent over a month in hospital. I had some down days, it all seemed so unfair. I resented my family at times for being able to carry on with their lives as normal while I was confined to a room having punishing treatment” Tammy Guide from Yorkshire, 53 years old*

### **The opportunity:**

There is a current focus on ensuring that people living with and beyond cancer can access comprehensive cancer treatment, support and follow up care based on their tailored needs. Investment in the development of treatment and care programmes led by dedicated health teams with

the right knowledge and expertise is essential to address the current NHS crisis, including workforce shortages, ensuring the varied needs of leukaemia patients during their treatment and care are met.

## **Our recommendations:**

The next government should:

- Make available cutting-edge treatments in the NHS. The next government should focus on a balanced regulatory environment which incentivises real innovation, fostering a responsive and fair health system to access novel treatments as a standard of care for everyone. Currently, many people who would benefit from innovative CAR-T therapy miss out because it is not available everywhere and there is not a standardised approach on patient eligibility. The next government should build the capacity required so that all eligible patients are offered CAR-T therapy. The next government should ensure that the right workforce, infrastructure and health service specification are in place across the UK to meet the diverse needs of different leukaemia types but also of different age groups, including children and young people.
- Ensure everyone with leukaemia is offered a holistic needs assessment. Every individual with leukaemia should be offered a holistic needs assessment at the point of diagnosis, as well as after treatment to ensure that all physical and emotional needs are identified, addressed and monitored. The next government should ensure that the right workforce and resourcing are in place to ensure a coordinated approach between healthcare teams to meet immediate and long-term needs of the patients.

## **Priority 4: Publication of more and better health data and clinical audits to improve quality of diagnosis, treatment and care of leukaemia**

### **The challenge:**

Across the UK, population health data with respect to leukaemia incidence, prevalence, survival and mortality is never reported promptly and is often several years out of date. Data which is published is typically reported inconsistently and without sufficient granularity, particularly in terms of different types of leukaemia. Thus, it is difficult to understand the disease, monitor improvements and highlight what needs to change for better outcomes. Moreover, current publicly available cancer data focus on solid cancers but not blood cancers.

*“There is still a serious lack of understanding towards patient quality of care. I would advocate for more information and real-world evidence to be widely accessible to both patients and physicians that defines the quality of care for patients with leukaemia.” Darren from Hampshire, who lost his 67-year-old mum Jeya*

### **The opportunity:**

The National Cancer Registry and Analysis Service (NCRAS) has made strides in collection and publication of systematic health data across most cancers. Moreover, there are multiple national programmes in NHS England looking at systematic health data to assess the quality of healthcare services and clinical practice on multiple cancers, e.g. the Getting It Right First Time (GIRFT) and the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

## **Our recommendations:**

The next government should:

- Publish more and better health data on leukaemia: We would like to see better, more consistent leukaemia health data, including data on diagnosis, incidence, mortality, survival, and emergency presentation broken down by leukaemia type. Also, to better understand the leukaemia landscape across the UK, collaboration among Scotland, Wales, Northern Ireland and England is needed to ensure that data is comparable and compliant.
- Undertake a review and an annual audit of leukaemia health services: A GIRFT review to understand how health services manage patients with leukaemia across England, as well as commissioning a national clinical audit for leukaemia on an annual basis like other cancers, will highlight where improvements are needed such as address variations in leukaemia treatment and care and health inequalities. These programmes will provide invaluable insights to understand health service improvement for leukaemia.