



Take Action. Save Lives

Our priorities for the Government

Leukaemia^{UK}

Foreword

Leukaemia research has already fueled breakthroughs in other cancers for over 40 years. Now, we have a once-in-a-generation chance to increase survival and improve the lives of those with leukaemia. With a focused commitment to research, diagnosis, treatment, and care, we can make this a reality.

Every day, 28 people in the UK are diagnosed with leukaemia – over 10,000 each year. Leukaemia affects everyone, from children who endure harsh treatments with lifelong consequences, to adults over 65, who represent the majority of cases¹.

Despite advances in childhood survival rates, leukaemia remains a relentless killer, especially among adults. Half of all leukaemia patients will not survive beyond five years, and for those diagnosed with Acute Myeloid Leukaemia (AML), the outlook is even bleaker. Only 22% survive beyond five years, leaving the UK lagging behind much of the rest of the world². A shocking 37% of leukaemia patients are diagnosed in emergency settings, which can severely limit their treatment options¹. These late diagnoses often result in poor quality of life and drastically reduce one-year survival. This is simply unacceptable.

Depending on their type of leukaemia, patients face unique challenges in treatment and care, and outcomes differ. A one-size-fits-all approach is not possible. If we want to save and improve the lives of those affected by leukaemia, we must

adopt tailored strategies to address the specific needs and improve outcomes for those affected.

This report calls for urgent and decisive action from the Government. We need earlier diagnosis, more effective treatments, and comprehensive support for the 60,000 people currently affected by leukaemia³, as well as those yet to be diagnosed. We are ready to work with the Government and everyone with the power to drive change to make it happen – once and for all. Leukaemia doesn't discriminate – neither should our response.



**Fiona Hazell, Leukaemia UK
Chief Executive**



"As a mother, watching my son Bodhi battle acute lymphoblastic leukaemia has been the most heart-wrenching experience of my life. It's a journey no parent, child, or family should ever have to endure. A cancer strategy is desperately needed to improve survival and quality of life for everyone affected by leukaemia – from our children to young adults, to parents and grandparents. We have to act now, so that families like mine have hope for a future where leukaemia no longer devastates lives."

**Hannah Peckham,
Leukaemia UK Ambassador**

We are asking the Government to ensure that the new Cancer Strategy includes commitments to save and improve the lives of those affected by leukaemia and other less common and rare cancers. This should focus on five key priorities:

Priority 1

Investment to find kinder, more effective treatments of leukaemia

Priority 2

Improvements in early diagnosis of leukaemia

Priority 3

Access to the best treatments for all leukaemia patients

Priority 4

Access to holistic needs assessment of leukaemia patients from the point of diagnosis, throughout treatment and into recovery

Priority 5

Publication of better, more consistent health data and clinical audits to improve quality of diagnosis, treatment and care of leukaemia

Facts and stats about leukaemia in the UK

Incidence

Most common childhood cancer. It mainly affects people over 65 years old.

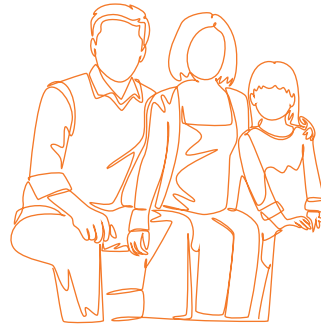


Leukaemia is the **12th** most common cancer

Prevalence

Nearly **60,000**

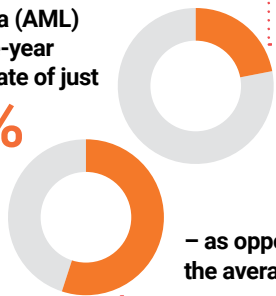
people currently living with leukaemia or are in remission



Survival

Acute myeloid leukaemia (AML) has a five-year survival rate of just

22%



– as opposed to the average

55%

five-year survival of all cancers

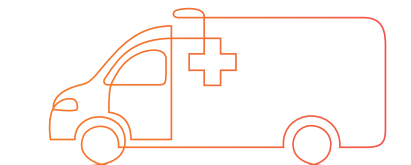
AML five-year survival in the UK lags behind international standards – 8th out of 12 countries.

Emergency

Leukaemia diagnosis in emergency settings is

37% vs **21%**

average of all cancer diagnoses



A fully funded cancer strategy to drive improvements in leukaemia

Currently, national plans and strategies mainly focus on solid cancers, such as breast, bowel, lung and prostate, without taking into account the different nature of leukaemia and the unique needs of the 60,000 people affected by this devastating disease in the UK.

As highlighted in the recent Darzi review of the NHS state in England, outcomes for diagnosis, treatment and care for patients with leukaemia and other cancer types are still lagging behind other countries⁴. It is well-established that consistency in cancer policy positively correlates with improvements in outcomes, including survival, which evidences the need for a long-term strategy for cancer⁵. This is the best way for the UK to drive improvements in cancer outcomes, not only to meet the standards of other comparable countries, but also to become the world's leading country in treating and curing cancer.

A national approach is necessary if we want leukaemia to see the progress that other cancers have seen in long-term survival and quality of life. The ten-year cancer strategies in Scotland and Northern Ireland have commitments to improve blood cancers such as leukaemia and we urge the Government to do the same.

We are calling on the Government to:

- publish a cancer strategy that commits to improving survival and quality of life for patients with leukaemia and other less common and rare cancers. This cancer strategy should also include a target to double five-year survival for Acute Myeloid Leukaemia (AML), from 22% to 44% in the next ten years,
- appoint a National Blood Cancer Committee to oversee implementation of the national cancer strategy, accountable to the Government,
- ensure the Children and Young People Cancer Taskforce represents leukaemia, which is the most common cancer among children.

Our five priorities

Priority 1

To find kinder, more effective treatments



"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

Leukaemia patients are often dependent on new treatments to survive the disease as surgery is not an option for them (unlike solid cancers).

Leukaemia research in the UK depends on a healthy research ecosystem with interdependencies across its universities, research institutes and hospitals, and good two-way engagement with commercial innovation. This, in turn, is supported by funding and mechanisms designed to attract and retain top research talent, both from within the UK and abroad. It also depends on providing the resources and research infrastructure necessary to keep them at the forefront of international innovation. The great potential of the NHS as a powerful platform for patient-centred research remains unfulfilled. Appropriate incentives for commercial investment are also required – from support to spin out companies from academia to an environment that supports real innovation for patients across clinical trials and market access.

Research is making good progress in understanding the causes of leukaemia and, from this, developing targeted treatments that are potentially less gruelling and more effective. However,

there is less progress in delivering high-quality clinical trials to test these promising new treatments and ensuring that new innovations arising from research reach the patients who need them.

Clinical trials provide the vital evidence-base for new treatment approaches and thereby the potential for improving the survival rates of those diagnosed with leukaemia. All new treatment regimens, new drugs, or previously licensed drugs need to go through the process of clinical trials.

Since the COVID-19 pandemic, there has been a reduction in the number of clinical trials taking place in the UK and therefore a reduced number of patients participating in new trials. Almost half of Cancer Patient Experience Survey⁶ respondents with leukaemia said that they would have liked someone to have discussed with them whether there were any cancer research opportunities they could take part in – such as clinical trials – but this did not happen. This was further evidenced by the findings of our own survey which 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**⁷. This is consistent with wider evidence that shows that there is an inequity in patient access to clinical trials.

We are calling on the Government to:

- establish a cross-sector Task and Finish Group involving the NHS, universities, and industry in the Government's new Innovation Strategy to ensure that the UK remains a world-leading hub of life sciences and medical research, including leukaemia research,
- **increase funding for leukaemia research on the translational path from discovery science through to clinical trials,**
- implement the recommendations from Lord O'Shaughnessy's 2023 review to streamline the clinical trial process, increase patient participation in clinical trials and address current inequity⁸.

Our five priorities

Priority 2

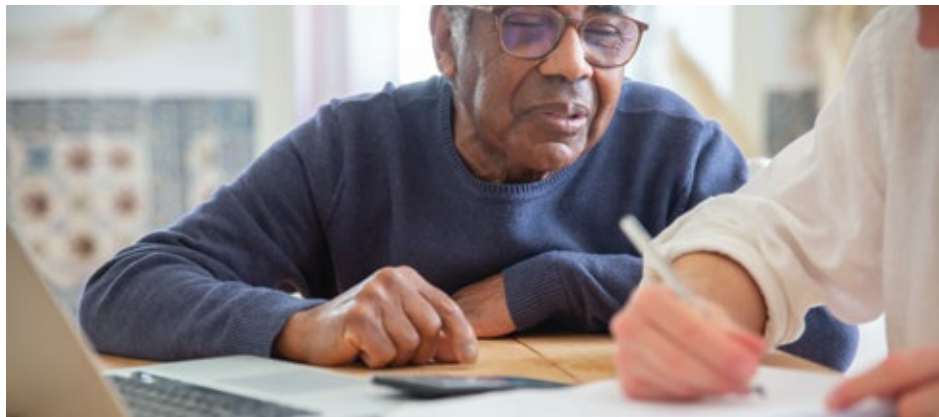
Improvements in early diagnosis of leukaemia

Delays to diagnosis can lead to fewer treatment options and a reduced chance of survival.

A full blood count is a simple blood test that can detect or rule out leukaemia. The current NICE guidelines recommend GPs organise an urgent full blood count test within 48 hours of anyone presenting with any leukaemia symptoms⁹. However, in a survey of leukaemia patients, we found that only a third reported being given a full blood count test within 48 hours after first presenting to their GP with symptoms; 23% of patients with acute leukaemia types said that it took three to four months to have a full blood count test. Moreover, our recent GP polling survey

carried out by Savanta stated that lack of capacity in phlebotomy services poses a significant barrier to referring people with symptoms for urgent full blood counts¹⁰.

As a result, in England, **37% of all leukaemia cases are diagnosed after presenting to the NHS as an emergency** compared to an average of 21% among all cancer diagnoses¹¹. Only 3% of breast cancer and 7% of prostate cancer cases were diagnosed at an emergency setting. For acute types of leukaemia, an overwhelming majority of cases are diagnosed in emergency departments compared to other settings. For chronic types of leukaemia, emergency diagnosis is the second most common route to diagnosis after GP referral.



There is a tendency for national NHS targets to focus on prognosis and outcomes based on solid tumour staging. But blood cancers, including leukaemia, are not staged in the way that solid tumours are. So, there's a real risk that they may be neglected as effort is focused on meeting the current NHS long-term target of 75% of people with cancer being diagnosed at either stage one or two by 2028.



"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

We are calling on the Government to:

- fund and lead public and GP symptom awareness campaigns for leukaemia,
- ensure that everyone presenting with leukaemia symptoms has a full blood count test within 48 hours, as recommended in the NICE NG12 guidelines,
- reform the primary and secondary care structures to increase phlebotomy capacity,
- develop and implement a best practice timed pathway for leukaemia,
- develop a proxy measure for leukaemia and other blood cancers to track progress made in early diagnosis as current targets serve solid tumours only.

Our five priorities

Priority 3

Access to the best treatments for all leukaemia patients



"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

Our research has revealed the profound toll that leukaemia treatment can take on patients, both physically and mentally. Nearly half (44%) of those diagnosed report a significant decline in their physical well-being during the early stages of diagnosis and treatment.

Even after treatment has ended, one in five patients (20%) continue to struggle with severe physical effects. The mental health impact is equally concerning, with about one-third of patients experiencing a noticeable decline in their psychological well-being during treatment¹².

These findings underscore the urgent need for kinder, more effective treatments. It's vital that leukaemia patients have access to new, less toxic therapies, supported by a robust and sustainable cancer care system and workforce. This is key to sparing them from the intense physical and mental hardships associated with current gruelling treatments.

Currently, many people who would benefit from the innovative CAR-T therapy miss out because it is not available everywhere and there is not a standardised approach on patient eligibility. Greater capacity is

required to allow all eligible patients to be offered CAR-T therapy. Emerging evidence also suggests that CAR-T therapy as a first treatment option, rather than after relapse, could be more beneficial for both the long-term physical and mental health of patients, and their loved ones, than current chemotherapy treatments.

We have identified a rising trend of pharmaceutical companies not submitting their blood cancer treatment innovations for UK approval, despite them being made available to patients in other countries. Often this is because the pharmaceutical companies and the NHS cannot agree on cost, or because of complexities in the appraisal system and processes. **The large number of non-submitted, potentially groundbreaking drugs represents a missed opportunity for blood cancer patients to access potentially life-saving treatments.**



"CAR-T therapy was the last option and the only one that worked for my son Opie. Why wasn't it the first option?"

Lucy Ellerker-Jones, mum of four-year-old Opie, now cancer-free who was diagnosed with leukaemia at five months old

We are calling on the Government to:

- ensure 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,
- greater availability and equitable access to CAR-T for those with B-cell Acute Lymphoblastic Leukaemia (ALL) and potentially offering this novel treatment as a first treatment option,
- ensure that the right infrastructure and workforce expertise is available in the NHS across the UK, so that everyone can access novel treatments regardless their location, age and background.

Our five priorities

Priority 4

All leukaemia patients to have a full holistic needs assessment from the point of diagnosis, throughout treatment and into recovery.



"Mum had never been ill before, and it felt like it was all over very quickly. Mum aged ten years overnight once she was diagnosed and underwent treatment. She was very upset because she wanted to live another ten years to see her grandchildren grow up. I wish there was better awareness and understanding of how patients feel emotionally."

Darren from Hampshire, who lost his 67-year-old mum Jeya

A leukaemia diagnosis comes with many challenges, such as hidden costs and difficulties accessing routine treatment and care, combined with the vulnerabilities that come with having a weakened immune system.

Leukaemia patients face many hidden costs when living with cancer; travel expenses to and from hospital, food costs associated with specialist diets and additional use of home heating to keep warm, due to treatment side effects. Evidence suggests that nearly 65% of patients are forced to reduce their working hours or even stop working completely following a leukaemia diagnosis. The median financial impact on a blood cancer patient is £181 per month, compared with £120 for a patient with breast cancer or with £52 for a patient with prostate cancer¹³.

While information is given to patients about their physical health and the treatment procedures they will undergo, the psychological aspect of receiving treatment or being placed on "Watch and

Wait" can be mentally challenging for those with chronic types of leukaemia.

Therefore, addressing the psychological concerns of leukaemia patients is important. For example, during their treatment, stem cell transplant patients need support from family and friends, clear information about treatment and options, and reassurance that the treatment is working. Evidence shows that 87% of 'Watch and Wait' patients would like to have more support after diagnosis, and to improve emotional wellbeing, there is a need for timely signposting to trusted sources and improved doctor-patient communication to ensure patients are better informed about 'Watch and Wait'¹⁴.

A Holistic Needs Assessment (HNA) is a simple questionnaire which is completed by a person affected by cancer. It allows patients to highlight the issues which they feel are, or are likely to be, most important to them. A HNA ensures that people's physical, practical, emotional, spiritual, and social needs are met in a timely and appropriate way, and that resources are aligned with need. A HNA guides the development of a care and support plan by a nurse or key worker. This should be undertaken at different stages in the cancer patient's pathway, particularly at diagnosis and following treatment.

In 2017, it was reported that HNAs were used by 77% of NHS Trusts, with an estimated 31% of patients having had a HNA¹⁵. Aside from this data, little has been published on whether HNAs have been carried out and how many leukaemia patients have completed them. Shockingly, our own data has found that **only 9% of people with leukaemia had been offered a HNA to identify their supportive care needs and inform the development of a care and support plan**¹⁶.

We are calling on the Government to:

- ensure that people with leukaemia have access to financial support that meets their needs,
- ensure everyone with leukaemia is offered a **HNA** at the point of diagnosis, as well as after treatment to ensure that all physical and psychological needs are identified, addressed, and monitored,
- ensure the **right expert workforce and resources are in place so that healthcare teams can meet the immediate and long-term needs of the patients.**

Our five priorities

Priority 5

Publication of better, more consistent health data and clinical audits to improve quality of diagnosis, treatment, and care of leukaemia

There are gaps and inconsistencies in the way that leukaemia data is reported in England, including a lack of data by leukaemia type. This is a key barrier in understanding the issues and developing targeted strategies to improve survival and quality of life for those affected by the disease.

Health data on leukaemia is vital to better understand the disease as a health condition, but also to monitor where improvements have been made or highlight where improvements are needed.

The National Disease Registration Service (NDRS) in England has made strides in collection and publication of compelling 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. Getting It Right First Time (GIRFT)

and the National Clinical Audit and Patient Outcomes Programme (NCAPOP).

However, **data for leukaemia** such as incidence, mortality and survival, routes to diagnosis, treatments and cancer waiting times **are generally inconsistently reported, if at all, and often without sufficient granularity**; particularly, with regards to different types of leukaemia. Moreover, **data reporting on leukaemia differs between Scotland, Wales, Northern Ireland, and England.**

References

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- 14 Leukaemia Care (2022) Left to #WatchWaitWorry: The experience of Chronic Lymphocytic Leukaemia (CLL) patients living on Watch and Wait
- 15 NHS England (2018) Living With and Beyond Cancer - Baseline Activity
- 16 Leukaemia UK patient survey, February 2024



"Leukaemia is a complex disease, and with Acute Myeloid Leukaemia having an unacceptably low survival, high-quality, granular data is crucial. Such data is essential for making the improvements that patients with leukaemia desperately need."

Alex Smith, Professor of Cancer Epidemiology and Co-Director of the Epidemiology & Cancer Statistics Group at the University of York.

We are calling on the Government to:

- **publish better, more consistent data on leukaemia** and with the granularity needed to be able to understand quality of care, patient and clinical outcomes,
- **fund a GIRFT review for leukaemia** to identify best clinical practice and issues in quality of health service for leukaemia,
- **fund an annual National Clinical Audit** to understand and address issues in quality and consistency of diagnosis, treatment and care of leukaemia.

Leukaemia UK is a
leading research
and advocacy
charity with a clear
vision – to
stop leukaemia
devastating lives