

Turning ambition into progress for people with leukaemia in Scotland

- ✓ Diagnose earlier, diagnose better.
- ✓ Access to world-class treatment.
- ✓ A cancer system that delivers.

INTRO



We can turn
ambition into
progress



FOREWORD:

JOSEPH BEAVER

Leukaemia Patient

When I was diagnosed with T-Cell Large Granular Lymphocytic Leukaemia, it came as a total shock. It was identified during tests carried out while I was in hospital with Guillain-Barre Syndrome.

Like many people, I was left frightened, uncertain, and unsure what the future would hold.

I have been fortunate to connect with others who understand what this diagnosis means. However, too many people across Scotland face very different experiences depending on where they live.

This report matters because it reflects those realities. With the right political leadership, Scotland can transform the future for everyone diagnosed with leukaemia.



FOREWORD:

Fiona Hazell

Chief Executive
Leukaemia UK

Scotland has the power to transform the future for people with leukaemia, and the next five years will be decisive.

The Scottish Cancer Strategy has set out an ambitious vision for cancer diagnosis, treatment, and care.¹ Now is the time to turn that ambition into tangible progress for patients.

Cancer remains the most common disease in Scotland, with 35,000 people diagnosed each year, and the number of cases continues to rise.²

This growing burden sits alongside other profound and persistent challenges. Inequalities are deeply entrenched, with cancer deaths 74% higher in Scotland's most deprived communities and the mortality gap between the most and least deprived has continued to widen over the past 25 years.³

Despite this, Scotland also has the foundations needed to act.

With a focused national policy framework, committed workforce and strong research and funding infrastructure, there is a clear opportunity to translate the ambitions of the 2023 – 2033 Scottish Cancer Strategy into real, tangible progress for those affected by cancer, including leukaemia.⁴

Leukaemia affects babies, children, and adults across Scotland, who often face significant challenges across diagnosis, treatment and care.

At Leukaemia UK, we know change is possible. We have a clear vision to stop leukaemia from devastating lives, and we believe Scotland can lead the way in delivering the change that people with leukaemia desperately need.

This parliament must be one of delivery for Scotland.

We are ready to work with the Scottish Government to turn ambition into progress for patients. By working together, we can transform survival and ensure that everyone diagnosed with leukaemia is supported to live well, with and beyond their cancer.

With your political leadership, the future for people affected by leukaemia in Scotland can be transformed.

Let's work together to stop leukaemia devastating lives.

Why leukaemia must be a priority in Scotland

Each year in Scotland around 700 people are diagnosed with leukaemia,⁵ and only half survive for more than five years following their diagnosis.⁶ Every diagnosis and death has a profound impact, devastating families and communities.

Leukaemia often presents with vague, non-specific symptoms, making it difficult for both patients and healthcare professionals to recognise.

This can result in a delayed diagnosis, or a diagnosis in an emergency setting. For too long, this has been accepted as the norm in leukaemia.

While it may sometimes be the fastest route, an emergency diagnosis is associated with poorer patient outcomes.

Experiences vary widely: some people are diagnosed after their first GP visit, while others endure prolonged uncertainty, multiple appointments, and the emotional strain of waiting for answers.

"It was a total shock. During tests for another condition, Guillain–Barre Syndrome, they discovered something wasn't right and diagnosed me with T–Cell Large Granular Lymphocytic Leukaemia (T–LGL). I immediately thought I was going to die. Speaking to people on social media who also have T–LGL has helped me a lot.

Even since my diagnosis I have faced issues in accessing full blood count tests to monitor my blood levels, being told by my GP that they could only be asked for by my haematologist.

This needs to change. Everyone diagnosed with leukaemia or anyone presenting with leukaemia symptoms should have access to an urgent full blood count test, with results readily available to them, and provided in a accessible way."

–Joseph Beaver, 50 from, Glasgow

We often hear from our patient community that experiences of diagnosis, treatment and care vary depending on where people live.

Publicly available data reflect this and show stark disparities in outcomes across Scotland. People living in Health Boards with the highest leukaemia mortality, such as the Western Isles, are almost three times more likely to die from leukaemia than those in areas with the lowest mortality, such as Shetland.⁷

For acute myeloid leukaemia (AML), which has the poorest survival rates, mortality is more than twice as high in the worst-affected areas.⁸

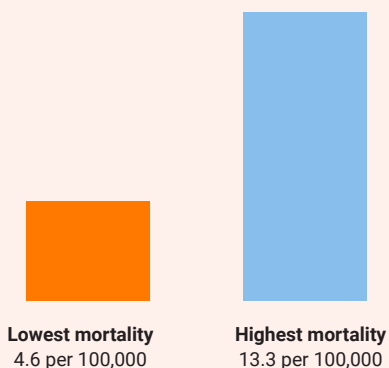
Our message for Scotland's leaders is clear: ensure a future where everyone diagnosed with leukaemia, wherever they are from, will survive and live long and well.

It should not be the case that an individual's postcode determines their chance of survival.

The Scottish Parliament must act to address these variations in diagnosis, treatment, and care.

Mortality Rate Variation⁹

Leukaemia mortality rates vary significantly between Scotland's Health Boards.





The next decade:
A future
where more
people survive
leukaemia and
live well

Scotland has the power to transform the future for people with leukaemia, and throughout this Parliament significant progress can be made. We know change is possible.

Over the next decade, the landscape for leukaemia patients in Scotland can be radically different: a country where more people survive leukaemia and live well, and where fewer lives are devastated by the disease.

It is our ambition at Leukaemia UK to work with the Scottish Government and those with the power to drive change to make this a reality.

With strong leadership and an empowered system, focused on diagnosing leukaemia earlier and better, and ensuring access to world-class treatments and care, we can achieve a future where:

1. Survival of leukaemia types with poorer prognosis, such as AML, is transformed.
2. Everyone diagnosed with leukaemia has the best possible quality of life.

Incidence in Scotland¹⁰

690

people every year
are diagnosed with
leukaemia



Diagnose earlier, diagnose better

If Scotland is to transform survival for leukaemia types with poorer prognosis, it must deliver earlier and better diagnosis for leukaemia patients, and address existing disparities.

A full blood count is all that is needed to rule out or indicate leukaemia. Any patient presenting to their GP with suspected leukaemia symptoms should be referred for this simple and inexpensive blood test within 48 hours. Yet we hear from our patient community that too many people are not offered this test.

By focusing specifically on addressing the issues for leukaemia, and further strengthening the systems already in place, we can change this.

By working with the NHS, the Scottish Government can turn this ambition into progress for people with leukaemia. Earlier and better diagnosis can be delivered through:

- ✓ Delivering an optimal cancer diagnostic pathway for leukaemia.

- ✓ Providing direct access to full blood counts for those with non-specific symptoms indicative of leukaemia.

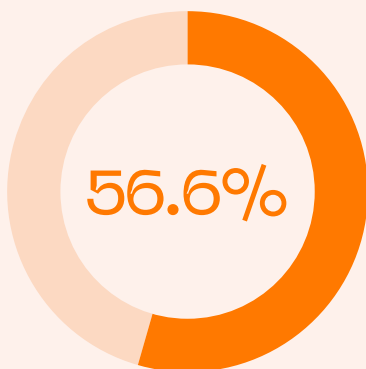
- ✓ Strengthening the Scottish referral guidelines for suspected cancer covering acute leukaemia types in adults.

- ✓ Running a symptom awareness campaign to empower the public and GPs to recognise leukaemia and act urgently.

- ✓ Developing a single patient record with automatic prompts built-in to encourage healthcare professionals to refer suspected leukaemia patients for a full blood count.

Access to world-class treatment and care across Scotland

Overall five-year
survival rate for
leukaemia¹¹



Scotland cannot allow these significant variations in access to treatments and care outcomes to continue.¹² These must be addressed if we are to stop leukaemia from devastating lives. Every patient, regardless of where they live, deserves access to world-class leukaemia treatments, wherever and whenever they need them.

The Scottish Government must deliver cutting-edge and high-quality treatments to all patients, from the best treatments currently available to clinical trials developing the next big breakthroughs. Access to high-quality cancer treatment and care must be a priority.

Leukaemia presents in both acute and chronic types. Chronic types typically develop more slowly over time. Whereas acute types, like AML, progress more quickly and aggressively, often requiring immediate treatment.

Timely decision-making is critical for patients to have the best chance of survival. This is particularly important in aggressive leukaemias such as AML.

Timely genomic testing is also essential to ensure patients can access the most appropriate and effective treatments for their cancer. Patients must have equitable access to genomic testing where clinically appropriate.

The Scottish Genomic Medicine Strategy identifies cancer genomics as a central strategic priority, aiming to improve diagnosis, enable personalised treatment, support clinical decision making, and enhance outcomes for people affected by cancer in Scotland.

The strategy commits to expanding access to advanced genomic testing, strengthening infrastructure and data systems, supporting research and clinical trials, and developing workforce capability across the system.¹³

The Scottish parliament can work with NHS systems to save and improve more lives affected by leukaemia in Scotland by:

- ✓ Ensuring genomic testing is available as a standard of care to those patients who would benefit.

- ✓ Guaranteeing all leukaemia patients can access a clinical trial as part of their treatment.

- ✓ Developing a clinical management pathway for blood cancers, with a specific focus on leukaemia.

- ✓ Developing and funding solutions to enable equitable access to specialists for patients in geographically remote areas.



Building a cancer system that delivers for leukaemia

Leukaemia must be included in national health policy. The 2023–2033 Scottish Cancer Strategy sets out an ambitious vision for cancer policy in Scotland. The challenge is now delivery. For that vision to be realised, the Scottish Government must address the specific and persistent challenges facing leukaemia and ensure that everyone in Scotland can access high-quality, life-saving diagnosis, treatment, and care.

By building a cancer system that works for all patients, Scotland has the opportunity to transform survival and ensure that everyone diagnosed with leukaemia is supported to live well, with and beyond their cancer.

This requires targeted action, sustained political leadership, and a clear focus on outcomes.

Leukaemia is a non-stageable cancer, and as a result, is neglected by existing early diagnosis targets.

The Scottish Cancer Strategy recognised this gap and committed to developing a meaningful measure of earlier diagnosis in non-stageable cancers.

That commitment has yet to be delivered. Without it, there is a real risk that people with leukaemia and other blood cancers continue to be excluded from efforts to diagnose cancer earlier.

Robust, transparent data is essential if Scotland is to deliver meaningful progress for leukaemia.

Inconsistent data collection and publication currently limit the ability to monitor performance, address inequalities, and hold the system to account across diagnosis, treatment, and care. To maximise its value, data must be granular, site-specific, and comparable with other UK nations. For leukaemia, this means that breakdowns with sufficient granularity across the four main leukaemia types must be available.¹⁴

Ambition alone will not deliver change. The cancer system cannot meet the goals of the strategy without an adequate and appropriately specialised workforce, particularly across diagnostics, haematology, and pathology.

The Scottish Government should work closely with Public Health Scotland and the NHS to ensure that the system delivers for all leukaemia patients by:

- ✓ Establishing leukaemia as a focus condition in the next Cancer Action Plan for Scotland.

- ✓ Delivering on the promise of a meaningful measure of earlier diagnosis for non-stageable cancers.

- ✓ Developing a national cancer data roadmap, co-produced with clinicians, researchers, and people with lived experience.

- ✓ Ensuring data is comparable with other UK nations.

✓ Undertaking a comprehensive NHS workforce audit, using the findings to inform a fully funded workforce plan.

✓ Ensuring the 2024–2029 Genomic Medicine Strategy is delivered in full, and adequately represents leukaemia.

✓ Investing in clinical trial infrastructure and workforce capacity across the NHS, academia, and clinical trial units.

✓ Addressing the systematic de-prioritisation of blood cancer trials.

✓ Strengthening Scotland’s attractiveness for pharmaceutical investment in clinical trials.

By championing leukaemia throughout this Parliament, you can help us turn ambition into progress and ensure that everyone living with and beyond leukaemia has the best possible experience and outcomes.

References

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- 3 [Cancer Research UK Cancer in the UK: Data and Research Deprivation and cancer inequalities in Scotland](#)
- 4 [Cancer Strategy for Scotland 2023 – 2033](#)
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- 11 [Public Health Scotland: estimates of survival from leukaemias](#)
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- 13 [Acute myeloid leukaemia, acute lymphocytic leukaemia, Chronic myeloid leukaemia, and chronic lymphocytic leukaemia](#)
- 14 [The Scottish Genomic Medicines Strategy 2024 to 2029](#)

Research has
the power to
change lives

Leukaemia^{UK}

Together, we can change the future for people affected by leukaemia

With your leadership and
commitment, Scotland can transform
the future of leukaemia. Let's
work together to stop leukaemia
devastating lives.