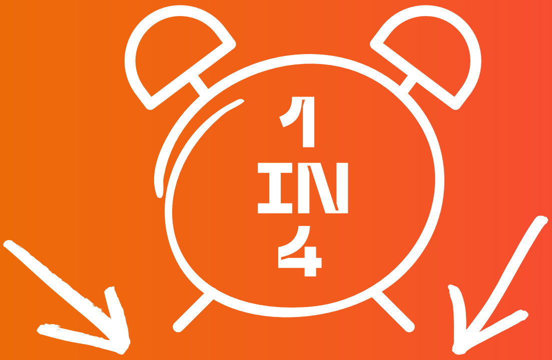

COUNT US IN

1 in 4
leukaemia patients
faces avoidable delays.
Let's change that.

Leukaemia UK

Foreword

In the UK, over 10,000 people are diagnosed with leukaemia each year, and nearly 60,000 are living with and beyond the disease.[1,2] Leukaemia affects people of all ages – from children, for whom it is the most common cancer, to adults. Leukaemia presents in both acute and chronic types. Chronic types typically develop more slowly over time, while acute types progress quickly and aggressively and usually require immediate treatment. Acute myeloid leukaemia (AML) is the most aggressive type of leukaemia, with a devastating overall average 5–year survival.[3] Delays to starting treatment for acute leukaemia types, can negatively impact a patient's treatment options, likelihood of remission and survival.

Despite progress in cancer research and patient outcomes, over a third (37%) of leukaemia patients are diagnosed in emergency settings – far higher than the cancer average of 21%.[4]

Emergency diagnosis is linked to poorer patient outcomes and higher costs, yet it has long been accepted as the norm in leukaemia diagnosis. For many people with leukaemia, the warning signs were there, but they weren't diagnosed in time. Often, all this takes is a simple full blood count test. New evidence from a study commissioned [5] by Leukaemia UK shows that up to 1 in 4 (26%) leukaemia patients experienced avoidable delays in diagnosis, of whom a further quarter were diagnosed in emergency settings.

These new findings also showed that delayed AML diagnosis had a bigger impact on one–year survival than the emergency diagnosis alone; the one-year survival of those with AML diagnosed in emergency settings was 55% as opposed to 20% one–year survival of those with avoidable delays.

For AML patients alone, an estimated additional £11 million in direct NHS costs were expended because of these delays in the last five years – highlighting the urgent need for earlier diagnosis and intervention.

In some cases, a leukaemia diagnosis through an emergency setting may be the fastest route. However, we now know that not every emergency diagnosis is inevitable. Many are the result of avoidable delays and missed opportunities – opportunities we can and must act on.

The new data outlined in this report is also timely. The forthcoming National Cancer Plan in England presents a vital opportunity to commit to ending avoidable delays in leukaemia diagnosis, and to ensure that non–stageable cancers such as leukaemia are not left out of national measures of diagnostic delay which are currently focussed on cancer staging.

We are ready to work with policy makers, patients, healthcare professionals and other charities to ensure that earlier and better diagnosis in leukaemia can help save and improve more lives.

"Too many people with leukaemia are slipping through the cracks. Every patient, every diagnosis counts to diagnose earlier, diagnose better and save more lives. Despite having one of the cheapest and most accessible diagnostic test available, we are still failing patients. We must do better for the thousands diagnosed with leukaemia every year. We are asking the Government to urgently prioritise the needs of people with leukaemia in the upcoming National Cancer Plan. Count Us In."

Fiona Hazell,
Leukaemia UK Chief Executive

We are calling on the Government to commit through the National Cancer Plan to stopping avoidable delays in leukaemia diagnosis – from the first presentation of symptoms to referral for tests and timely escalation to specialist care.

1 IN 4

COUNT US IN

References

1 National Disease Registration Service (NDRS)
2 Haematological Malignancy Research Network (HMRN)
3 National Disease Registration Service (NDRS) Get Data Out
4 Leukaemia UK calculations through NDRS data on emergency presentations
5 Health Economics Unit, NHS England

Introduction

Early diagnosis is critical to improving cancer outcomes, yet too many leukaemia patients report delays that were unnecessary and avoidable. Leukaemia symptoms are vague and often missed — less than 14% of the public can identify the four main symptoms.[6]

In acute types of leukaemia, symptoms can escalate rapidly, leading to emergency diagnosis and poorer prognosis.

While some emergency diagnoses are appropriate, patient stories reveal a troubling pattern: many report spotting symptoms and repeatedly consulting their GP without being offered a full blood count – a simple, inexpensive test that can confirm or rule out leukaemia. Our survey of 300 patients found that 50% waited a week or more after reporting symptoms before receiving a blood test,[7] far longer than the 48–hour window recommended by national clinical guidelines.[8]

In 2024 our commissioned poll of 1,000 GPs revealed that the most common reason for not referring for a full blood count is because of capacity issues in phlebotomy services.[9]

Therefore, some emergency diagnoses of leukaemia may result from avoidable delays earlier in the process.

These delays can have serious consequences for patient outcomes and the healthcare system itself.

In recent years, several national programmes have focused on earlier and faster diagnosis, with Non-Specific Symptom (NSS) pathways and Community Diagnostic Centres (CDCs) proving vital for diagnosing cancers with vague and non-specific symptoms such as leukaemia. However, no national policy to date has focused on monitoring progress in early diagnosis for leukaemia and other blood cancers while current national metrics to improve early diagnosis focus on solid tumours and staging[10] which are not relevant to non–stageable cancers such as leukaemia.

This must change.

In order to identify potential solutions, we aimed to gain insight from real–world NHS data for leukaemia diagnosis routes and outcomes. We commissioned an analysis of anonymised data from over 12,700 people diagnosed with leukaemia in England. The study covered patients diagnosed between April 2015 and March 2023 (excluding COVID–19 pandemic years).

"I saw my GP several times over months with symptoms including bone pain, exhaustion, bruising and mouth ulcers. I wasn't offered a full blood count test and was told it was rheumatoid arthritis, but the medication didn't help. It wasn't until I fainted and ended up in A&E four months later that I was finally diagnosed with AML. While the care I received was exceptional and I feel very lucky to be in remission, that is not the case for everyone with leukaemia. I fully support Leukaemia UK's call for change, early diagnosis saves lives."

Tracey Palmer-Hole,
AML survivor

This report presents new findings and clear recommendations for action. The National Cancer Plan is a unique opportunity to deliver the change patients need and deserve.

1 IN 4
COUNT US IN

References

6 Spot Leukaemia survey (2024)

7 Leukaemia UK supporter survey (2024)

8 NICE NG12 referral guidelines

9 Blood testing capacity issues slow down leukaemia referrals, say GPs – Pulse Today

10 The NHS Long–Term Plan 2019

1 in 4 people

with leukaemia faces avoidable delays in diagnosis

Delays in diagnosis were seen across all types of leukaemia – both chronic and acute types.

Avoidable delays were observed from the point of symptom reporting and referral for full blood count tests (GP/primary care), during diagnostic testing (secondary care) as well as escalation to specialist care for those with abnormal blood tests. Moreover, over a quarter (26%) of those with an avoidable delay were also diagnosed in emergency settings. These delays pose significant missed opportunities of earlier and better diagnosis of leukaemia.

Chronic types of leukaemia typically develop more slowly over time, while acute types progress quickly and aggressively and usually require immediate treatment. Acute Myeloid Leukaemia (AML) has an average five-year survival of 22%,[11] one of the lowest average five-year survival of all cancers, and half the combined all–cancer average. [12]

Any delays to starting treatment can negatively impact treatment options, and the likelihoods of remission and survival.The findings showed that patients with AML mainly experienced avoidable delays at the primary care (GP) level. These included a delay in escalation after presenting to a GP with symptoms (28%) as well as a delay in escalation after multiple GP visits (21%). Albeit at lower scale, they also experienced delays in secondary and specialist care, especially in escalation following an abnormal full blood count (15%).

From an economic perspective, delays in the diagnostic pathway shifted health care activity from planned to emergency care and resulted in increased costs. In AML, delays in diagnosis resulted in 4,100 healthcare contacts that could have been avoided. This cost the NHS an estimated £1.7 million in avoidable healthcare activity across GP, outpatient, and hospital services in the three months before and six months after diagnosis.

This is equivalent to over £11 million over the last five years.

Avoidable delays in diagnosis of AML had also a bigger impact on one–year survival than emergency diagnosis itself. The one–year survival of those with AML diagnosis in emergency settings was 55% as opposed to the 20% one–year survival seen in those with avoidable delays in diagnosis.

We must put a stop to these avoidable delays.

Unnecessary emergency diagnoses clog up already overstretched A&E departments, diverting patients from primary to secondary care and doubling hospital activity both before and after diagnosis.

References

[11] National Disease Registration Service (NDRS) Get Data Out

[12] Leukaemia UK calculations through NDRS data

1 in 4
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Let's change that.

The National Cancer Plan offers a vital opportunity to deliver for patients, their families and the NHS. To save and improve more lives of people with leukaemia while building a sustainable NHS, the Government must take action to close gaps and tackle early diagnosis.

For patients to have the best chance of surviving leukaemia we need appropriate testing capacity, effective standards of care and a healthcare workforce and public who know the signs of the disease and what to do about them.

We are calling on the Government to commit through the National Cancer Plan to stopping avoidable delays in leukaemia diagnosis – from the first presentation of symptoms to referral for tests and timely escalation to specialist care.

To achieve this, the Government should work with the cancer community – including charities, clinicians, researchers and patients – towards implementing the following recommendations:

① **Stop avoidable delays in emergency diagnosis. Commit to reducing the number of leukaemia diagnosis in emergency settings. This should be tracked through a national measure and used as a key indicator of progress in the National Cancer Plan.**

② **Harness technology to develop the single patient record and enable automatic prompts for GPs and other healthcare professionals to refer everyone with alarming leukaemia symptoms for urgent full blood counts.**[13]

③ **Resolve phlebotomy capacity issues to enable full blood count testing within 48 hours of referral via Community Diagnostic Centres and Non-Specific Symptoms pathways.**

④ **Establish and implement new and existing guidelines through NICE and a Best Practice Timed Pathway for leukaemia to ensure people with abnormal full blood counts are:**

- ✓ Seen by a haematologist within a week if there is suspicion of chronic leukaemia and has symptoms requiring urgent assessment.
- ✓ Admitted and seen by a haematologist on the same day if there is a suspicion of acute leukaemia.

⑤ **Partner with Leukaemia UK to run an awareness campaign that:**

- ✓ Empowers the public to recognise leukaemia symptoms, report them to their GP and request urgent full blood count testing within 48 hours.
- ✓ Encourages self–referral for full blood counts among individuals with relevant symptoms where appropriate.
- ✓ Drives accountability among GPs and healthcare professionals to urgently refer patients with alarming symptoms for full blood counts and specialist care symptoms for full blood counts and specialist care.

References

[13] NICE NG12 referral guidelines

Acknowledgements

Evidence presented in this report was from a project conducted by NHS England Health Economics Unit (HEU) and commissioned by Leukaemia UK. Leukaemia UK would like to thank the HEU and the many experts: data analysts, healthcare professionals, researchers and individuals affected by leukaemia whose insights and contributions were invaluable throughout the scoping, design, development and review of this study. This work was supported in part with funding from AbbVie, J&J and Novartis. These organisations had no input into the development, design, delivery or interpretation of the evidence, and no editorial input into this report.

Prof. Alex Smith, Professor of Cancer Epidemiology & Co–Director Epidemiology & Cancer, University of York

“This study provides novel insights into the diagnosis of leukaemia, clearly demonstrating that avoidable delays occur at multiple points across the healthcare system. Crucially, this is true for both acute and chronic leukaemia types, with particularly important implications for acute myeloid leukaemia. These new findings are vital for driving improvements in earlier and faster diagnosis, which will not only benefit patients but also improve the efficiency of the NHS. I’m delighted to have supported Leukaemia UK throughout the development and delivery of this work, and I look forward to continuing our collaboration in the next phase of the project.”

Dr Pramila Krishnamurthy, Consultant Haematologist at King’s College Hospital NHS Foundation Trust

“Acute myeloid leukaemia has one of the lowest five–year survival rates among all cancers, making early diagnosis absolutely critical. This study is a powerful reminder of the urgency to diagnose leukaemia earlier. The report offers important new findings and practical recommendations that can help make earlier leukaemia diagnosis a reality. I was pleased to contribute to the scope and design of the study and to provide clinical input in shaping the insights it has delivered.”

Dr Anjum Khan, Consultant Haematologist at Leeds Teaching Hospitals NHS Trust

“Every minute counts when it comes to recognising AML – delays can have a serious impact on a patient’s chance of survival. This study provides vital evidence of where those delays are happening and how we can address them. Having seen the impact of delayed diagnosis I fully support this important work. Getting the basics right, including urgent blood testing, is crucial to improving patient outcomes.”

Dr Anthony Cunliffe, General Practitioner and Macmillan National Lead Medical Adviser, Joint Clinical Director, South East London Cancer Alliance

“This study provides valuable new insights into the diagnosis of leukaemia, showing that avoidable delays happen at multiple points across the healthcare system—including in general practice. As a GP, I know how critical it is to have the right tools and clear guidance to support timely decisions, especially around referring patients for full blood counts. Earlier and faster diagnosis, particularly for acute myeloid leukaemia, can make a real difference to patient outcomes and NHS efficiency. I’m proud to have supported Leukaemia UK in developing and delivering this work, and I look forward to continuing working with the team in the next phase of the project.”

✓ DIAGNOSE EARLIER.

✓ DIAGNOSE BETTER.

✓ SAVE LIVES.

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