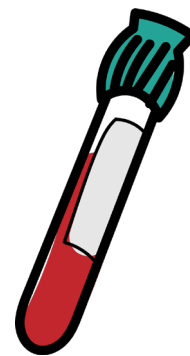


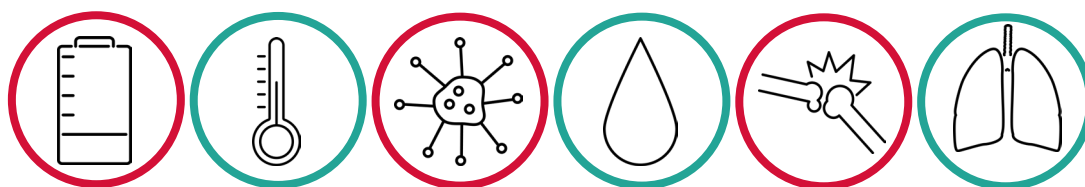
Access to blood tests and diagnosis of leukaemia - an exploratory report



Executive summary:

The challenge of diagnosing leukaemia

Nearly 10,000 people are diagnosed with leukaemia in the UK every year, or 27 people every day [1]. Leukaemia has a significantly higher rate of emergency diagnosis, e.g. via A&E, (averaging at 37%) than the overall cancer average (21%) [2]. There are nearly 5000 deaths attributed to leukaemia every year in the UK [1]. Emergency diagnosis saves lives, as diagnosis in A and E is linked to reduced survival. The challenge with the early diagnosis of leukaemia is multi-faceted, but can be attributed in part to the non-specific symptoms of leukaemia, which can also be indicative of more common and less sinister illnesses. This makes leukaemia hard to spot for both members of the public and healthcare professionals.



The role of blood testing

The Spot Leukaemia campaign highlights a number of ways to address the challenge of leukaemia diagnosis. This includes improving public awareness and more timely publication of emergency diagnosis statistics; a full analysis of the challenges can be found [here](#). However, a full blood count is all that is needed to diagnose leukaemia early or to rule it out, and this report explores this issue in particular. Leukaemia Care and Leukaemia UK conducted a large patient survey to understand more about patient experience of obtaining the full blood count. We also spoke with our GP advisors. Our key findings include:

According to the NICE NG12 guidelines, **everyone presenting with the symptoms of**

- **leukaemia should get an urgent 48-hour full blood count** [3]. However, in our survey, only 1/3 reported that they got a blood test straight away after seeing a GP about their symptoms (i.e. following one appointment only)[4].

In addition 23.5% of acute leukaemia respondents said it took up to 3-4 months after first

- presenting to the GP to get a blood test [4].

Furthermore, our GP advisors informed us that the system and capacity pressures they

- face stop them from conducting full blood counts every time they see a patient with the symptoms in the NG12 guidelines, even though they are aware that they should be [5].

GPs are in need of further support beyond the publication of guidelines. Therefore, the recommendations we propose to address these issues are:



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GPs need to know more about leukaemia symptoms and who it affects.

Recommendation 1: All stakeholders should promote GP education tools that are available on the topic of leukaemia, to help GPs become more familiar with the symptoms of leukaemia.

NICE guidelines are not fit for purpose without further support provided to GPs alongside them.

Recommendation 2: NICE should conduct a review of the guidelines to ensure the description of symptoms is accurate according to the experiences of general practitioners and patients.

Recommendation 3: All relevant stakeholders should come together to create decision support tools based on the symptoms experienced by patients, that will prompt GPs to refer to the NICE (NG12) guidelines regardless of whether cancer is initially suspected. This must cover non-specific symptoms.

Recommendation 4: Local and national NHS bodies to work together to ensure that GPs have better access to advice and guidance from haematology and access to education around interpreting full blood counts.

System pressures are preventing GPs from actioning the guidelines, even when they are fully aware of them.

Recommendation 5: Departments of Health across the UK must address the GP and other primary care or diagnostic workforce pressures, providing adequate investment for this.

Recommendation 6: The Royal College of Pathologists should advise members on best practice for providing information to GPs alongside the full blood count test results, abnormal or otherwise, and ensure an urgent blood film is done on all abnormal full blood counts.

Recommendation 7: Pharmacists should receive equivalent training on the symptoms of leukaemia. They should be able to refer patients presenting with symptoms to GPs for urgent appointments. Studies investigating the potential of conducting blood testing elsewhere in the community, including pharmacies, must also be encouraged.



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The challenges patients face

Results from Leukaemia Care's '[Living with Leukaemia](#)' survey show that on average, 15% of leukaemia patients said they visited their GP more than three times before they were referred to hospital [6]. This is also reinforced by data from the 2021 Cancer Patient Experience Survey (CPES) which highlights that 22.6% of leukaemia patients spoke to their GP or other healthcare professional 3 or more times before being diagnosed [7]. Also in the Living with Leukaemia Survey, only half (48%) of leukaemia patients felt their GP had a complete understanding of blood cancers, and this has shown no significant improvement over time [6]. The non-specific nature of blood cancer symptoms and the relative rarity of leukaemia could contribute to a 'doctor interval' (delays in testing, referral and diagnosis once a patient presents to primary care, potentially leading to a patient to present as an emergency instead - e.g. in Accident and Emergency - as symptoms become more severe).

In a new survey of leukaemia patients conducted by Leukaemia Care and Leukaemia UK in 2022, only 1/3 reported that they got a blood test straight away after seeing a GP about their symptoms (i.e. following one appointment only). Patients diagnosed with a chronic form of leukaemia were more likely to get the blood test, possibly due to these leukaemia types having symptoms more closely associated with cancer and therefore more likely to prompt action (e.g. spleen or lymph node swelling). Additionally, 17% of people surveyed said they were the ones to suggest the initial blood test. This does not mean that GPs weren't considering blood tests in all of these cases, as other insight illustrates that it is common for people to hint at a blood test [4].

However, the most recent survey analysis shows that it takes longer between a patient first presenting to the GP and getting a blood test for the group who suggest getting a blood test themselves [4]. This indicates there could have been multiple visits with inconclusive outcomes which made it more likely that a patient would suggest a blood test themselves. Additionally, once the decision to do a blood test was made, patients who suggested it themselves were less likely to get the blood test within 24 hours, as should be the case for people presenting with the symptoms of leukaemia [4]. This could point to a lack of GP understanding of the non-specific symptoms of leukaemia and the NICE NG12 guidelines.

In our survey [4], some patients recounted their struggles with getting a blood test via the GP:

"Despite presenting with all the common leukaemia symptoms, I was repeatedly told I didn't need a blood test. In the end, my mum told me I should insist on them booking me in for one before I would leave the appointment, and so they very reluctantly did so, but they weren't happy about it and never seemed to recognise why I thought I needed it."



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"I felt the practice I had attended was uninterested in me and my symptoms. As a young person at the time I took what my doctor told and tried to trust in it. My parents who lived in Northern Ireland were concerned about my health and my mum travelled to Scotland to help me and take me back to Ireland for some TLC. She pushed for the blood test in the GP. And even after asking the doctor was hesitant. My haemoglobin was 54 when I was sent to the hospital."

"GP delayed for 2 years to give me a blood test. Kept saying I was a busy working mum and I was stressed. My white blood cells were 495 when I finally got a blood test after the 5th visit with the same symptoms that had got progressively worse over the 2 year period."

GPs need a greater awareness of the signs and symptoms of leukaemia so that patients can be given a blood test quickly after presenting with symptoms of leukaemia. A blood test is all that is needed to either diagnose leukaemia or rule it out, and may also give information about a potential alternative diagnosis. The patient survey shows there remain misconceptions and misunderstandings about leukaemia and who can be affected.

Recommendation 1: All stakeholders should promote GP education tools that are available on the topic of leukaemia, to help GPs become more familiar with the symptoms of leukaemia.

However, our evidence suggests early diagnosis is more than just an issue of awareness of the symptoms and GPs need further support to know when to suspect leukaemia.

Issues with NICE guidelines

NICE's NG12 guidelines call for an urgent blood test (within 48 hours) for anyone presenting with any of the symptoms listed, including unexplained bruising, persistent fatigue and unexplained fever [3]. However, in our 2022 patient survey, 23.5% of acute leukaemia respondents noted it took up to 3 to 4 months after presenting to the GP with symptoms listed in the NG12 guidelines to get a blood test. In contrast, for 2.9% of chronic leukaemia patients, it took 3 to 4 months [4]. When we discussed this issue with our GP advisors, they admitted that even though they are aware of the NICE NG12 guidelines, they wouldn't always adhere to them in practice due to a combination of factors, including system pressures [5]. To our knowledge, a full audit into the use of and adherence to the NG12 guidelines isn't available.

In our recent survey of patients, once the decision to do a blood test had been made, only 68% of people were given a blood test within 48 hours; it was much higher for those subsequently diagnosed with acute leukaemia but still about a quarter waited longer than 48 hours [4]. Combined with our evidence that GPs are not always aware of the need for a urgent blood test and getting an appointment, we are concerned about the cumulative impact of each delay.

There are some minor problems with the guidelines themselves, that could be leading to some confusion about their usage. A symptom of leukaemia is described as "persistent" fatigue. However, those GPs we spoke to who have diagnosed leukaemia in the past say this does not



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illustrate the experience of patients or the assessment made by the GP. The nature of fatigue is important, rather than the length of time it has been experienced for. This is important to ensure people are not missed, as the symptoms are so non-specific. Work must be done to ensure the guidelines cannot lead to ambiguity or confusion.

Recommendation 2: NICE should conduct a review of the guidelines to ensure the description of symptoms is accurate according to the experiences of general practitioners and patients.

What support GPs currently get to conduct blood tests

Training is available and free for all GPs, in partnership with both the Royal College of General Practitioners (RCGP) and GatewayC. GatewayC are also working to encourage medical students at university to take these courses too, work which should be supported by the NHS. This learning covers the symptoms of leukaemia and complements the NICE guidelines. It illustrates why a blood test must be done within 48 hours. Cancer Alliances, CCGs and local trusts should be encouraged to promote the learning materials to GPs and other primary care professionals in their area.

However, we recognise that GPs are general practitioners and must diagnose or refer for a vast array of conditions. Therefore, tools to help diagnose a patient in the moment they are in front of a GP may also be useful, reinforcing learning. There are a number of tools and webpages that GPs can use (e.g. the NG12 guidelines), but some are predicated on the suspicion of cancer being already in the GPs mind. We propose that more point of care tools be explored for use by GPs, helping them to identify leukaemia as a potential cause based on symptoms in front of them, even when they are not thinking about leukaemia before. This is tricky for leukaemia as no one symptom has a positive predictive value of more than 1% for leukaemia, yet the NG12 guidelines state that any symptom is enough for investigation [3]. Therefore, a symptom-based point of care tool or risk score may still have value. Another avenue could be to use point of care tools to reinforce the "double check" factor; if a more likely and common diagnosis is suspected and reported (e.g. anaemia, reactive lymph nodes), a tool could encourage GPs to double check the diagnosis with a blood test including an FBC.

However, guidelines alone are not enough. GPs need continued support from haematology, who are better equipped to diagnose these conditions. Our GP advisors told us that access to "advice and guidance" varies around the country, yet this support is vital [5].

Recommendation 3: All relevant stakeholders should come together to create decision support tools that work based on symptoms experienced by a patient, leading GPs to discover NICE guidelines regardless of whether they are already suspecting cancer. This must cover non-specific symptoms.



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Recommendation 4: Local and national NHS bodies to work together to ensure that GPs to have better access to advice and guidance from haematology and access to education around interpreting full blood counts.

Addressing capacity challenges in general practice

At our recent advisory panel meeting, GPs raised that capacity issues can in some cases deter them from offering blood tests, knowing that analysing the results will take time that they simply don't have [5]. We welcome this honesty and it is important that we incorporate workforce pressures into this challenge around blood tests.

The experience of patients we have spoken with also illustrates GP capacity constraints, with some patients telling us that they are increasingly finding accessing a GP difficult, particularly for face to face appointments - they consider this "dangerous for those with symptoms of leukaemia who really need to be seen face to face for a diagnosis".

Indeed, in their recent inquiry into workforce recruitment, training and retention, the Health and Social Care Select Committee, reported that the number of full-time equivalent GPs fell by more than 700 over three years to March 2022, despite a pledge to deliver 6,000 more [8].

GP capacity constraints must be addressed, both through direct GP investment, and through making use of additional capacity elsewhere in the community. We support the recommendation made by the RCGP for politicians and decision makers with responsibility for the NHS to commit to a bold new plan, including a new recruitment and retention strategy that allows for the number of GPs to grow and an increase in GP training places [9]. Additionally, as we and almost 50 other charities have recently recommended in our response to DHSC's consultation on the 10 Year Cancer Plan, to support workforce planning and meeting patient demand, a national 'designated body' should regularly publish workforce projections with their being be a duty on the Secretary of State for Health and Social Care to respond to projections with a plan for what the Government will do.

A decision about whether to refer to a specialist can be made quickly if leukaemia is suspected via a blood test. It is vitally important that blood testing and pathology capacity is increased to meet this demand, especially given the calls from our GP advisors that not only do they need to do more blood tests, they need more support to interpret them fully too.

Recommendation 5: Departments of Health across the UK must address the GP and other primary care or diagnostic workforce pressures, providing adequate investment for this.

Recommendation 6: The Royal College of Pathologists should advise members on best practice for providing information to GPs alongside the full blood count test results, abnormal or otherwise, and ensure an urgent blood film is done on all abnormal full blood counts.



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It is also important that other healthcare professionals in the community, who have the correct skill sets, are utilised to relieve capacity on general practice. The Health and Social Care Committee recently reported that there is an opportunity to better utilise the pharmacy workforce, and in doing so, to optimise workloads across primary care and reduce pressure on general practice [8]. In our recent survey of leukaemia patients, 39% of patients saw a health care professional who was not a GP about their symptoms at some point prior to diagnosis [4]. This is possibly due to an inability to get a GP appointment in an appropriate time frame, or due to the patient not realising the severity of symptoms. Further to our support for the recommendations of the Health Select Committee above regarding pharmacists, we welcome the opportunities to expand the healthcare professionals that a person can discuss their symptoms with, with the launch of the NHS England pilot using community pharmacy as a route to diagnosis. However, plans at present mean the patients still must see a GP and no route is available to prioritise those referred by pharmacists, nor to allow direct to hospital referral. This fails to remove the barrier of reduced access to GPs or reduced capacity of GPs caused by pressures described above. Further innovations in this area should be explored to reduce pressure on GP services, such as whether blood testing can be also done in the community.

Recommendation 7: Pharmacists should receive equivalent training on the symptoms of leukaemia. They should be able to refer patients presenting with symptoms to GPs for urgent appointments. Studies investigating the potential of conducting blood testing elsewhere in the community, including pharmacies, must also be encouraged.



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ABOUT LEUKAEMIA CARE

Leukaemia Care is the UK's leading leukaemia charity.

For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support. We are here for everyone affected by leukaemia and related blood cancer types – such as myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN). We believe in improving lives and being a force for change. To do this, we have to challenge the status quo and do things differently.

ABOUT LEUKAEMIA UK

We are Leukaemia UK. We believe research has the power to stop leukaemia devastating lives.

Despite decades of incredible progress, only half of leukaemia patients live longer than five years after their diagnosis*. We won't stop until we change this.

Bringing together the leukaemia community, we will accelerate progress through life-changing research, doing everything we can to make sure that the next person with leukaemia has the best possible experience of diagnosis, treatment and care.

*(53.5% - 5 year survival rate across all leukaemia types and age groups, Office for National Statistics, Cancer survival by stage at diagnosis for England, 2019).



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- [8] Health and Social Care Committee Inquiry, 'Workforce: recruitment, training and retention in health and social care' available at: <https://committees.parliament.uk/publications/23246/documents/171671/default/>
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