



**Blood
Cancer
Alliance**

Our manifesto

2024

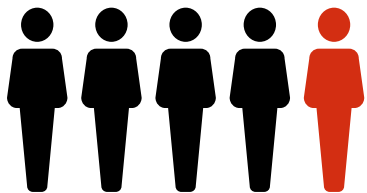
A Strategy for Blood Cancer

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The NHS is the tool that should enable the UK to deliver the best cancer outcomes in the world. It has the capability to offer universal high standards of care and attract clinical research and investment to support treatment innovations that save lives. However, the UK is falling behind its comparable European and international counterparts in cancer outcomes¹. The relative wealth of the UK, coupled with the clear public and political appetite for NHS improvement, provide the basic foundations for the next government to begin work to return the UK to the top of the global cancer outcomes league tables. This ambition can only be fully realised, however, with greater focus on cancers that are harder to diagnose, and harder to treat – and blood cancer must be a starting point.

Right now, over 240,000 people are living with blood cancer. Every year, over 40,000 people receive a blood cancer diagnosis, and over 15,000 people will lose their life to this disease². It is the most common childhood cancer, and overall, is the UK's fifth most common cancer, and the third biggest cancer killer. Yet, from awareness, to diagnosis, to information, care and support, blood cancer patients are less likely to have their needs fully met than patients with the four most common cancers – breast, colorectal, lung and prostate³.

Blood cancer has historically not been prioritised within UK cancer policymaking and health service design. No cancer strategy to date from an English, Welsh or Scottish health administration has included specific measures to address the distinct unmet needs within this patient group.



**Blood cancer the UK's
5th most common cancer**

¹Cancer Research UK data, 2024 / ²Blood Cancer Dashboard data

³Blood Cancer Alliance Forgotten Fifth Report 2022



Call to Action

The next UK government should produce a new national cancer strategy within its first year, which includes recognition of the distinct challenges faced by both adult and paediatric blood cancer patients and contains specific initiatives to address them.

The Ambition

The Blood Cancer Alliance supports Cancer Research UK's call for the next UK government to adopt of target of a 15% reduction in the overall cancer mortality rate by 2040⁴. We also support the current government ambition of 75% of all cancer diagnoses by Stage 1 or 2⁵.

However, if the focus continues to be on corresponding policy initiatives that are designed around the 'Big Four' solid tumour cancers, we do not believe these targets are either achievable or equitable. Given its prevalence, no government can hope to meet universal cancer diagnosis or survival targets without addressing the distinct and specific challenges faced by patients with blood cancer. The current one-size-fits-all method does not and will never work for patients with complex cancers like blood cancer. **We need a fresh approach.**

⁴Longer, Better Lives: A manifesto for cancer research and care, Cancer Research UK 2024

⁵NHS England Long-Term Plan target 2018

The Plan

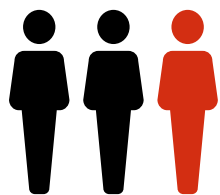
Equal priority must be given to cancers, like blood cancer, that are more difficult to diagnose and rarely have surgical options for treatment. We strongly urge the next government to prioritise three key areas to achieve better patient outcomes within blood cancer:

1. Reduce delays to blood cancer diagnosis

Blood cancer patients experience longer delays to diagnosis compared with other common cancers. The number of blood cancer patients who had to see their GP five or more times before being referred to a specialist is more than double that of patients with other cancers. Around 30% of blood cancer patients are diagnosed in an emergency setting, when their cancer is likely to have progressed and their outcomes will be worse. For comparison, only 7% of prostate cancer patients are diagnosed via this route.

A challenge within blood cancer diagnosis is that, unlike many other cancers, it has non-specific symptoms that can be more challenging for GPs to recognise. While NICE guidance on diagnosing blood cancers is broadly appropriate, there is inconsistency in the way it is implemented across the healthcare services, leading to unacceptable variation in patient access to diagnostic pathways that can detect their cancer at an earlier stage. We therefore would support a target of achieving 100% national coverage of the NHS' Non-Specific Symptom (NSS) diagnostic pathways for blood cancer. This would rapidly reduce regional variation in patients' experience of blood cancer diagnosis.

Some blood cancers are non-stageable, meaning that late-diagnosis reduction targets are difficult to apply. This lack of clarity leads to inconsistency and lack of consideration of reducing late diagnosis in blood cancer and therefore a lack of national prioritisation of measures that will improve time-to-diagnosis. **This must change.**



**1 in 3 blood cancer diagnoses
are delivered via emergency
presentation at A&E**

Policy Recommendation 1

Invest in, and consistently evaluate the performance of, Non-Specific Symptom diagnostic pathways for blood cancers to achieve 100% national coverage, with best practice learnings and proven approaches shared nationally and embedded into national standards.

Policy Recommendation 2

Introduce patient emergency presentation as a proxy staging measure for non-stageable blood cancers and apply the corresponding national target for reducing late diagnosis.

2. Improve access to innovation in treatment

With few surgical treatment options available for blood cancer, innovation in treatment, including cutting edge cell and gene therapies, is critical to reducing mortality in this complex disease area. However, there are significant challenges within the current UK model for adopting new treatments into the NHS.

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 countries⁶. Often this is because the pharmaceutical company and the NHS cannot agree on cost. No NHS patient should be denied an available proven treatment that will give them the best chance of extending their life, particularly if it is available to patients overseas.

Clinical research and trials are of vital importance to blood cancer patients, developing, and allowing them earlier access to, new and more effective treatments. We are extremely concerned that issues within the UK's treatment appraisal and reimbursement processes will lead to the de-prioritisation of the UK for the development and launch of innovative treatments by the global bio-pharmaceutical industry. The consequent trickle-down effect will be disinvestment in the UK life sciences sector, with companies less incentivised to invest in research or hold clinical trials in the UK in the future.

Many new and innovative therapies, such as CAR-Ts and other Advanced Therapy Medicinal Products (ATMPs), are designed for use in blood cancer. There is, however, growing concern that the NHS is not adequately resourced to deliver their roll-out, in terms of skills, infrastructure and finances. This situation could lead to gaps in availability of these treatments, or delays to patients receiving them, which will in turn, affect their outcomes.

⁶Blood Cancer Alliance Access to Medicines Report 2021.

To reverse this rising trend of NHS patients being denied new proven blood cancer treatments, the next government should work with the pharmaceutical to analyse the underlying causes of existing barriers to access and create solutions that promote both commercial flexibility and system readiness for new and cutting-edge therapies. This will also ensure the UK remains a viable proposition for clinical trials and life sciences investment.

Policy Recommendation 3

Review the UK's treatment appraisal system to assess its readiness for evaluating the new generation of cell and gene-based blood cancer treatments.

Policy Recommendation 5

Invest in the NHS infrastructure and workforce to deliver the next generation of cell and gene therapies.

Policy Recommendation 4

Reform the UK's commercial framework for new therapies to introduce greater flexibility and ensure it can support the prioritisation of the UK for the launch of new blood cancer treatments and establishing clinical trials.

feeling less informed than they would like to be about their care, in comparison to only 3% of patients from the whole blood cancer cohort.

It is unacceptable that any group of patients experiences poorer outcomes and experience based on their ethnicity, gender, socio-economic status or where they live. The next government must develop strategies to address inequalities within cancer care provision that are impacting blood cancer patients.

Policy Recommendation 6

A new cancer strategy must include specific measures to reduce inequality of care and experience among blood cancer patients.

3. Tackle inequalities in access to and quality of care

Blood cancer patients should have access to fair, equitable treatment, and the NHS must ensure national policies and health service design takes into account their specific and complex needs. Our research shows that from awareness, to diagnosis, to information, care and support, blood cancer patients are less likely to see their needs fully met than patients with the four most common cancers- breast, colorectal, lung and prostate⁷. We know that geography impacts patients' access to and experience of care within the NHS. Reducing regional variation in care must be a key priority for the next government.

Blood cancer patients from minority ethnic backgrounds have specific and additional unmet needs within blood cancer. Research we commissioned in 2022 has shown that blood cancer patients from minority ethnic backgrounds experience greater delay to diagnosis and poorer experience of care and support. For example, in the National Cancer Patient Experience Survey 2019, 27% of blood cancer patients from minority ethnic backgrounds reported

Enablers

We recognise the scale of the challenge for delivering improvements in earlier diagnosis, access to treatment and addressing inequalities in the NHS. There are some key enabling factors that must be considered if the ambitions in this strategy for blood cancer are to be achieved. These are:

Data: Data is central to achieving any improvement within NHS cancer care. Without better data we cannot hope to improve outcomes and quality of life and reduce inequalities. Good data can also facilitate and expedite clinical research, service improvement, and treatment development. There are significant issues with the quality and availability of blood cancer data across the four regions of the UK, which must be addressed.

NHS Workforce: The issues within the NHS workforce are high-profile and well-understood. They are reflected within the haematology workforce. We support Cancer Research UK's call for a new 10-year cancer workforce plan to identify and address staffing gaps that will present barriers to delivering on the UK's strategic cancer targets. Any new plan needs to include specific initiatives to address both workforce and skills gaps in haematology.

Infrastructure: The NHS must be equipped to deliver treatment to blood cancer patients in an equitable manner across the UK. The next government must have a plan for investment in NHS haematology infrastructure to both reduce regional variation in care and ensure preparedness for the next generation of blood cancer treatments.

⁷Blood Cancer Alliance, *Forgotten Fifth Report*, 2022



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For more information, please
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