Blood Cancer UK's response to the Call for Evidence to shape the National Cancer Plan for England

April 2025

Prevention and awareness

Which cancer risk factors should the government and the NHS focus on to improve prevention? (Select the 3 most important risk factors)

- *Alcohol*
- ***Tobacco***
- *Obesity*
- *Physical inactivity*
- *UV radiation*
- *Air pollution*
- *I don't know*
- ***Other (please specify): occupational hazards, such as the fire service and blood cancer***

Blood cancer, including leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPN) and myelodysplastic syndromes (MDS), is the fifth most common cancer and third biggest cancer killer in the UK. Unlike many solid tumour cancers, most types of blood cancer are not preventable and the biggest risk factor is age. With an ageing population, an increase in blood cancer incidence in England is unfortunately expected. The most effective and efficient way to prevent a rise in blood cancer becoming a national crisis and to save lives is to bring about systemic changes to how blood cancer is diagnosed, treated and cared for, increase support for people affected by blood cancer, enable the blood cancer workforce to deliver the standard of care they want to deliver (but are not currently able to) and invest in the discovery, development, regulation and delivery of new, innovative treatments.

Our 2024 *UK Blood Cancer Action Plan* [1] sets out 17 recommendations to improve survival from blood cancer in the UK. The report's findings and recommendations have informed our response to this Call for Evidence. Our response is also informed by a survey of our blood cancer community specifically for the National Cancer Plan for England. Over 856 people affected by blood cancer and healthcare professionals responded to the survey during March 2025, including 678 with a blood cancer diagnosis.

On prevention, our community acknowledged the importance of prevention for other cancers and also for the prehabilitation and rehabilitation of blood cancer treatment. However, they also emphasised that the focus on prevention needs to be balanced with other measures, so that blood cancer and other non-preventable cancers are not ignored or deprioritised, as blood cancer has historically been. One member of our community told us:

> *'The preventative health agenda is incredibly important for supporting conditions that are preventable as it both improves outcomes and relieves pressure on the NHS. However, it must be acknowledged that not all conditions, such as many blood cancers, are preventable and therefore should not be ignored from priorities which would only worsen outcomes and increase inequalities.'*

The blood cancer community also expressed concern that the prevention focus can lead to a culture of blame when someone is diagnosed with cancer. Another member of the community told us:

> *'I have lived a healthy life with a good diet and focus on exercise to prevent future health problems but this did not make a difference. I think awareness of the fact that many blood cancers are not preventable needs to be considered also alongside lifestyle advice and symptoms of blood cancer. I think people need to know that not all cancers are preventable to lessen the guilt and shame as I often am asked what caused my cancer as if it is my fault or I did something and I don't think people understand that it's not because of something I did.'*

Early diagnosis

What actions should the government and the NHS take to help diagnose cancer at an earlier stage? (Select the 3 actions that would have the most impact)

- ***Improve symptom awareness, address barriers to seeking help and encourage a timely response to symptoms***
- ***Support timely and effective referrals from primary care (for example, GPs)***
- *Make improvements to existing cancer screening programmes, including increasing uptake*
- *Increase diagnostic test access and capacity*
- *Develop and expand interventions targeted at people most at risk of developing certain cancers*
- ***Increase support for research and innovation***
- *I don't know*
- *Other (please specify)*

Late diagnosis reduces treatment options for an individual, increases potential years of life lost and increases the economic burden of cancer on the NHS.

> *"My GP sought advice from Haematology as soon as she saw that my low blood count was sustained. Haematology wanted to see me but it still took three months before my appointment."*

Recommendation: GPs need safety-netting techniques, such as scheduling follow-ups, targeted testing and clear guidelines on seeking urgent care to ensure potential red flags aren't missed for the early detection of blood cancer. The Blood Cancer Awareness Measure is a tool to help assess and improve awareness, including among primary care providers [2].

For blood cancer, the pace of diagnosis is poorly monitored in England. While NHS targets focus on the stage of cancer at diagnosis, no measurements are currently in place for cancers that are not stageable, including some blood and brain cancers.

Recommendation: We would like to see the Department consider if the current staging targets are a fair assessment of the quality and timeliness of diagnosis for all cancers and drive timelier diagnosis through non-emergency pathways. We would like to see the Department establish a working group with relevant healthcare professionals, charities, academics focussed on diagnosis and people affected by cancer to explore this and make recommendations.

The NHS should build on the success of its Non-Specific Symptom pathways for cancer. Analysis from the Ipsos *Faster Diagnosis Programme Evaluation* in 2025 found that blood cancer was one of the most commonly diagnosed cancers in Rapid Diagnostic Centres in England – making up 15.3% of cases [3].

Recommendation: The Department must now ensure Integrated Care Boards (ICBs) have sufficient funding to maintain and accelerate the development and capacity of these successful pathways. The restructuring of NHS England and ICBs should not put this worthwhile service at risk.

NICE guidelines on Specialist Integrated Haematological Malignancy Diagnostic Services (SIHMDS) [4] are vital for ensuring the accuracy of complex blood cancer diagnoses and informing Multidisciplinary Teams' (MDTs) decisions. However, we are concerned that the model has changed on the ground, creating inconsistencies.

Recommendation: These guidelines must be monitored and the impact of these changes on the timely provision of essential test results reviewed.

Through our support line, we are increasingly aware that the experience of monitoring for people with pre-cursor conditions to blood cancer, such as Monoclonal Gammopathy of an Undetermined Significance (MGUS), is inconsistent and inequitable. Monitoring conditions like MGUS is a straightforward way to detect blood cancer early, yet primary care providers feel it is too significant and specialist, while secondary care professionals feel that there is no need for consultants to oversee it.

Recommendation: The Department needs to take responsibility for dedicated monitoring programmes for conditions like MGUS, so that blood cancer can be detected earlier and the impacts of late diagnosis curtailed.

Torbay Hospital has a successful MGUS tracker, where patients receive timely requests for blood tests, accessed through their GP. Results are reviewed by an Advanced Clinical Practitioner who can immediately arrange a clinical review if needed.

Treatment

What actions should the government and the NHS take to improve access to cancer services and the quality of cancer treatment that patients receive? (Select the 3 actions that would have the most impact)

- ***Increase treatment capacity (including workforce)***
- ***Review and update treatment and management guidelines to improve pathways (processes of care) and efficiency***
- *Improve the flow and use of data to identify and address inconsistencies in care*
- *Improve treatment spaces and wards, including facilities available to carers*
- *Improve communication with patients, ensuring they have all the information they need*
- *Increase the availability of physical and mental health interventions before and during cancer treatment*
- ***Increase the use of genomic (genetic) testing and other ways of supporting personalised treatment***
- *I don't know*
- *Other (please specify)*

While developing our *UK Blood Cancer Action Plan*, healthcare professionals told us that they weren't able to work at the top of their professional skills and license. Critical staff shortage, increasingly complex treatments and poor information sharing and IT infrastructure have left the blood cancer workforce under untenable pressure. There's also a dwindling pipeline of clinical academics, threatening the development of new treatments in the UK. This is all compounded by the increase in acuity of blood cancer patients, who are more unwell, having more complex treatments and require more attention [1]. One healthcare professional told us:

> *'More and more people are being diagnosed with blood cancers but the workforce does not always increase to reflect the capacity of those requiring treatments.'*

The majority (61%) of the blood cancer community surveyed about the National Cancer Plan selected 'Increase treatment capacity (including workforce).' It is an absolute priority for people affected by blood cancer and the workforce treating them. The blood cancer workforce includes haematologists, haemato-oncologists, Clinical Nurse Specialists (CNSs), Advanced Nurse Practitioners (ANPs), haematology pharmacists and other Allied Health Professionals (AHPs) and administrative staff. Haematology teams also provide essential services across all types of cancer and many other health conditions, such as through unrecorded liaison work like managing transfusions [5]. At every opportunity in the past, the NHS and the Department have failed to include haematology colleagues in cancer workforce commitments.

Recommendation: This National Cancer Plan for England is an opportunity to meaningfully include haematology in workforce commitments for the first time and acknowledge the life-saving and innovative work they do to treat cancer across the country.

Treatments for people with blood cancer can span across primary care, local and specialist services, and co-ordination is often challenging. Both patients and healthcare professionals have shared frustration about delays and interruptions to treatment because of communication failures between different services:

> 'My treatment start date was delayed because of a failure in communication by the Professional responsible for my care.'
>
> 'The sharing across the specialist hospital, local hospital and doctors is very disjointed. As the trusts are different it is frustrating for all parties involved. As I initially fought to get diagnosed, I continue to be heavily involved in driving my tests, results and treatments between the locations.'

Healthcare professionals and pharmaceutical companies raise concerns that, despite some drugs being approved for use on the NHS, local funding decisions mean that people with blood cancer only have access after considerable pressure from their medical team. Geographical challenges, compounded by health inequalities, may prevent people from being offered or being able to accept the best treatments available.

Blood cancer is often the ‘first in line’ for new innovative treatments (e.g. immunotherapies, personalised medicines, upcoming bi-specific antibodies). These are exciting developments for our community but means that we are the first to come up against inflexible regulations.

Recommendation: Approval processes should be streamlined and focussed on ensuring patients in the UK have access to cutting-edge blood cancer treatments – both the Department and the pharmaceutical industry should be more flexible.

Living with and beyond cancer

What can the government and the NHS do to improve the support that people diagnosed with cancer, treated for cancer, and living with and beyond cancer receive? (Select the 3 actions that would have the most impact)

- ***Provide more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and (if applicable) after treatment***
- ***Improve the emotional, mental health and practical support for patients, as well as their partners, family members, children and carers***
- *Offer targeted support for specific groups, such as ethnic minority cancer patients, children and bereaved relatives*
- ***Increase the number and availability of cancer co-ordinators, clinical nurse specialists and other staff who support patients***
- *Increase the support to hospice services and charities who provide care and support for patients*
- *Improve access to high-quality, supportive palliative and end-of-life care for patients with incurable cancer*
- *I don’t know*
- *Other (please specify)*

Recommendation: Cancer charities are ready to support more people. Direct referral from the NHS to the third sector will expedite this. Given the cost involved is for charities, and not the NHS, incentives, encouragement and support for ICBs and Trusts to engage with charities in this way, is an obvious and immediate way for the Department to ensure people have access to the support they need. Removing barriers and standardising information governance procedures is essential to support this collaborative work.

Blood Cancer UK is scaling-up its Direct Referral Service: a simple referral form for healthcare professionals to consent their patients at diagnosis, followed by a blood cancer specific email or phone journey from our nurse-staffed Support Services team. The journey is designed to remove the isolation, financial worries and lack of understanding people with blood cancer experience after diagnosis and ensure that people find and feel a part of a supportive community for the duration of their experience.

> *'I would have benefitted from more information on my condition when I was diagnosed and connection to a trusted source of information and support. I would like to have been connected with or referred to a blood cancer charity such as Blood Cancer UK.'*
>
> *'I found that after my completion of treatment I still required a lot of support both physically and mentally. I referred myself to local cancer charities and hospice.'*
>
> *'For minority ethnicities (including myself and my family) further work needs to be done to target the communities whether that be for stem cell donation, further research or healthcare professional awareness etc but to ensure that minority ethnicities are understood and supported'.*

Blood Cancer UK is a member of the Healthcare Charity Collective, seven charities exploring the design of a new standardised referral pathway, interoperable between NHS system into condition-specific charities offering specialist information and support. We estimate the Collective could generate benefits in the range of £424 million and £574 million over the next five years through reduced healthcare costs and demand on NHS resources, and improved individual health-related quality of life [6].

We know that blood cancer Clinical Nurse Specialists (CNSs) are the cornerstone of blood cancer care. We also know that cancer patients not given a named CNS have the lowest survival rate [7].

Recommendation: With acuity on the increase, the NHS needs more cancer (including haematology) CNSs to support people with cancer and must immediately take new action to increase numbers through training, recruitment, retention and encouraging and supporting returners.

> *'My CNS has been invaluable, and when she was on mat leave it was big gaping hole in the provision.'*

The community also stressed the importance of emotional, mental health and practical support for individuals and their loved ones being embedded in care and after treatment:

> *'I had no real understanding of how a bone marrow transplant could make such devastating changes to my mental and emotional health. My wife felt so alone and in need of support but felt she had to remain strong for me.'*

Research & innovation

How can the government and the NHS maximise the impact of data, research and innovation regarding cancer and cancer services? (Select the 3 actions that would have the most impact)

- *Improve the data available to conduct research*
- ***Improve patient access to clinical trials***
- ***Increase research into early diagnosis***
- *Increase research into innovative treatments*
- *Increase research on rarer and less common cancers*
- ***Speed up the adoption of innovative diagnostics and treatments into the NHS***
- *I don't know*
- *Other (please specify)*

Recommendation: The third sector must be updated on the progress in implementing the recommendations of the Lord O'Shaughnessy review [8]. These recommendations deal with the systemic and practical barriers to commercial clinical trials in the UK and, if implemented, will have a profound impact on cancer research and patients' access to it.

Recommendation: Efforts are also needed to ensure that academic trials are not deprioritised in favour of commercial trials.

£1.7 billion was invested into medical research by members of the Association of Medical Research Charities (AMRC) in 2023, totalling 27% of non-commercial clinical research in the UK [9]. Academic clinical trials are an essential part of the country's research and innovation landscape and must be supported to flourish alongside the reinvigoration of the commercial sector. This will be aided by dedicated support and increasing suitable posts for clinical academics, safeguarding clinical time for research activities and decentralising trials so that more can take place in District General Hospital settings. Actions taken in this area will in turn benefit people with cancer, as their healthcare professionals, by being more involved with research themselves, will have increased awareness of ongoing trials.

> *‘Although various clinical trials have been running since her diagnosis, my mum has been repeatedly told she "lives in the wrong place to be eligible.”’*

53% of the blood cancer community surveyed selected ‘improve patient access to clinical trials’ in response to this question. At Blood Cancer UK, we have a flagship Clinical Trials Support Service for people with blood cancer, one of only two services of its kind in the UK [10]. Our team of highly experienced nurses provide in-depth support to people with blood cancer before, during and after clinical trials, conducting trial searches, supporting them to discuss trial options with their consultant and staying in touch during and after clinical trials to maximise retention. The service has supported 616 people since its launch in 2020, with a 15% enrolment rate for those eligible for clinical trials.

Recommendation: The National Cancer Plan could support our service’s work by delivering a clinical trial directory as a single source of information and encouraging the NHS to work with and refer to charities like Blood Cancer UK. This directory should include blood cancer and its sub-types as categories when filtering trials by cancer type [1].

52% also selected ‘speed up the adoption of innovative diagnostics and treatments into the NHS.’ This reflects the way bureaucratic medicine and technology appraisals in England are being felt by people with blood cancer.

Recommendation: The National Cancer Plan must identify and implement ways to speed up access to innovative treatments and diagnostics.

> *‘I feel that with the introduction of NICE guidelines it has stopped doctors thinking outside the box. Innovation is required when the conventional treatment doesn’t work to try new ideas.’*

Recommendation: The Rare Cancers Bill [11] offers an opportunity for the UK Government to show leadership in the development of rare cancer research.

We hope this Bill continues to progress and that the National Cancer Plan will be a vehicle for its implementation.

Inequalities

In which of these areas could the government have the most impact in reducing inequalities in incidence (cases of cancer diagnosed in a specific population) and outcomes of cancer across England? (Select the 3 actions that would have the most impact)

- *Improving prevention and reducing the risk of cancer*
- ***Raising awareness of the signs and symptoms of cancer, reducing barriers and supporting timely response to symptoms***
- *Reducing inequalities in cancer screening uptake*
- *Improving earlier diagnosis of cancers across all groups*
- *Improving the access to and quality of cancer treatment*
- ***Improving and achieving a more consistent experience across cancer referral, diagnosis, treatment and beyond***
- *Improving the aftercare support for cancer patients*
- *I don't know*
- ***Other (please specify): Improve the collection, curation, analysis and publication of cancer diagnosis, treatment and outcome data disaggregated by demographic characteristics including ethnicity, rurality and socioeconomic background, so that disparities can be identified and addressed***

Recommendation: Health inequalities and actions to address them must be woven through all areas of cancer prevention, pathways and experience in the National Cancer Plan.

We know that some people are more likely to get blood cancer e.g. myeloma is more common among Black African and Black Caribbean men and women and Hodgkin lymphoma is more common among British South Asians [12]. Disparities also exist in diagnosis – ethnic minorities are four times more likely to experience delays in referral for a blood cancer diagnosis [13] – and treatment – Black or mixed-race blood cancer patients with leukaemia have a 37% chance of finding a 10/10 matched unrelated stem cell donor compared to 72% of white patients [14]. Data commissioned for our *UK Blood Cancer Action Plan* found that deprivation impacts survival from blood cancer [1].

Just 68% of people with blood cancer surveyed for our *Raise the Profile, Reduce the Harm* report fully understood their diagnosis and 76% were not told they had a type of blood cancer at diagnosis – some found out during the survey [15]. The likelihood of people finding out that they had a type of blood cancer during our survey doubled for the over 85s, those with a secondary level education, a below-average income or who classify themselves as an ethnic minority.

> *‘Ethnic minorities, such Black and Asian patients need more support in regards of investigation, treatment, especially when it comes to blood and bone marrow transplants.’*

We also know from the National Cancer Patient Experience Survey (NCPES) that ethnic minorities consistently report a less positive experience of their care [16].

Recommendation: We want the National Cancer Plan to be bold in making targets to improve patient experience, measured through patient reported metrics, like reducing the variability between how different ethnic groups score their care in the NCPES question: ‘overall, how would you rate your care?’

Our current understanding of blood cancer disparities is informed by the data available. However, this is too often inconsistent and of variable quality.

Recommendation: The National Cancer Plan should set out actions to improve the collection, curation, analysis and publication of cancer diagnosis, treatment and outcome data, disaggregated by demographic characteristics including ethnicity, rurality and socioeconomic background.

Only with this data can we uncover currently unknown disparities, create targeted actions to address them and, crucially, monitor improvements and save lives from cancer.

> *“It is harder for rural patients to participate in trials because the centres are (in general) in cities.”*

Targeted actions include Blood Cancer UK’s project to improve access to clinical trials for people from minority ethnic backgrounds [17]. Despite the increased incidence statistics above, people from minority ethnic groups are less likely to take part in clinical trials. We’re working with community researchers from Black and Pakistani backgrounds, healthcare professionals, researchers and other organisations to understand the barriers to trial participation and co-design solutions.

Recommendation: The National Cancer Plan should see the Department commit to working with charities to understand their learning in specific cancer types and how communities can inform efforts to improve cancer inequalities across the country.

Priorities for the national cancer plan

What are the most important priorities that the national cancer plan should address? (Select the 3 most important priorities)

- *Prevention and reducing the risk of cancer*
- *Raising awareness of the signs and symptoms of cancer*
- *Earlier diagnosis of cancer*
- ***Improving the access to and quality of cancer treatment, including meeting the cancer waiting time standards***
- ***Improving patient experience across cancer referral, diagnosis, treatment and beyond***
- *Improving the aftercare support for cancer patients*
- ***Reducing inequalities in cancer incidence, diagnosis and treatment***
- *Other (please specify)*

Part of the ambitious vision of this National Cancer Plan should be to meaningfully include all types of cancer, including blood cancer, rare and less common cancers and children and young people's cancer. This is a timely opportunity to write the first plan of its kind that does not overlook blood cancer and the haematology workforce treating it.

> *'Feels like blood cancer is not considered a cancer - more research and awareness needed.'*

We welcome the Department's vision for this National Cancer Plan and would like to suggest our methodology for a pan-cancer measure of its success. For our *UK Blood Cancer Action Plan*, we analysed the number of potential years of life lost from blood cancer in the UK over a 10-year period – this is the sum of the number of remaining years of life expectancy among people who died of a certain cause [1]. Unlike mortality rates, this measure gives greater weight to deaths at younger ages. As we implement our Action Plan, we will be able to assess our progress against this measure and feel it would create an appropriate and ambitious target for the long-term scale and vision of the National Cancer Plan for England: reducing the number of potential years of life lost to cancer.

> *'My biggest hope for the future is that blood cancer is no longer a death sentence for some and, with research, certain blood cancers, like AML are treatable and one day curable.'*

Monitoring a measure such as potential years of life lost would be simpler if issues with cancer data held by the NHS and the National Cancer Registration and Analysis Service (NCRAS) were swiftly addressed. Efforts must be made to support MDT coordinators responsible for initial cancer data entry, as the quality of this initial entry matters as it progresses through the NHS and to the registry. NCRAS also needs to be adequately resourced so that it can carry out essential analysis and improvements to its work. One improvement we would like to see is efforts to make cancer data, including specific issues with blood cancer data, consistent and comparable with other UK cancer registries.

The Department should encourage further positive collaboration between UK cancer registries so that improvements in cancer outcomes can be measured and compared between UK nations and internationally.

We also think the National Cancer Plan could mark a shift in how the Department and the NHS measures improvements in cancer care. This should be done by making commitments and taking action to reduce variability around cancer experience in patient reported data including patient-reported outcome measures (PROMS), patient-reported experience measures (PREMS) and the National Cancer Patient Experience Survey (NCPES). For blood cancer, we know that in the NCPES, ethnic minorities evaluate their overall care more negatively than white respondents [12]. Despite this persistent inequality, the NHS has never made measurable commitments around the experiences of people with cancer that track NCPES metrics. We would be encouraged to see NCPES metrics included in measures of the National Cancer Plan.

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