Blood Cancer UK submission to Change NHS, 10-Year Health Plan for England consultation

2 December 2024

Q1: What does your organisation want to see included in the 10-Year Health Plan and why?

At Blood Cancer UK, we want to see fewer lives lost to blood cancer and its treatments. We are committed to achieving this through research; the NHS must be fit to deliver the best care. Cancers that affect the blood, such as leukaemia, lymphoma, myeloma, myeloproliferative neoplasms (MPNs) and myelodysplastic syndrome (MDS), are complex conditions that share many of the challenges facing solid tumour cancers and chronic conditions, and its workforce shares many of the burdens on the entire NHS workforce. However, blood cancer also requires unique considerations and interventions, as we outline in our response to this consultation and in more detail in our UK Blood Cancer Action Plan [1].

Our UK Blood Cancer Action Plan found that shockingly, **over one million years of life have been lost to blood cancer over a 10-year period** in the UK – that's the sum of remaining years of life expectancy among people who died of blood cancer. When looking at international data, for every type of blood cancer subtype, survival in the UK falls short of that seen in some nations with similar wealth and health systems [1]. More than anything, we want to see survival from blood cancer in the UK be as good as the best countries in the world. **This response sets out how we think the NHS 10-Year Plan, and the forthcoming National Cancer Plan, can fix the NHS and make that happen.**

Workforce & estate

The blood cancer workforce is doing an exceptional job in unacceptable circumstances. The workforce includes haematologists, haemato-oncologists, Clinical Nurse Specialists (CNSs), Advanced Nurse Practitioners (ANPs), haematology pharmacists and other Allied Health Professionals (AHPs) and administrative staff. Like the entire NHS workforce, healthcare professionals treating blood cancer are struggling to provide the highest standard of care that they can and want to deliver, due to systemic issues like the inability to quickly share information and data; staff shortages; challenges to recruit and retain staff; too few opportunities and hours protected for professional development and research; and too few beds or up-to-scratch facilities.

'Ten, twenty years ago, one patient on average might generate two to three treatment episodes and then run out of options. But now one patient generates about four times that many. So I think we should be counting not just the number of new patients coming into the system, but also the number of treatment episodes – that's probably a more meaningful way of counting our activity.' – Consultant Haematologist

Blood cancer healthcare professionals have also expressed concern to us that staffing numbers have not changed to reflect the increasing acuity of patients in their care, with new treatments and the increasing age of patients meaning that the profile of inpatient and outpatient blood cancer populations is today much more poorly [1]. 70% of the haematology workforce surveyed by the British Society for Haematology (BSH) in 2024 said that complexity was a significant factor that added to their workload. In response to the same question, 83% selected staff shortages [2], [3]. In the area of workforce and estate, we want to see:

- Cancer **workforce modelling** that considers acuity and not just incidence, accompanied by short and long-term plans for training, recruitment, retention and welcoming returners. Any cancer workforce plan must include haematology, haemato-oncology and the wider blood cancer workforce, including administrative staff, and reflect the work they do to treat the fifth most common cancer in the UK.
- **Transformation of basic IT infrastructure, interoperability of data** and information accessible to healthcare professionals and patients when they need it, and mandated streamlining of the programmes used across the NHS. It is essential that these changes consider how data also travels across the borders of all four UK nations.
- An **increase in the number of cancer and haematology CNSs** and CNS-informed support for them so that we can reach **equity of access to CNS support** for all people with cancer. This will require incentives for CNSs to specialise, such as through the removal of local caps on the number of band seven nurses on a ward and protected time and funding for CNS continued professional development.
- Dedicated support and protected time for **clinical academics** and researchers within the NHS to drive research, including support for more clinical trials to take place in the NHS, including at District General Hospitals (DGHs) – this will require commitments to improve **research facilities** at DGHs.
- Ensure there are sufficient infection-controlled beds in haematology/haemato-oncology departments and **reduce the need for blood cancer patients to be treated in other, inappropriate wards.**

'Putting them on another ward strains relationships between the patient, the medical team and the family. They are further away from us and may be being treated by a head and neck cancer team which is absolutely not acceptable.' – Consultant Haematologist

Diagnosis

More timely and accurate diagnosis of blood cancer can bring greater chance of living longer. But more than a quarter of new blood cancer diagnoses present as an emergency [4] and 45% of people with blood cancer from an ethnic minority reported visiting their GP three or more times before referral to testing [5]. Blood cancer symptoms are vague and non-specific but they can be spotted quickly if appropriate blood tests are ordered. When it comes to diagnosis we want to see:

- The development and introduction of **timed diagnostic pathways for all cancers** that do not have them, including all types of blood cancer.
- Action to **address the barriers** that prevent people from some groups, such as those from ethnic minorities, deprived backgrounds or those living in geographically remote locations, from receiving a timely diagnosis of blood cancer.
- A **proxy staging measure for non-stageable blood cancers**, so that trends and barriers can be identified and solutions monitored.
- Strengthening of **safety netting practices for non-specific cancer symptoms in primary care** and ensure the Non-Specific Symptom pathway for unsuspected cancer is available across the whole population, with commitments to long term funding for the pathway.
- Implement **targeted monitoring programmes for people at higher risk of developing cancer**, including people with MGUS who are more likely to develop blood cancer.
- Ensure that all NICE guidelines for diagnostic services are fully implemented and maintained, such as the **Specialist Integrated Haematological Malignancy Diagnostic Service (SIHMDS)** guidelines.

Delivery of care

The third sector is ready and willing to support the NHS with the delivery of care, such as through offering specialist support services related to the conditions they serve. The NHS needs to encourage these partnerships, which will in turn support people using the NHS to advocate for themselves and take a bigger role in their own health and care. In this respect, we want to see:

- **Incentivised direct referral opportunities from the NHS to the third sector** to increase the offer of support, education and self-advocacy for patients, such as through Blood Cancer UK's direct referral service.

'Just from my own experience, one of the most important things about the early stages of watch-and-wait was a need for self-monitoring. Because myelofibrosis has such an array of strange symptoms, my treatment team suggested I keep a diary of how they affected me; the frequency and severity, and how much my medication was helping. As a patient, I found this incredibly helpful – it made me feel much more involved in the whole watch-and-wait process; and, most importantly, my haematologist could tailor my treatment plan accordingly.' – Person living with blood cancer

Clinical trials

Discussion of trial opportunities should be an integral part of patient consultation, but too few cancer patients are currently consented for research. We also know that healthcare professionals including clinical academics don't have enough protected time for research and, in DGH settings, often don't have the facilities or capacity to increase their research participation, despite wanting to. Many blood cancers are rare and therefore have small and dispersed patient groups, which can make having a single study site at a large teaching hospital incredibly difficult. Decentralised studies and involving primary care in research are important to rectify this [6]. To improve access and involvement in clinical trials, we want to see:

- Evidence of action on the recommendations outlined **in Lord O'Shaughnessy's review of commercial clinical trials** [7], [8].
- Comprehensive and targeted support for both investigator-led and commercially sponsored clinical trials through **streamlined regulatory processes, funding and access to research networks.**

Treatments

Every person with blood cancer has the right to receive drugs and treatment that have been approved for use on the NHS and recommended by their medical team, but too often bureaucratic approval processes, funding limitations and geographic disparities means this is not the case. At Blood Cancer UK, we're trying to facilitate access to treatments and trials, such as through our dedicated Clinical Trials Support Service (CTSS) [9], which last year had 235 service users and conducted 122 trial searches, matching people with blood cancer with potentially life-saving and life-extending clinical trials. Our pilot Direct Referral project [10] is looking to take our services, like our CTSS, to even more people with blood cancer. While we will continue to scale up this work, systemic issues must also be addressed by the NHS.

Blood cancer is frequently the 'first in line' for new innovative treatments. Although this is a huge positive for the blood cancer community, it also means

that blood cancer treatments can often be the first to come up against Health Technology Assessment (HTA) regulations, compared to other conditions that will come to benefit from similar treatments and the precedent set by blood cancer HTAs. In the area of treatments, we want to see:

- **Streamlining of approval processes across the UK drug and treatment bodies** to focus on ensuring patients in the UK have access to cutting-edge treatments.
- The definition of a **minimum standard of care for all blood cancers** to support clinical excellence and equity of access to approved treatments in all settings and locations.

Data

The NHS has the potential to drive improvement through its national data. We must overcome the complexities of blood cancer data to provide consistent, meaningful and comparable national data that allows blood cancer to be routinely included in national cancer planning and initiatives. We want to see:

- Commitments to make cancer data, including blood cancer, in England **comparable and consistent** with other UK nations, including cell morphology data, with the possibility to disaggregate the data by demographic characteristics including age, ethnicity and indices of deprivation.
- **Inclusion of blood cancer as a distinct category** alongside solid tumours in NHS cancer policy and reporting.
- Uptake of the recommendations of the Sudlow Review [11] to ensure health data captured by the NHS is ready to be safely used in research to improve the health and wellbeing of the public and specific patient groups.

Q2: What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

People with blood cancer have told us they want to access care closer to home. However, because of the complexity of blood cancer, specialist care is often the best option and, if receiving care in the community means people with blood cancer can't access specialist haemato-oncology care, then they are often willing to travel. This shift requires bringing specialist care to local settings but also, when this isn't possible, ensuring that the NHS supports people to travel for specialist care. Some of the challenges and enablers we have identified for this shift are as follows.

Challenges

Data, like blood test or imaging results, fails or takes too long to transfer between primary, secondary and community care providers. This barrier becomes more complex when a patient's care does not fit within the boundaries of an ICB or even NHS England.

Many people with blood cancer would prefer to have monitoring blood tests done in the community, so that they don't have to travel, sometimes significant distances, repeatedly to their treating hospital. This is especially true for people with chronic blood cancer on Watch and Wait, frail patients and those that require fortnightly monitoring blood tests. Despite the clear need and appetite for blood tests to take place in the community and at home, test results get lost and stretched local phlebotomy services too often give these blood tests low priority, resulting in them being cancelled or postponed with a knock-on impact on appointments with their secondary care team.

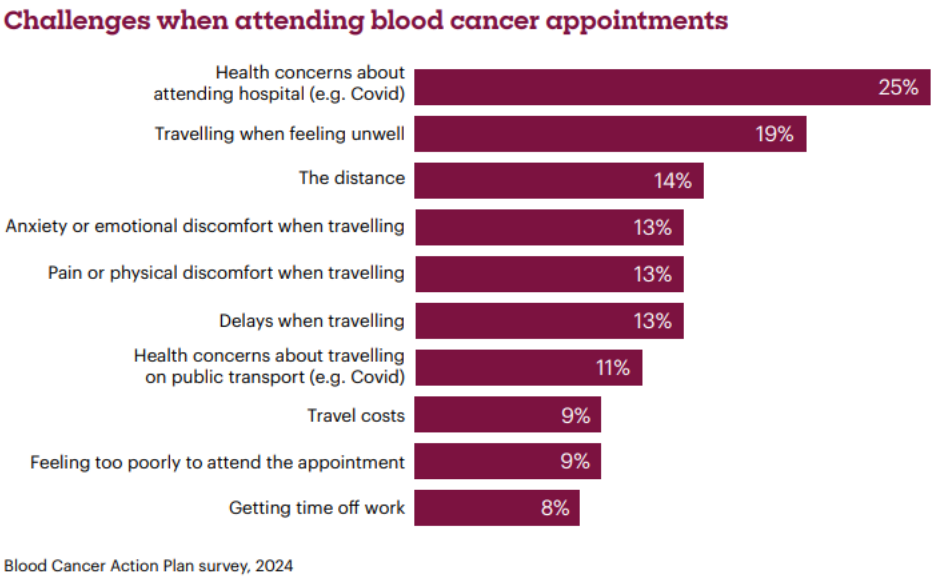
'It's hard because you want to empower the patient and support them in their Watch and Wait pathway but they're not having their bloods done.' – Haematology AHP

Connectivity issues like poor bandwidth and phone signal in rural areas and in hospitals can prevent patients and their treating teams to successfully see and hear each other in virtual appointments [1].

Blood cancer CNSs told us that the main reason for Do Not Attends in blood cancer care is due to patients not knowing about the appointment, often due to it being cancelled or rearranged and the communication of the change being delivered too slowly to count [1].

Enablers

When we asked people with blood cancer and their carers across the UK what challenges they had experienced when attending in-person appointments for their blood cancer, 19% selected travelling when feeling unwell, 14% selected distance, 13% selected emotional discomfort when travelling, 9% selected travel costs, and 8% selected getting time off work [1]. We feel that this translates into appetite from patients for the proposed shift to receive care in the community, but only if they can access specialist care.



Numerous projects across the UK, including in England, are piloting home and community delivery of Systemic Anti-Cancer Treatments (SACT). In one project led by Lead Myeloma CNS, Sarah Henshaw at Nottingham University Hospitals (NUH), SACT are being delivered in the community and at home. In this pilot project, patients still have opportunities to see their CNS face-to-face in local settings, so it reduces the risk of patients glossing over symptoms and side effects in virtual appointments. This particular outreach model works well in a densely populated urban environment and is made possible not just by the nurses delivering the service, but also by the vital administrative staff who ensure they are able to see five to seven patients a day. The administrative oversight ensures that the service runs effectively and is cost effective – part of the reason NHS funding was continued after charities funded the initial pilot. Different models need to be considered for rural populations.

Regardless of population, cancer and haematology CNS numbers must increase and their time be protected if pilots like this are to be scaled up and replicated. Capacity is already a barrier for the NUH team to start its plans to expand the outreach service to deliver specialist bispecific treatments in the community.

Q3: What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

Challenges

In early findings shared from its workforce study, the British Society of Haematology found that 67% of the haematology workforce said that IT was a significant factor that added to their workload [2]. This statistic is a modest reflection of the feedback we've heard from the blood cancer workforce. With the most basic IT infrastructure lacking across the NHS and an overreliance on paper and postal communications, using technology to transform care can feel like an unrealisable dream.

'When I got to the clinic this morning, I had to open about six different programmes'. - Consultant Haematologist

Too often, when Trusts and Integrated Care Boards (ICBs) introduce new digital and technological tools, such as electronic health record programmes, no clinical time is safeguarded so that the healthcare professionals who will be using the software can shape its set up or even its selection. Moreover, the procurement of these tools often fails to consider, or does not care, how interoperable they are across the NHS.

The need for joined up, compatible electronic health records across the NHS is clear; to enable different colleagues treating blood cancer, other disciplines looking after the same patient, and the patient themself, to connect and share information quickly. However, we've heard from healthcare professionals that when Trusts introduce new electronic health record software, it frequently creates more problems than it solves at initiation. There is often no ring-fenced time or cover for healthcare professionals to shape how programmes are set up and so, despite their potential, when new programmes are rolled out, it can be disjointed with how healthcare professionals carry out their work on a daily basis.

'I wish we'd known more about [the new electronic health record software] before we launched it... it turned out to be a massive increase in our workload.' – Lead Nurse in Haematology

We have also observed that there is low awareness of existing digital tools, such as GP Connect, among the haematology and wider blood cancer workforce, something that this shift could easily address with training [1].

Enablers

There is a significant sense of urgency to address this issue among healthcare professionals and a desire from them to shape how these changes are decided and implemented, but only if cover of their service is secured. There is similar

urgency for people with blood cancer using the NHS, who tell of their frustration when they and their GPs cannot access results from secondary care ordered blood tests or scans. The NHS should use this urgency to transform its basic IT and digital infrastructure, in order to deliver this shift of better using innovative technology in health and care in the future.

Q4: What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Unlike many solid tumour cancers, prevention is often not a significant factor with blood cancer, but we can monitor those at high risk and more can be done to identify who is at high risk.

Blood cancer monitoring is crucial for both high-risk individuals and those diagnosed without needing immediate treatment (Watch and Wait/Active Monitoring). For people with monoclonal gammopathy of unknown significance (MGUS), they carry an increased risk of developing myeloma or non-Hodgkin lymphoma, and people who have had chemotherapy for breast cancer have an increased risk of developing MDS. Early detection of changes through monitoring is critical and needs to be standardised through this shift.

The NHS has developed non-specific symptom (NSS) pathways, designed to investigate vague cancer symptoms, many of which are blood cancer symptoms.

We're aware of disparities by ethnicity in blood cancer diagnosis, with 45% of blood cancer respondents from ethnic minority communities reporting that they have had to visit their GP three or more times before referral for testing [5]. Awareness of blood cancer and awareness of symptoms among these groups is also low.

Challenges

We are aware there is uncertainty in the NHS regarding who should be responsible for MGUS monitoring. Primary care providers feel it is too significant and specialist to fall with them, while secondary care professionals feel the monitoring is so straightforward that there's no need for consultants to oversee it. The NHS needs to take responsibility for monitoring programmes for conditions like MGUS, so that cancer can be detected earlier.

NSS pathways require continued funding and effective access to haematology and multidisciplinary expertise to ensure this pathway continues to be effective at diagnosing blood cancer.

77% of people from black ethnic groups had not heard of myeloma, even though ethnicity is a risk factor [12] and therefore should have an accelerated diagnostic pathway.

Enablers

There is a successful MGUS Tracker in Torbay Hospital, where patients with intermediate or high-risk MGUS receive timely requests for blood tests, accessed through their GP. Results are reviewed by an Advanced Clinical Practitioner who can immediately discuss concerns with a consultant-led team and arrange a clinical review if needed.

In England, blood cancer is one of the most likely cancers to be diagnosed through the NSS pathway, accounting for 20% of all cancers diagnosed this way [13].

'It was not clear what the cancer might be, or indeed at that stage if it actually was cancer. The referral to the NSS pathway then happened, and a nurse from the hospital got in touch — she was absolutely brilliant, explaining what was happening and why. She advised me about each result and next step and initiated action very promptly. Information was provided by her in a very digestible way, the whole process felt proactive and engaged.' – Person living with blood cancer diagnosed through the NSS pathway

Increasing accessibility to information is an important step towards levelling inequalities and empowering people affected by blood cancer. Providing information in different languages or tailored to raise awareness and support a specific community, like Blood Cancer UK's information for the African Caribbean community [14], is a simple but effective step towards this ambition that the NHS could spearhead in this shift. Applying the learnings from other successful inequality initiatives to other cancer diagnosis pathways could significantly contribute to closing the gap in health inequalities. Targeting high-risk populations, such as people in areas with the highest deprivation rates, has proved successful for other cancers, for example, the Targeted Lung Health Checks Programme [15].

The Galleri blood test can detect more than 50 different types of cancer with a reasonable degree of accuracy of its location, including some subtypes of

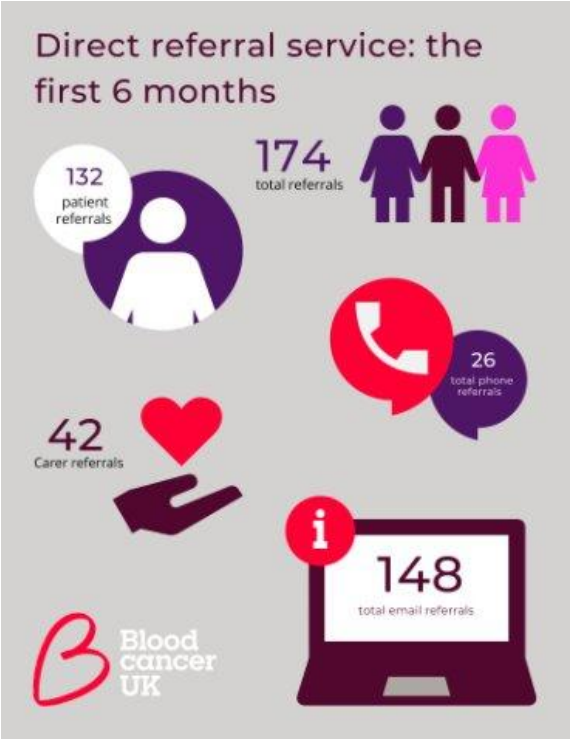
blood cancer. We would support a pilot roll-out of this test, given the potential benefits for diagnosis, particularly for those cancers, including blood cancer, which are harder to diagnose.

Q5: Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in.

Short term

Direct Referral Service

Charities are ready to support more people affected by the conditions they cover. Direct referral from the NHS to the third sector will expedite this. Blood Cancer UK has developed a prototype direct referral service [10], currently being piloted in NHS Hospital Sites, so that everyone with blood cancer can be proactively referred to our services at diagnosis. Our model is made up of a simple referral form for healthcare professionals to consent their patients [16], followed by a tailored email or phone journey. The service is available in more than 170 languages via an interpretation service.



'It's given me a resource to refer to when I need information, encouragement or support.' – Patient feedback on the direct referral service at a pilot site

'It's just about daily activity – I'm doing it now without even thinking about it.' – Healthcare professional feedback on the direct referral service at a pilot site

The journey is designed to remove the isolation, financial worries and lack of understanding we know [17] too many people with blood cancer experience after diagnosis, and ensure that people find and feel a part of a supportive community. The service will in turn support the NHS by ensuring patients learn how to self-monitor symptoms and side effects, know who is in their treating

team so that the NHS can easier shift to trial different models of delivery of care and support people to advocate for themselves or their loved one.

'We're not getting calls from the newly diagnosed ones asking about vaccines.' – Healthcare professional feedback on the direct referral service at a pilot site.

So far in England, we're piloting our direct referral service at University Hospital North Midlands, Northumbria Healthcare NHS Foundation Trust, Mid and South Essex NHS Foundation Trust, Bedford Hospital, Ormskirk Hospital and Guy's Hospital.

Blood Cancer UK is also a member of the Healthcare Charity Collective, a group of charities exploring the design of a new standardised referral pathway, interoperable between NHS system into condition-specific charities that can offer specialist information and support, with the aim of improving health outcomes and quality of life.

We estimate the Collective could generate benefits in the range of £424 million and £574 million over the next 5 years through reduced healthcare costs and demand on NHS resources, and improved individual health-related quality of life [18]. These figures are based on each charity's current reach of new diagnoses each year over this period; each charity has an aim to grow their reach significantly over the next five 5 years, in which case these figures will likely grow.

What we need from NHS England to transform who we reach with our support is top-down incentives, encouragement and support for ICBs and Trusts to engage with charities in rolling out services like this. Pending pilots have stalled because of conflicting governance decisions and processes that vary from Trust to Trust. This could be done quickly and transform patient experience.

Targeted monitoring

We want to see clarity from the NHS on who is responsible for monitoring people with MGUS at risk of developing blood cancer. The responsibility is currently being inconsistently passed between primary and secondary care, guidance is needed to ensure this population receives timely diagnosis.

Streamline approval processes for new treatments

Drug approval decisions can have life-or-death consequences, especially for those with rare or less common cancers, including some types of blood cancer.

The cost-effectiveness judgements, informed by the NHS, are often too inflexible to meet the complex nature of treating cancers like blood cancer. The NHS needs to work constructively with NICE and pharmaceutical companies to improve the approval process so that British patients aren't disadvantaged in what treatments they can access because they live in the UK.

Medium term

Increasing Clinical Nurse Specialist numbers

We know that blood cancer CNSs are the cornerstone of blood cancer care [1]. We also know that cancer patients not given a named CNS have the lowest survival rate [19]. With complexity and acuity on the increase, the NHS needs more cancer CNSs to support people with cancer and must immediately take new action to increase numbers through training, recruitment, retention and encouraging and supporting returners.

Routine publication of comparable, consistent and detailed cancer data

We want the NHS to commit to reviewing and delivering changes to how it collects, analyses and publishes cancer, including blood cancer, data. **Cancer data should be comparable and consistent across all four UK nations, so this work should be carried out in tandem and collaboration with devolved cancer registries.** The revamped reporting should report blood cancer as a distinct category and include essential aggregation by demographic data like age, ethnicity and deprivation, as well as cell morphology and behaviour.

Timed diagnostic pathways for all cancers

The NHS should commit to developing timed diagnostic pathways for all types of cancer, including blood cancer. These pathways support improvement efforts to shorten diagnostic pathways and ensure earlier diagnosis [20].

Long term

Workforce modelling

We want to see modelling of the cancer workforce that, for the first time in NHS policymaking history, is truly inclusive of the haematology and wider blood cancer workforce. Modelling should be followed by a cancer workforce plan that sets in motion actions to ensure we have the multidisciplinary workforce and administrative support to deliver cancer care in the immediate and long-term.

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