Leukaemia UK National Cancer Plan Response

Section 1- 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) Secondary Leukaemia, Proactive infection management and vaccinations**
- **Please explain your answer. Maximum 500 words.**

Surveillance and screening for familial AML
In the USA, institutions like Dana-Farber and Memorial Sloan-Kettering have pioneered genetic testing and counselling for families with a history of acute myeloid leukaemia (AML). These programmes help identify individuals at higher risk, enabling early monitoring and intervention. Incorporating genetic testing into clinical trials and routine care in the USA, has helped our understanding of familial AML.
Recommendation: The Plan should introduce genetic testing and counselling for those with a family history of AML, following successful models from the USA. Routine risk assessments could enable earlier detection and targeted monitoring, improving outcomes by identifying at-risk individuals before symptoms appear.

Pilot and if successful roll out full blood counts at relevant touch points
Each year in the UK, around 10,000 people are diagnosed with leukaemia, diagnoses are more common in those over the age of 60. AML, the deadliest blood cancer, has a five-year survival rate of just 22% and is linked to tobacco smoking. Currently, full blood counts (FBC), a simple and cost-effective method to detect blood cancers like leukaemia, are not routinely included in standard screening programmes. This is a missed opportunity, particularly for populations that are already engaged with healthcare services.
Recommendation: While we welcome the recommitment to the Tobacco and Vapes Bill, the Plan should take steps to improve early detection of leukaemia in individuals at higher risk. Given the strong link between smoking and AML, and the fact that older adults are more likely to develop leukaemia, we recommend piloting and if successful rolling out the incorporation of full blood count (FBC) tests into existing NHS screening programmes such as lung health checks for smokers and routine check-ups or other healthcare touchpoints for individuals over 60. By doing so, we can enable earlier detection of leukaemia, particularly AML, improving patient outcomes. .

Awareness and monitor for secondary leukaemia
Cancer survivors, particularly those treated for common cancers like breast cancer, are at increased risk of developing secondary leukaemia because of prior treatments such as chemotherapy and radiation. Leukaemia UK's feasibility study with the Health Economics Unit at NHSE estimates that 25.2% of those diagnosed with leukaemia, have been treated for a previous cancer. Many of these patients are unaware of this risk, despite being in follow-up care for their primary cancer. This group is easy to reach for targeted education and monitoring.
Recommendation: The Plan should integrate secondary leukaemia monitoring into follow-up care for cancer survivors, particularly those who have undergone intensive treatments. Raising awareness of the risk of secondary leukaemia will enable earlier detection and intervention, improving outcomes for these patients.

Preventative care for immunocompromised patients
Leukaemia patients often have weakened immune systems, making them susceptible to severe infections, which can be fatal. However, current healthcare provisions do not adequately address the needs of immunocompromised patients. Preventative measures are crucial to improving outcomes.
Recommendation: The Plan should prioritise infection prevention for leukaemia patients by including timely vaccinations, proactive infection management, and increased monitoring, particularly for those with weakened immune systems.

Section 2 - 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)

Please explain your answer. Maximum 500 words.

Access to full blood counts
Only 1/2 people diagnosed with leukaemia survive beyond five years, with Acute Myeloid Leukaemia (AML)'s five-year survival just 22%. While diagnostic tests for many cancers require high-tech equipment, a simple, inexpensive full-blood count (FBC) is needed to indicate or rule out leukaemia. NICE NG12 guidelines advise GPs to consider an urgent FBC (within 48 hours) for anyone presenting with suspected leukaemia symptoms. However, only 1/3 of leukaemia

patients receive a FBC within the 48-hour window; nearly half visit their GP more than once and 27% over three times about a pre-diagnosis health problem caused by their cancer. Leukaemia patients are often diagnosed via emergency presentation (37%), higher than the all-cancer 21% average. In 2013-2020, AML diagnosis through A&E rose by 10%, while diagnoses through GP visits dropped by 50%.

Recommendations

The Plan should address why so many leukaemia patients are diagnosed in emergency settings and identify opportunities for faster access to FBC tests to diagnose earlier. This will improve outcomes and treatment options for patients and benefit the health service, freeing up GP appointments and A&E capacity. On average, each GP appointment costs the NHS £46, while a FBC costs only £7.98.

Develop diagnosis pathways: Leukaemia UK has commissioned a project linking primary care (CPRD) and NHS England cancer data to develop solutions to diagnose leukaemia earlier and more cost-effectively. Once published, the Department should reflect on any findings from this study and implement interventions/solutions to deliver improvements to diagnosis.

Strengthen NICE NG12 guidelines and their adherence: The wording of NICE guidelines should be strengthened to help GPs order FBC tests promptly with suspected leukaemia symptoms.

Increase phlebotomy service capacity: Our GP poll found capacity shortages in phlebotomy services are the main reason for an FBC non-referral. Auditing and addressing phlebotomy capacity is vital to reduce diagnostic delays, the number of GP visits for suspected leukaemia symptoms, freeing up critical GP appointments and increasing efficiency.

Utilise community diagnostic centres: Community diagnostic centres should be equipped to directly order FBC tests. National guidance should ensure that FBC tests (rather than routine blood tests) are prioritised for people with nonspecific cancer symptoms. This approach would allow for quicker diagnostics and a reduction in unnecessary visits to A&E.

Adopt innovations: The Plan should prioritise a pilot to test the adoption of diagnostic innovations, such as the Pinpoint test and fingerprick FBC tests followed by rolling this out if effective. Especially for patients with nonspecific symptoms, this would make it easier for GPs to order tests quickly, even in community settings. This could also reduce the burden on both GPs and A&E departments.

Symptom awareness: Our poll showed that only 14% of the public can identify the warning signs of leukaemia. Better symptom awareness of leukaemia among the public and healthcare professionals as well as GP training, supported by technology could help them recognise symptoms of rare and less common cancers like leukaemia, making it more likely to order FBC tests on the first visit, speeding up diagnosis.

Section 3 - 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)

Please explain your answer. Maximum 500 words.

National clinical guidelines and audits
Our clinician and patient representatives often report variations in treatment. Unlike other cancers, there is a lack of formal, national clinical guidelines for leukaemia. The inconsistency in clinical practice often leads to suboptimal patient care, particularly in regions without specialised centres. Unlike other cancers, national policies to standardise treatment and identify variations and gaps do not exist for leukaemia.
Recommendation: The Plan should commit to a Getting It Right First Time (GIRFT) review for leukaemia to identify best practice and gaps in leukaemia treatment and outcomes. Additionally, commitment to an annual National Clinical Audit should be established to systematically assess the quality of leukaemia treatment across the country and address variations, ensuring treatment is delivered consistently at high-quality care and accountability. Furthermore, the development of national clinical guidelines for leukaemia by NICE would provide evidence-based standards for diagnosis, treatment, and management, standardising leukaemia care across the NHS.

Data collection and granularity
There are significant gaps in the data related to leukaemia treatment, including inconsistencies in how data is reported across regions and leukaemia subtypes. This lack of detailed data hinders efforts to improve care, target interventions, and monitor treatment effectiveness.
Recommendation: The Plan must include provisions for more consistent and granular data collection on leukaemia, including detailed breakdowns by leukaemia type, treatment intent, and patient demographics. Improved data linkage between primary care datasets (e.g. through CPRD), national cancer registries (NCRAS), and cell therapy data (EBMT) will enable a more comprehensive understanding of leukaemia treatment and outcomes. This will also allow for better tracking of progress and identification of areas needing attention.

Genomic testing
Genomic testing is crucial for identifying targeted therapies for leukaemia, yet it is not consistently offered as a standard of care for adults with leukaemia. Genomic data provides prognostic information, helping to predict disease progression and patient outcomes. This information is vital for clinicians and patients when making informed decisions about treatment intensity and monitoring strategies. Delays in receiving genomic test results often result in missed opportunities to tailor treatment effectively.
Recommendation: The government and NHS should commit to standardise genomic testing for all leukaemia patients. This will enable appropriate adjustments to treatment plans, improving outcomes, especially for aggressive forms of leukaemia like acute myeloid leukaemia (AML).

Section 4 - 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)

Please explain your answer. Maximum 500 words.

Ensuring supportive care services have true impact
Leukaemia patients face significant physical, psychological, emotional, and financial challenges. Through collaboration with clinicians and patient representatives, we've identified the core elements of a good quality of life, including the ability to lead an active life and achieve holistic well-being. For children, returning to school full-time is a key goal. However, the need for support extends beyond treatment. Long-term survivors often face ongoing issues, such as fertility challenges caused by treatments like chemotherapy. Many survivors report that these long-term effects, including emotional and psychological struggles, are often overlooked after treatment ends. Fertility preservation is not consistently discussed during treatment, leaving patients unprepared for these lasting consequences. Support services must be consistent and long-term, focusing on issues like fertility, emotional health, and quality of life. Clinical Nurse Specialists (CNSs) are essential in providing regular Holistic Needs Assessments (HNAs) at key stages to identify and address these needs. Yet, Leukaemia UK's survey showed only 9% of patients were offered an HNA, highlighting a significant gap in care.
Recommendation: The NHS should ensure every leukaemia patient is assigned a dedicated CNS to conduct regular HNAs and refer patients to appropriate support services. Patient outcomes, including fertility preservation and emotional well-being, should be consistently tracked.

Treatment and care closer to home
Patients with chronic lymphocytic leukaemia (CLL) are often placed on a 'Watch and Wait', where they are monitored regularly rather than immediately treated. This approach, while appropriate in many cases, can lead to confusion and anxiety for patients who may feel uncertain about the lack of immediate treatment. Additionally, attending regular hospital check-ups can be a challenge for patients due to the increased risk of infections, travel difficulties and the psychological strain of repeated hospital visits. One solution to these challenges is ambulatory care—care provided outside

traditional hospital settings, closer to home. In particular, the HMDS Outreach programme in the Yorkshire Cancer Network allows patients with CLL to be monitored through home visits and remote testing, reducing the need for frequent hospital visits.
Recommendation: To alleviate the burden on leukaemia patients, the Plan should prioritise the development of community and ambulatory care services so that patients are monitored at home or in community settings. This would reduce hospital visits, lowering the risk of infection and minimising logistical barriers. For patients on the 'Watch and Wait' pathway, clear communication and psychological support should be provided to help them understand the rationale behind this and to reassure them about the safety and benefits of being monitored at home. The Outreach model should be expanded nationally, ensuring that everyone with CLL can benefit from this approach.

Section 5 - Research and 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)

Please explain your answer. Maximum 500 words.

Find kinder, more effective treatments
Leukaemia, particularly acute myeloid leukaemia (AML), remains a deadly cancer, with a five-year survival rate of only 22%. There is an urgent need for better treatments to improve survival outcomes. For children with leukaemia, survival rates have improved to 90% but many still face lifelong side effects from treatment, and 1/10 children still die from the disease. Current therapies cause severe physical and psychological impacts, highlighting the need for kinder, more effective treatments.
Recommendation: The Plan should prioritise research on the development of less toxic therapies, particularly for AML and childhood leukaemia. This includes focusing on innovative treatments, such as oral drugs and risk stratification methods, which can predict treatment responses and reduce unnecessary side effects. Additionally, investments in treatments that can be administered in ambulatory settings would reduce the burden on patients. To support these advancements, the NHS must ensure robust infrastructure and research workforce planning as well as better procedures to access health data for research as recommended in the Sudlow report.

Access to clinical trials
Leukaemia patients depend upon clinical trials of new treatments, as surgery isn't a viable option for them. Almost half of leukaemia Cancer Patient Experience Survey respondents would have liked someone to discuss research participation opportunities such as clinical trials, but this did not happen. There are significant disparities in patient access to trials, often depending on whether they live near a large teaching hospital.

Recommendation: The Plan should commit implementing the Lord O'Shaughnessy review, including decentralisation of clinical trials, using digital tools to enhance accessibility and participation, particularly among underrepresented groups. Insights from successful trials for leukaemia, like the European Union-funded RESOLVE will help ensure equitable access across the UK.

Access to treatments

Blood cancer treatments in England and Wales are often slower to be approved compared to other oncology treatments. The Blood Cancer Alliance's report on 'Access Barriers to Blood Cancer Treatments' revealed that blood cancer therapies face higher rejection rates during the appraisal process. Only 56% of blood cancer treatments submitted to NICE are approved, compared to 74% for other oncology treatments. This delay is often due to disagreements over costs and complexities in the appraisal system despite treatments being available internationally.

Recommendation:

The cancer plan should task NICE and the NHS with reviewing the treatment approval process, identifying barriers, and developing strategies to improve access. It is essential to ensure that the NHS has the infrastructure and expertise to offer novel treatments to all patients, regardless of location or background.

Adoption of innovative treatments

Innovative treatments such as CAR-T cell therapies are not available everywhere because they need sophisticated infrastructure and trained expert workforce.

Recommendation: The Plan should provide clear strategies for ensuring rapid adoption of cutting-edge treatments everywhere, such as CAR-T. This includes investing in specialised training for healthcare professionals and ensuring the availability of necessary resources to administer these therapies efficiently. Additionally, ensuring equitable access to these treatments—especially in underserved or remote areas—is vital to prevent geographic disparities.

Section 6 - 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)

Please explain your answer. Maximum 500 words.

Unequal access to specialist treatments

A key challenge contributing to disparities in care and outcomes is the postcode lottery in access to specialist centres. For example, CAR-T therapy—a promising treatment for certain blood cancers—is currently only available in 17 hospitals in England, with no provision in Wales or Northern Ireland. Patients living further from these centres face additional travel burdens, accommodation costs, and potential delays in receiving care.

Recommendation: Expand equitable geographic access to CAR-T therapy and other advanced treatments across the UK, including in Wales and Northern Ireland. Ensure that patients required to travel significant distances receive financial support for travel, accommodation, and associated costs. The necessary infrastructure and capacity to deliver CAR-T therapy more widely should be established, addressing the variation in its availability.

Address geographical variation in care

Our clinical experts and patient representatives consistently report a disparity in the quality of care that leukaemia patients receive depending on whether they are treated in specialised haematology centres or in general hospitals and community services. This highlights a gap in specialist knowledge and capacity outside of major centres. Albeit with data limitations, research from the London School of Hygiene and Tropical Medicine has shown that five-year survival of Acute Myeloid Leukaemia (AML) is higher among least deprived (28%) as opposed to most deprived (22%) patients.

Recommendation: Invest in enhanced education and training for primary and community healthcare providers to better recognise, manage and refer patients with complex conditions like leukaemia and other rare cancers. Promote collaborative models of care between specialist centres and local services to ensure all patients benefit from specialist expertise, regardless of location.

Incomplete ethnicity data reporting

There are significant issues with the accurate collection of ethnicity data in blood cancer and in cancer care more broadly. This limits the ability to monitor inequalities or design interventions that meet the needs of underrepresented groups.

Recommendation: The National Cancer Plan should include a clear NHS commitment to complete and accurate ethnicity data reporting to cancer registries. NHS bodies must be mandated to fund data manager roles to ensure adequate resource and capability to collect, analyse, and act on ethnicity data in cancer care.

Section 7 - 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)

Please explain your answer. Maximum 500 words.

About leukaemia:

- The 11th commonest cancer, ~60,000 people affected, 28 new diagnoses daily
- High emergency presentation at diagnosis: 37% versus 21% all cancer average linked to lower one-year survival
- Non-stageable cancer, complicating efforts to track and improve early diagnosis
- Five-year survival rate is 55%, varying between leukaemia types - 22% for Acute Myeloid Leukaemia (AML) among most socially deprived and 28% in the least deprived populations
- Leukaemia is the most common childhood cancer with1-in-10 children do not survive beyond five years
- Five-year AML survival in England lags other countries
- Increased early appraisal terminations mean many novel treatments for blood cancers used elsewhere are unavailable in the UK
- Differences in clinical expertise and treatment availability across UK regions results in stark variations in treatment and care
- Complex treatments need expert workforce and infrastructure, making treatment and care closer to home difficult

We analysed public resources and consulted over 300 people with lived experience and professionals. To drive progress, the Plan should commit to:

1. Introduce a Blood Cancer Committee of clinicians, academics, industry, national and local NHS and government officials, parliamentarians, patient organisations and people affected to ensure the cancer plan delivers for blood cancers
2. Double five-year survival for AML from 22% to 44% within the next decade
3. Pilot and if successful roll out full blood counts in routine screenings - health lung checks and routine health check-ups for those over 60 years old given the higher risk of leukaemia. Also, targeted screening for those at increased risk of familial AML and risk stratification for secondary leukaemia.
4. Consider implementing interventions/solutions found to improve diagnosis from Leukaemia UK's health economic analysis
5. Invest in diagnostic innovations like the pinpoint test and fingerprick full blood count; include FBC in existing settings, including Community Diagnostic Centres.
6. Improve data systems by linking primary care records to cancer data and refining treatment categorisation to understand treatment uptake and intent (curative vs palliative) in leukaemia patients
7. Develop and roll out a Best Practice Timed Pathway for leukaemia
8. Carry out a GIRFT review and a national clinical audit to identify best practice and variations in leukaemia diagnosis, treatment and care
9. Develop and publish NICE national clinical guidelines for the management of leukaemia patients to standardise diagnosis, treatment and care
10. Foster a world-class research environment and improve participation in clinical trials, especially from underrepresented communities to find kinder, more effective treatments; including oral leukaemia drugs that can be given closer to home. Learn from international models like the EU-funded RESOLVE trial.

11. Make genomic testing a standard of care for everyone with leukaemia to ensure personalised, effective treatment for all eligible patients
12. Expand ambulatory and community-based services, including roll-out of the Outreach service for chronic lymphocytic leukaemia patients on ‘Watch and Wait’, bringing care closer to home.
13. Ensure all leukaemia patients are assigned to leukaemia CNS, have frequent holistic needs assessments and are referred to support services consistently to have emotional, physical and financial needs met