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.

For leukaemia patients the shift to preventing sickness, not just treating it, is of extreme importance. Many patients who are diagnosed with blood cancers, particularly leukaemia, have a weakened immune system. This means they are much more prone to infections, which can be more severe and, in some cases, fatal. Preventative measures, such as timely vaccinations, proactive infection management, and close monitoring, are essential to improving patient outcomes. It is important the National Cancer Plan considers those with weakened immune systems.

Acute Myeloid Leukaemia (AML) is one of the 15 cancers known to be caused by tobacco smoking. We welcome the Governments recommitment to the Tobacco and Vapes Bill but feel more should be done to test at risk populations for conditions known to be caused by smoking. Leukaemia UK would like the National Cancer Plan to include a full blood count as part of the tests conducted during a lung health check. Full blood counts are simple inexpensive tests and are the easiest way to indicate or rule out a diagnosis of leukaemia. Since there is a known link between smoking and risk of AML, conducting a full blood count during a lung health check could be an effective means of identifying leukaemia cases earlier.

When focusing on disease prevention, it is important to consider secondary leukaemia, which can develop as a result of prior cancer treatments. Early identification of at-risk patients who have undergone intensive therapies for a previous cancer is essential. These individuals are at an increased risk of developing secondary leukaemia and should be closely monitored to ensure timely intervention and management.

For rare and less common cancers, including leukaemia, opportunities to utilise existing screening programme touchpoints to support earlier diagnosis should be maximised. Most leukaemia cases occur in people over the age of 60, many of whom will already be in the NHS system. There will be more effective ways to detect blood cancers including leukaemia in the future. For example, using the HIV opt out screening in A&E to complete full blood counts.

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.

Only 1 in 2 people diagnosed with leukaemia survive beyond five years. For Acute Myeloid Leukaemia, the five-year survival rate is just 22%. Improvements in diagnosis of leukaemia is key to saving lives. Delays in leukaemia diagnosis pose significant risks.

While diagnostic tests for many cancers require complex, high-tech equipment, a simple and inexpensive full-blood count is all that is needed to indicate or rule out leukaemia. NICE NG12 guidelines advise GPs to consider an urgent full-blood count (within 48 hours) for anyone presenting with any suspected leukaemia symptoms. However, only a third of patients with leukaemia had received a full-blood count within 48 hours of presenting with symptoms. Alarmingly, 45% of leukaemia patients report visiting their GP more than once about a health problem caused by their cancer before being diagnosed, with 27% of patients making three or more visits.

In England, 37% of leukaemia patients are diagnosed through emergency presentation, significantly higher than the average of 21% for all cancers. Between 2013 and 2020, the proportion of people diagnosed with acute myeloid leukaemia (AML) in A&E rose by 10%, while diagnoses through GPs reduced by more than half.

These missed opportunities for a leukaemia diagnosis contribute to inefficiencies in healthcare delivery; on average, each GP appointment costs the NHS £46, while a full-blood count costs only £7.98. Ensuring referral for a full-blood count during the first GP visit, will not only improve the outcomes and treatment options of the patient but also serve to improve the efficiency of the health service and free up much needed GP appointments.

A Savanta poll of 1,000 UK GPs, conducted for Leukaemia UK, found that 92% of participants could identify the need to conduct a full-blood count when a patient presents with the four most common symptoms of leukaemia. However, 30% of GPs surveyed reported reasons for why referring a patient for a full blood count may not be possible, with the most frequently cited reason being a lack of capacity within phlebotomy services. This highlights the need for increased capacity and investment in blood services within the NHS.

Increasing phlebotomy capacity could reduce the number of GP visits required before diagnosis, free up GP appointments, and lead to long-term cost savings for the NHS. It also has the potential to avoid costly visits to A&E departments by self-presenting patients.

Leukaemia can be hard to spot, symptoms are often vague and easily misdiagnosed. A lack of awareness of symptoms amongst the public and healthcare professionals, particularly those in primary care and community settings, can often lead to a late diagnosis. A Leukaemia UK survey found only 14% of the public know the warning signs of leukaemia. Increased awareness of leukaemia among the public, primary healthcare practitioners and policymakers is critical to achieving progress in early detection and diagnosis of leukaemia. Better training and utilisation of technology is needed to support GPs in recognising when a patient may be presenting with symptoms of a rare and less common cancer such as leukaemia.

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.

Currently, there are no formal national clinical guidelines for leukaemia, no national clinical audit, and no comprehensive efforts to assess where best clinical practice exists or identify gaps in care. Insights from Leukaemia UK’s work with the clinical and patient community confirm that significant variation exists in the availability of treatment and leukaemia-specific clinical expertise across the UK.

To ensure the highest quality of care and standardise clinical practice for all patients, regardless of their location, personal circumstances, or background, it is essential to implement the following:

- A GIRFT (Getting It Right First Time) review to assess variations in leukaemia care and identify opportunities for improvement.
- A National Clinical Audit to systematically evaluate the quality of leukaemia diagnosis, treatment, and outcomes, ensuring accountability and driving improvements in patient care.
- The development and rollout of formal National Clinical Guidelines (published by NICE) to establish clear, evidence-based standards for leukaemia treatment and management across the NHS.

Research conducted by Leukaemia UK has revealed the profound toll that leukaemia treatment can take on patients, both physically and mentally. Nearly half (44%) of those diagnosed report a significant decline in their physical well-being during the early stages of diagnosis and treatment.

Even after treatment has ended, one in five patients (20%) continue to struggle with severe physical effects. The mental health impact is equally concerning, with nearly a third of patients experiencing a noticeable decline in their psychological well-being during treatment.

These findings underscore the urgent need for kinder, more effective treatments. It’s vital that leukaemia patients have access to new, less toxic therapies, supported by a robust and sustainable cancer care system and workforce. This is key to protecting patients from the intense physical and mental hardships associated with current gruelling treatments.

The National Cancer Plan needs to support the publication of better and more consistent health data to improve the quality of diagnosis, treatment, and care of leukaemia. There are gaps and inconsistencies in the way that leukaemia data is reported in England, including a lack of data by leukaemia type. This represents a significant barrier to understanding the issues and developing targeted strategies to improve survival and quality of life for those affected by leukaemia.

Health data on leukaemia is vital to better understand this challenging disease, but also to monitor where improvements have been made or highlight where improvements are needed. Currently, data for leukaemia such as incidence, mortality and survival, routes to diagnosis, treatments and cancer waiting times are generally inconsistently reported, if at all, and often without sufficient granularity; particularly, with regards to different types of leukaemia. Additionally, data reporting on leukaemia differs between the devolved nations, and England.

To improve the outcomes for those diagnosed with leukaemia, including the shockingly low five-year survival rate of acute myeloid leukaemia (AML), the NHS must publish better, more consistent data, with the granularity needed to be able to understand the quality of care, and patient and clinical outcome

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.

Leukaemia patients require ongoing monitoring due to the complexity of the disease, its physical and emotional impact and a weakened immune system.

Primary care and community services can play a vital role in supporting leukaemia patients. Cancer Nurse Specialists should be able to refer leukaemia patients to primary and community services for managing psychological effects, mild treatment side effects, or co-morbidities, where appropriate.

In chronic leukaemias, such as chronic lymphocytic leukaemia, not all patients need to start treatment immediately and can be assigned ‘Watch and Wait’ as a treatment approach with regular check-ups to monitor their condition. Many patients feel confused and worried when they’re told they will just be monitored, after receiving a cancer diagnosis. Check-ups are often conducted at a hospital, where patients have blood tests and may have a physical examination to check the state of their disease.

Attending a hospital setting for a check-up can present several challenges for leukaemia patients, including increased risk of infection, travel and accessibility issues, and increased psychological strain associated with regular visits to hospital.

Many aspects of chronic leukaemia patients’ care can be effectively handled in a community or primary care setting. The Yorkshire Cancer Network and The Yorkshire Coast and the Humber Cancer Network Haematological Malignancy Diagnostic Service (HMDS) has launched an ‘Outreach’ programme, that is designed to allow chronic leukaemia patients to be monitored from home without the need for regular visits to hospital. The Outreach programme is based on regular monitoring of blood test results and symptoms and has been shown to not only be a clinically effective approach but increases patient satisfaction. The HDMS team are looking to gradually expand the Outreach programme to a wider group of leukaemia patients. As the Department has stated ‘it is the responsibility of this Government to take the best of the NHS to the rest of the NHS’ therefore the National Cancer Plan should look to implement the learnings from the Outreach programme across the whole nation, so all patients can benefit from it.

To understand the true support and care needs of a leukaemia patient, or cancer patients more generally, a Holistic Needs Assessment (HNA) is meant to be conducted. A HNA ensures that people’s physical, practical, emotional, spiritual, and social needs are met timely and appropriately, and that resources are aligned with need. Due to the nature of the disease and the severity of treatments, leukaemia patients are particularly vulnerable cancer patients. Therefore, a HNA to assess their needs is critical. A HNA should be undertaken at different stages in the cancer patient’s pathway by a nurse or key worker to guide the development of a care and support plan - from diagnosis and following treatment.

Data from Leukaemia UK has found that only 9% of people with leukaemia had been offered a HNA. Given the complexity of leukaemia, a HNA at point of diagnosis and throughout their treatment and recovery are needed to ensure that all physical and psychological needs are identified, addressed, and monitored.

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.

Currently, many people who would benefit from the innovative CAR-T therapy miss out because it is not available everywhere and there is not a standardised approach on patient eligibility.

Emerging evidence also suggests that CAR-T therapy as a first treatment option, rather than after relapse, could be more beneficial for both the long-term physical and mental health of patients, and their loved ones, than current chemotherapy treatments. 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 countries. Often this is because the pharmaceutical companies and the NHS cannot agree on cost, or because of complexities in then appraisal system and processes. The large number of non-submitted, potentially groundbreaking drugs represents missed opportunities for blood cancer patients to access potentially life-saving treatments.

It is important the plan ensures that the right infrastructure and workforce expertise is available in the NHS across the UK, so that everyone can access novel treatments regardless their location, age and background.

Leukaemia patients are often more dependent on new treatments to survive the disease, as surgery is not an option for them, unlike those with solid cancers. Clinical trials provide the vital evidence base needed for new treatment approaches and offer the potential to improve survival for those diagnosed with leukaemia and other deadly cancers.

Progress needs to be made in delivering high-quality clinical trials to test promising new treatments for blood cancers, including leukaemia. Since the COVID-19 pandemic, there has been a reduction in the number of clinical trials taking place in the UK and fewer patients participating in new trials. Almost half of leukaemia Cancer Patient Experience Survey respondents reported that they would have liked someone to discuss whether there were any cancer research opportunities they could take part in, such as clinical trials, but this did not happen.

There are significant disparities in patients’ access to trials, often depending on where they live, with access best for those near a large teaching hospital. Decentralising clinical trials is an important tool to address these disparities. Digitalisation is essential for decentralising clinical trials, using digital tools and platforms to streamline processes such as patient recruitment, data collection, and analysis. Better integration and sharing of clinical trial data can strengthen collaboration between researchers and healthcare providers, leading to more comprehensive and efficient trials. Furthermore, digital platforms improve patient engagement by providing easier access to trial information and enabling remote participation. This approach not only simplifies participation but also makes clinical trials more inclusive and representative.

The current process for charities and researchers to access health data is complex and inconsistent. To improve this, data access procedures should be simplified and standardised, data quality should be enhanced, and a federated national data library should be developed as recommended in the Sudlow report. These measures would help unlock the full potential of health data to drive impactful research and improve patient outcomes.

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.

A key challenge contributing to disparities in care and outcomes is the postcode lottery in access to these specialist centres. For example, CAR-T therapy, a promising treatment for certain blood cancers, is only available in 17 hospitals in England, with no services in Wales or Northern Ireland. This limited access means that patients living further from specialist centres may face travel challenges and additional costs, including accommodation. Furthermore, CAR-T therapy could become more cost-effective and lead to better patient outcomes if it was used earlier in treatment and if the infrastructure to deliver it was properly established.

Every blood cancer patient should be able to easily access the best care in the appropriate specialist setting and receive appropriate support if this means significant travel or cost to them.

Clinical experts highlight the disparity in care quality for leukaemia patients between specialised haematology centres and general hospitals or community services, underscoring the need for specialised training. Enhancing education and training for primary and community care providers is crucial to improving the management of complex diseases like leukaemia and other rare cancers.

Leukaemia patients face many hidden costs when living with cancer; travel expenses to and from hospital, food costs associated with specialist diets and additional use of heating to keep warm, due to treatment side effects. Evidence suggests that nearly 65% of patients are forced to reduce their working hours or even stop working completely, following a leukaemia diagnosis. The median financial impact of a blood cancer patient is £181 per month, compared with £120 for a patient with breast cancer or with £52 for a patient with prostate cancer.

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.

To ensure the National Cancer Strategy drives meaningful improvements for leukaemia, there must be strong accountability and credibility mechanisms in place. The strategy should include a specific commitment to doubling the five-year survival rate for Acute Myeloid Leukaemia (AML) from 22% to 44% over the next decade. AML remains one of the deadliest cancers, and survival rates in the UK significantly lags other countries (8th out of 12 countries).

Leukaemia is not stageable in the same way as solid tumours, a new metric must be introduced to track improvements in early diagnosis of unstageable cancers. This would provide a more accurate measure of progress and help ensure that leukaemia is not left behind by national early diagnosis targets.

To oversee the delivery of these commitments, a dedicated Blood Cancer Committee should be established within the framework of the National Cancer Strategy. Furthermore, childhood leukaemia, the most common cancer in children, must be explicitly addressed within the scope of the Childhood and Young Lives Cancer Taskforce to ensure that the unique needs of young patients are met.

To develop kinder and better treatments for leukaemia, an environment that fosters cutting-edge research and equitable access to clinical trials is essential. Leukaemia research has already led to breakthroughs in other cancers, and continued investment in innovation is crucial to finding more effective and less toxic therapies. Clinical trial opportunities are not reaching all patients equally. Greater participation and equity in access to clinical trials is needed to ensure that those affected by leukaemia can benefit from the latest advancements. To ensure access to the best treatments for all leukaemia patients a balanced regulatory environment that incentivises innovation while ensuring timely access to life-saving therapies, is needed.

Delays in diagnosis of leukaemia can lead to fewer treatment options and a reduced chance of survival. Limitations in GP and blood testing capacity act as barriers to diagnosing leukaemia earlier. Investment in primary care and phlebotomy services is critical to ensuring that every patient presenting with leukaemia symptoms can access a full-blood count within 48 hours, as recommended by NICE guidelines.

Additionally, the development and rollout of a Best Practice Timed Pathway (BPTP) for leukaemia is essential to reduce variation in the diagnosis experience of patients and to improve patient experience of care. A comprehensive Holistic Needs Assessment (HNA) should be offered to every leukaemia patient at diagnosis and revisited throughout their treatment journey. This would help identify and address the physical, emotional, and financial challenges that leukaemia patients face.

Better and more granular data on leukaemia is needed. Current cancer data systems lack the granularity needed to track leukaemia-specific outcomes effectively. A commitment must be made to publish more comprehensive and consistent data, covering incidence, survival rates, treatment pathways, and patient outcomes. Additionally, a National Clinical Audit and a Getting It Right First Time (GIRFT) review should be commissioned for leukaemia to identify best clinical practice, address quality variations in care and ensure continuous improvements in diagnosis, treatment, and overall patient experience.