

ALK Positive Lung Cancer (UK)

Submission to the National Cancer Plan
Consultation – April 2025



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Prevention and Awareness Priority areas selected:

- Air pollution
- Tobacco
- Other (raising awareness of oncogene-driven lung cancer risk factors)

Lung cancer prevention efforts must continue to address well-known risks such as tobacco use, but the National Cancer Plan must also respond to the growing evidence around other significant risk factors, particularly air pollution. Air pollution has been classified as a Group 1 carcinogen by the World Health Organisation and is a rising contributor to lung cancer incidence, especially in people without a smoking history. Government strategies to tackle environmental risk factors, particularly in urban areas, need to be fully integrated into the Plan's prevention ambitions.

While tobacco control remains crucial, public health messaging must evolve. Around 20% of lung cancer cases occur in people who have never smoked. Many of these are driven by oncogene alterations such as ALK, EGFR, and ROS1. Continuing to position lung cancer solely as a smoker's disease damages efforts to achieve earlier diagnosis in these groups. It also perpetuates stigma, which affects patient experience, mental health, and fundraising for research.

Awareness campaigns must be broadened to educate both the public and healthcare professionals about the range of people at risk. Younger people, women, and those with no history of smoking are often misdiagnosed or diagnosed late because lung cancer is not suspected early enough. Prevention strategies should therefore include education about non-smoking-related lung cancer risks, the importance of symptom vigilance, and the role of genetic and environmental factors.

If the National Cancer Plan is to truly modernise cancer prevention, it must challenge outdated assumptions and actively promote a more inclusive understanding of who can be affected by lung cancer. This will help drive earlier engagement with healthcare services, reduce diagnostic delays, and save lives. A narrow focus on tobacco alone will no longer be sufficient to meet the ambitions for improved lung cancer outcomes.

Early Diagnosis

Priority areas selected:

- Improve symptom awareness, address barriers to seeking help
- Support timely and effective referrals from primary care
- Increase diagnostic test access and capacity

Early diagnosis is the single most effective way to improve lung cancer outcomes. However, current strategies remain too narrowly focused on smoking history, overlooking a growing group of people at risk who have never smoked. For people with oncogene-driven lung cancers, such as ALK-positive NSCLC, earlier diagnosis can significantly extend survival. Yet delays persist because healthcare professionals and the public often do not associate lung cancer with younger people, women, or never-smokers.

The National Cancer Plan must embed a modernised approach to symptom awareness. Campaigns should explicitly include messaging that lung cancer can affect people with no smoking history. Symptom profiles must be better understood across healthcare settings, recognising that cough, breathlessness, chest pain, fatigue, and even non-specific signs warrant investigation, regardless of risk factors.

Primary care plays a critical gatekeeping role. GPs must be supported through education, decision-making tools, and referral pathways that make it easier to escalate concerns. Current referral guidelines often rely heavily on smoking history and may inadvertently create barriers for people who do not fit the typical profile. This must change if we are to see real shifts in early-stage diagnosis rates.

Expanding diagnostic capacity is equally crucial. Delays in access to imaging, biomarker testing, and specialist review can erode the survival gains made by earlier presentation. Rapid diagnostic centres should be scaled up, and innovative diagnostic techniques, including liquid biopsy, should be incorporated into early-stage pathways where appropriate.

Finally, early diagnosis efforts must be sensitive to the persistent inequalities in lung cancer outcomes. Deprivation, geography, ethnicity, and smoking stigma all affect how quickly someone presents, is investigated, and is diagnosed. The Plan must include clear strategies to target under-served groups and ensure that progress in early diagnosis benefits all communities equally.

Early diagnosis saves lives — but only if it reflects the real-world diversity of lung cancer patients and addresses both system-level and public barriers to timely investigation.

Treatment

Priority areas selected:

- Increase the use of genomic (genetic) testing and personalised treatment
- Review and update treatment and management guidelines
- Improve the flow and use of data to identify and address inconsistencies

The future of lung cancer treatment lies in precision medicine. For people with oncogene-driven lung cancers such as ALK-positive NSCLC, identifying the correct genetic alteration at diagnosis directly determines access to the most effective treatments. The National Cancer Plan must place equitable access to genomic testing at its core. Comprehensive biomarker testing, including ALK, EGFR, ROS1, and others, should be performed upfront for every patient diagnosed with non-small cell lung cancer, regardless of smoking status, age, or clinical presentation.

Despite advances, biomarker testing across the NHS remains patchy. Delays in receiving results, inconsistent testing panels, and lack of standardised pathways lead to missed opportunities for patients to access targeted therapies. Investment in infrastructure, workforce training, and real-time monitoring of testing rates is urgently needed. Expanding the use of minimally invasive methods such as liquid biopsy (ctDNA testing) can also help overcome diagnostic barriers and speed up access to treatment.

Treatment guidelines must keep pace with emerging evidence. In ALK+ NSCLC, for example, targeted therapies have moved earlier in the treatment pathway, sometimes even before surgery. Updated national guidelines should reflect the latest data, support multidisciplinary decision-making, and reduce regional variation in practice. National audit data and real-world outcomes should be used proactively to identify gaps and drive quality improvement.

Data transparency is critical. Current variation in access to genomic testing and targeted therapies across different regions and demographic groups is unacceptable. Publishing clear, accessible data on testing rates, treatment uptake, and outcomes — broken down by factors such as age, sex, ethnicity, and deprivation — will be essential to holding systems accountable and addressing inequalities.

Every lung cancer patient should have timely access to personalised care based on their tumour's molecular profile. Precision medicine must not be a postcode lottery. Delivering on this ambition will improve survival, quality of life, and the overall efficiency of lung cancer services in the NHS.

Living With and Beyond

Cancer Priority areas selected:

- Provide more comprehensive, integrated and personalised support after diagnosis and treatment
- Improve emotional, mental health and practical support for patients and families
- Improve access to high-quality, supportive palliative and end-of-life care

The experience of living with lung cancer is changing. Thanks to advances in targeted therapies, people with stage IV ALK-positive and other oncogene-driven lung cancers are living longer, often for many years after diagnosis. However, the support available to them has not kept pace with these changes. Traditional models of survivorship often assume a clear transition from active treatment to post-treatment care, which does not reflect the realities faced by those on lifelong oral therapies or experiencing cycles of disease progression and treatment adaptation.

The National Cancer Plan must commit to building personalised, integrated support systems that recognise the needs of people living with incurable but treatable lung cancer. This includes access to specialist nurses, holistic needs assessments at key points in the disease journey, and tailored information that addresses the practical, emotional, and psychological challenges of living with advanced cancer.

Mental health support must be embedded into standard care pathways, not treated as optional. Anxiety, depression, fear of progression, and uncertainty about the future are common and can significantly affect quality of life. Support must extend beyond the patient to include family members, carers, and children, who are often deeply affected by a cancer diagnosis in a loved one.

Practical support is equally important. Many people living with lung cancer face challenges related to employment, finances, fatigue, and mobility. A genuinely person-centred approach to cancer care must address these real-world issues through access to benefits advice, vocational rehabilitation, and community support services.

High-quality palliative and end-of-life care must also be consistently available across the country. Access to early palliative care has been shown to improve both quality of life and survival in lung cancer, yet services remain variable. The Plan must ensure that palliative care is integrated from the point of diagnosis of incurable disease, not left until the final stages of life.

Living with and beyond lung cancer is a reality for a growing number of people. Their needs must be recognised, resourced, and embedded throughout the cancer care pathway if we are to deliver truly compassionate, effective cancer services.

Research and Innovation Priority areas selected:

- Increase research into early diagnosis
- Increase research into innovative treatments
- Increase research on rarer and less common cancers

Innovation is critical to transforming outcomes for people with lung cancer. The National Cancer Plan must prioritise investment in research that addresses the urgent challenges faced by those with oncogene-driven and rarer forms of the disease, such as ALK-positive non-small cell lung cancer. While targeted therapies have significantly improved survival for some patients, drug resistance and the development of brain metastases remain major barriers to long-term control of the disease.

Research into mechanisms of resistance, next-generation targeted treatments, and strategies to prevent or treat brain metastases must be a national priority. Clinical trials investigating novel therapies, combination regimens, and adaptive treatment strategies are essential to keep pace with the rapidly evolving science. Specific funding streams should be allocated to support research into these areas, recognising that rare and molecularly defined cancers are often under-represented in traditional research funding models.

Early diagnosis research must also be strengthened. Traditional symptom-based and smoking history-based approaches are inadequate for detecting oncogene-driven lung cancers, which often occur in younger, fitter individuals with no smoking background. Innovative approaches, including the development and implementation of liquid biopsy (ctDNA and cfRNA) technologies, blood-based screening, and novel imaging modalities, offer the potential to detect cancer earlier in these populations. The Plan must explicitly support translational research to validate and scale up these approaches within the NHS.

Research efforts must be aligned with faster adoption into clinical practice. Too often, there is a lag between scientific discovery and real-world implementation. Mechanisms to speed up NICE assessments, real-world data collection, and NHS adoption of new diagnostics and treatments should be integral to the Plan.

Finally, the UK must commit to improving opportunities for patients to participate in clinical research, regardless of where they live. Access to trials is a key part of modern cancer care, offering hope to individuals and contributing to system-wide improvements. Addressing geographic, socioeconomic, and molecular inequalities in trial access will be crucial to making research truly inclusive.

By committing to focused, equitable, and accelerated research and innovation, the National Cancer Plan can help drive a new era of progress in lung cancer care.

Inequalities

Priority areas selected:

- Improving earlier diagnosis across all groups
- Improving access to and quality of cancer treatment
- Raising awareness of signs and symptoms and reducing barriers

Addressing inequalities in lung cancer outcomes must be a central aim of the National Cancer Plan. Despite improvements in treatment and diagnosis, significant disparities persist based on geography, socioeconomic status, ethnicity, gender, and smoking history. These inequalities have a real impact on survival rates and quality of care, and they must be tackled urgently and systematically.

Earlier diagnosis remains unevenly distributed across different groups. People from deprived communities, ethnic minority groups, and those living in rural areas are less likely to be diagnosed at an early stage. For people with oncogene-driven lung cancers, such as ALK-positive NSCLC, the situation is compounded by a lack of public and professional awareness that lung cancer can occur in younger, never-smoking individuals. Awareness campaigns and symptom recognition efforts must be carefully designed to reach all at-risk groups, not just those traditionally associated with lung cancer.

Access to diagnostic services, biomarker testing, and targeted treatments also varies widely across the UK. The 2025 National Lung Cancer Audit highlighted that only 45% of people with ALK+ NSCLC and good performance status received targeted therapy. This represents a failure to deliver equitable, evidence-based care and must be addressed through national performance standards, transparent reporting, and targeted improvement initiatives.

Workforce shortages, capacity constraints, and variations in local commissioning decisions all contribute to the postcode lottery in cancer services. National leadership is needed to set clear expectations for equitable service provision and to monitor and intervene where necessary to close gaps. Regional Cancer Alliances must be tasked with explicit responsibility for reducing inequalities and provided with the resources and authority to do so.

In addition, tackling inequalities must include improving the cultural competence of services. Language barriers, mistrust of the healthcare system, and different cultural perceptions of symptoms and help-seeking behaviour all affect when and how people access cancer services. Community engagement, co-designed interventions, and better use of community-based healthcare workers could help bridge these gaps.

Reducing inequalities in lung cancer is not only a matter of fairness — it is essential to achieving overall improvements in survival and outcomes. The National Cancer Plan must set ambitious targets for narrowing the gap, backed by transparent data, accountability, and sustained investment.

Priorities for the National Cancer

Plan Priority areas selected:

- Earlier diagnosis of cancer
- Improving access to and quality of cancer treatment
- Reducing inequalities in cancer incidence, diagnosis and treatment

The National Cancer Plan must be bold, ambitious, and grounded in evidence if it is to achieve the improvements in outcomes that people affected by cancer urgently need. Earlier diagnosis, personalised and high-quality treatment, and a determined focus on reducing inequalities should form the foundation of the Plan's approach.

Earlier diagnosis remains the single most powerful lever for improving survival in lung cancer. For people with ALK-positive NSCLC and other oncogene-driven cancers, timely diagnosis not only improves survival but also enables access to targeted therapies that are most effective in early-stage disease. Modernising symptom awareness campaigns, improving referral pathways, and expanding diagnostic capacity are essential to achieving earlier diagnosis across all demographics.

Access to high-quality, personalised treatment must not be dependent on geography, socioeconomic status, or demographic factors. Universal access to comprehensive biomarker testing, multidisciplinary team input, and the latest evidence-based treatments must be the standard across the NHS. Investment in workforce, infrastructure, and real-time data monitoring will be critical to delivering this ambition.

Tackling inequalities must be embedded across all aspects of the Plan, not treated as a separate strand. Lung cancer has historically been affected by stigma and assumptions linked to smoking, leading to delayed diagnosis and poorer care in certain groups. Recognising the diversity of people affected by lung cancer — including never-smokers, younger people, women, and those from deprived communities — is essential. Transparent, disaggregated data on diagnosis, treatment, outcomes, and trial participation must be published regularly, and national and regional leaders must be held accountable for closing the gaps.

The Plan must also commit to supporting research and innovation, ensuring that advances in diagnostics and treatments reach patients quickly, and that rare and less common cancers like ALK+ NSCLC are properly represented in research priorities.

By focusing on earlier diagnosis, equitable access to personalised care, and tackling the deep-rooted inequalities that have long shaped cancer outcomes, the National Cancer Plan has the opportunity to drive real, lasting change for people affected by lung cancer and across the wider cancer community.

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