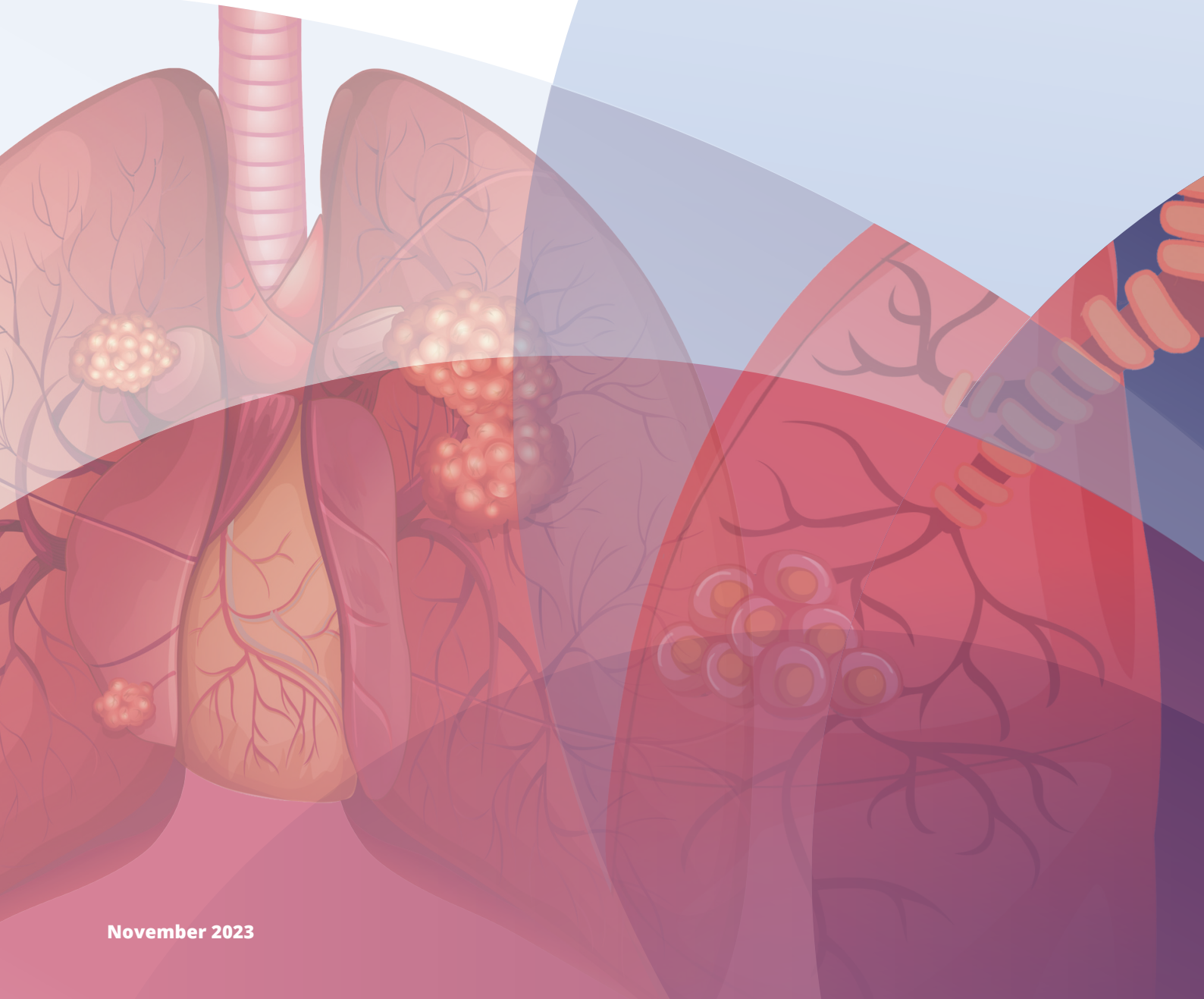




UNITED KINGDOM
LUNG CANCER COALITION

UKLCC IMPACT REPORT 2023

**Driving improvements in UK Lung Cancer Care -
The Power of Working Together**



November 2023

Introduction

We are delighted to present the UK Lung Cancer Coalition's (UKLCC) impact report - charting the progress and achievements made possible by the UKLCC and its members.

Since its launch in 2005, the UKLCC has worked tirelessly with health professionals, NHS trusts, cancer networks, other charities, Royal Colleges, and Government to help improve outcomes for UK lung cancer patients. In the last 20 years, because of the hard work and commitment from those actively working in the field, lung cancer has significantly moved up the political and clinical agenda and there have been some key milestones achieved, most notably the recent approval of targeted lung cancer screening in England. Parts of the UK have seen real improvements in service provision and curative treatment rates have been steadily improving. However, lung cancer remains the UK's biggest cancer killer, there are still huge variations in care and outcomes across the UK, and survival rates for lung cancer continue to compare poorly with other cancer types and many other countries.

The UKLCC has continued to be a key voice within the lung cancer community. Against a highly political backdrop, it has been able to say what others simply cannot.



In the late 1990s, when I started as National Cancer Director, I remember remarking to a colleague that there were very few dreamers in the lung cancer community - and that included experts. Since then, attitudes towards lung cancer have changed radically and survival rates have improved, albeit from a low base. The UKLCC has been at the heart of these improvements by bringing together the whole community - clinicians, researchers, health service managers, patient representatives, charities, and industry - to drive change. Improvements in diagnosis and treatment have been made and further progress can be confidently anticipated with the introduction of targeted lung screening. I would like to thank all concerned and wish UKLCC every success in the future."

**Professor Sir Mike Richards, CBE,
Chair, UK National Screening Committee**

Membership

The UKLCC continues to be the UK's largest multi-interest group in lung cancer. Its membership includes leading lung cancer experts, senior NHS professionals, health professional groups, charities, lay members, and healthcare companies. It was the first coalition to bring together all the patient groups with an interest in fighting lung cancer under one umbrella.

The work of the UKLCC is underpinned by its Clinical Advisory Group (CAG) which comprises experts from all clinical specialities across the pathway including lung cancer nurse specialists. The CAG, together with the UKLCC's Members' Forum, has representation across the four UK nations. The Members' Forum meets quarterly and there is a CAG meeting once a year to discuss key priorities. For more details of the UKLCC's membership, visit: www.uklcc.org.uk



32
members
of the Members'
Forum




20
members
Clinical Advisory
Group

Survival ambition

As well as bringing lung cancer out of the political and media shadow, the UKLCC's founding ambition was to tackle poor lung cancer survival rates and, specifically to double five-year survival within ten years. By 2015, this was effectively achieved in England.¹ In 2016, the UKLCC set a new ambition: to improve the five-year survival to 25 percent by 2025. Real progress was being made until Covid-19. Since the pandemic, the UKLCC has been focussed on getting lung cancer services back on track to achieve its '25 by 25' goal.

The UKLCC's '25 by 25' ambition has been widely quoted and adopted by third parties (including the NHS) as a key survival target across the community.

The UKLCC has pushed to **increase the 5-year survival**



16.2% to **25%**
in 2017 to by 2025
(In England)

In 2005, 5-year survival was just 8.6%.¹

1. Landscape and Service Provision

UKLCC submitted evidence to more than **40** Government and other consultations on issues such as **work-force, screening, the ten-year cancer plan, and major conditions strategy.**

National Lung Cancer Audit

Understanding what is happening in clinical practice and how this is affecting patient outcomes depends on having first-class data collection and reporting. Following the NLCA's formation in 2004, the UKLCC was a key protagonist in encouraging NHS Trusts to participate in the National Lung Cancer Audit (NLCA), which now represents data from more than 170 individual organisations. As a result, the NLCA's quality data and reporting has helped to transform the lung cancer landscape and drive-up standards. The UKLCC continually lobbies to ensure the long-term future of the NLCA so we can continue to drive further improvement in lung cancer care and outcomes – and help to reach the UKLCC's ambition of increasing five-year survival rates to 25% by 2025.

MDTs

Multi-disciplinary teams (MDTs) have been at the heart of delivering improved care for many cancers. However, early work undertaken by the UKLCC revealed there were insufficient specialists to effectively service the large number of lung cancer MDTs. It was also clear from NLCA data that a significant proportion of patients did not have their case discussed by an MDT, there was a variability of access to surgery and to specialist thoracic surgeons, and only three quarters of patients had access to a lung cancer nurse specialist (LCNS). The

UKLCC published two highly regarded reports on 'The Dream MDT for lung cancer' which, based on a consensus of what we would all want for ourselves and our loved ones, provided a series of robust recommendations to address these shortfalls. As a result of the invaluable work of the NLCA in setting targets, 92% of patients are now assessed at diagnosis by a LCNS compared to 80% in 2019.²

Recognising the vital role of LCNSs, the UKLCC organised a Nurse Fly-in event at Westminster which was attended by MPs from across the UK.

National Optimal Lung Cancer Pathway

The UKLCC also campaigned for the implementation of the National Optimal Lung Cancer Pathway (NOLCP) to help address delays in lung cancer diagnosis and treatment. Much of the UKLCC's work has focused on highlighting examples of best practice as well as identifying challenges and blocks in the pathway. In 2019, it produced a series of recommendations in its 'Pathways Matter' report, which served as helpful guidance to Integrated Care Systems (ICS) and the Cancer Alliances, as they developed their plans for meeting the objectives of the NHS Long Term Plan for cancer at a local level.

15 UKLCC reports published on issues such as **early diagnosis, optimising the lung cancer pathway, MDTs, and molecular diagnostics** – providing insightful commentary, best practice examples and pivotal recommendations.

2. Earlier and faster diagnosis

Lung cancer is a rapidly fatal disease and therefore early detection is vital. Yet over a third (35%) of lung cancers are still diagnosed via emergency presentation, with figures varying across parts of the UK.³

Lung cancer screening

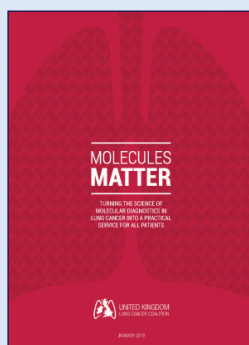
Since 2011, with publication of the National Lung Screening Trial results,⁴ the UKLCC and its members have been calling for the introduction of a lung cancer screening programme. Lung cancer screening will do more to improve lung cancer survival in the UK than any other single intervention. The UKLCC supported the roll-out of NHSE targeted lung health checks and called for the resumption of lung cancer screening programmes at the earliest opportunity after the pandemic.

Now, finally, the UK Government has approved the implementation of targeted screening among people aged 55 to 74 years with a history of smoking in England. Going forward, one of the UKLCC's key priorities will be to support colleagues across the UK to ensure that administrations in Scotland, Northern Ireland and Wales follow the lead of the UK Government by implementing their own national programmes. It will also monitor and evaluate implementation in England, especially against the backdrop of the current NHS workforce crisis, in particular, the shortage of thoracic radiologists.

Genomics and molecular diagnostics

Back in 2004, most clinicians were happy with a simple diagnosis of Non-Small Cell Lung Cancer (NSCLC) and did not quiz their

pathology colleagues too heavily about the sub type. With advances in the understanding of the cellular and molecular drivers of lung cancer, sub-typing and genomic testing are now a critical part of the lung cancer diagnostic and treatment pathway.



Molecules Matter Report

The increasing range - and complexity - of genomic tests for available systemic treatments provides new hope in delivering improvements in outcomes. Without them, lung cancer patients cannot access the innovative, personalised treatments which patients with actionable mutations might benefit from.

However, the genomic medicine service has been beset by problems – the biggest issue centering on testing turnaround times. In 2018, the UKLCC convened a group of highly qualified experts to define the issues and propose a set of actions in its report entitled '*Molecules Matter*' - to ensure that all lung cancer patients received timely access to all the pathological detail about their tumour. More recently, the UKLCC has engaged directly with the national clinical director and NHSE, calling for major improvements to the genomics testing services.

Public Awareness

The UKLCC has consistently campaigned to improve awareness of the early signs and symptoms of lung cancer. Public awareness initiatives are central to what has been described by the members of the lung community as a 'whole system response'. The UKLCC has called for public awareness and action campaigns which should be funded annually alongside regional and local campaigns to support improved understanding of signs and symptoms. It is also important that awareness programmes are targeted towards the characteristics and needs of local populations.

It was the UKLCC who brought the shelving of the Department of Health and Social Care's lung cancer public awareness initiative to the public's attention via an open letter published in *The Independent* newspaper which was followed by the immediate reinstatement of the national campaign.

In collaboration with its members, the UKLCC has surveyed patients and carers and clinicians on topics such as their diagnosis and care experience, and virtual consultations post COVID-19.

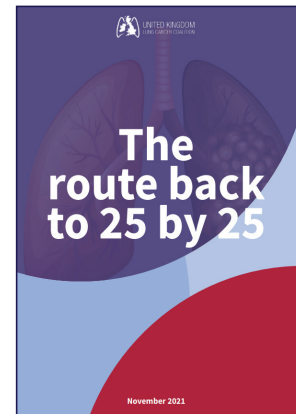
Clinical awareness

Improving clinical awareness around the symptoms of lung cancer and the timely referral of patients where there is any suspicion of lung cancer has been a key remit for the UKLCC. This has meant challenging preconceptions of lung cancer as an 'untreatable' disease and promoting the fact that early diagnosis really does make a difference in patients receiving treatments most likely to result in long term survival. Our report *'Millimetres Matter'* reviewed the evidence of the impact of delays in diagnosis, treatment and survival and highlighted the fact that a patient's prognosis can worsen significantly during the diagnostic testing process. It was the first report that clearly highlighted the difference between *early diagnosis and rapid diagnosis*.

The UKLCC has advocated closer working between primary and secondary care and recommended GP risk assessment tools and education programmes.

The UKLCC has presented its reports and recommendations at medical meetings across the UK, including the British Thoracic Oncology Group (BTOG), British Thoracic

Society (BTS), Lung Cancer Nursing UK (LCNUK) and the Oncology Forum – and taken numerous stands at conferences. In addition, it has presented posters and submitted abstracts to engage the clinical community. Following the publication of the *25 by 25* report, the UKLCC held a joint clinical meeting with Cancer Research UK (CRUK) in Manchester in 2018, entitled: *"Lung Cancer: the Ambition and case for change: Achieving 25% 5-Year Survival By 2025"* which was extremely well-attended.



25 by 25 Report

More **30 blogs** aimed at **clinicians, nurses, commissioners, and policymakers** including topics such as the RAPID Programme, NLCA, genomic hubs.

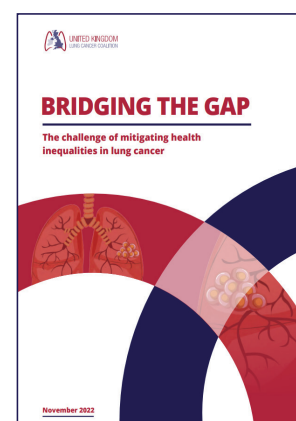
3. Health inequalities in Lung Cancer

The UKLCC's role was, and still is, to shine a light on inequalities in lung cancer care. Today, there are still too few patients undergoing potentially curative treatment and there are widely differing outcomes of care across the UK.

A quarter (25.3%) of people in England diagnosed with lung cancer in the least deprived group survive their disease for five years or more, compared with under a fifth (18.2%) of people in the most

deprived group (2016-2020).⁵

Almost 80% of lung cancer cases are potentially preventable. Addressing health inequalities successfully in lung cancer will have a huge impact on not only lung cancer



Bridging the Gap Report

outcomes but all UK cancer outcomes – thus helping the Government reach its Long-Term Plan target of diagnosing 75% of all cancers at stage 1 and 2 by 2028.

In 2022, the UKLCC published a report entitled: *'Bridging the Gap: the challenge of mitigating health inequalities in lung cancer'* which examined the challenge and scale of the problem and offered possible solutions for tackling a

broad range of disparities – including the NLCA collecting fuller data on inequalities such as ethnicity, and the introduction of a personal access card for patients. The report attracted a wide range of interest, especially from Integrated Care Boards across the country. Health inequalities will continue to be a key priority for the UKLCC going forward.

4. Research

Despite being the major cause of cancer death in the UK, when the UKLCC was formed lung cancer research received proportionately less funding than any other cancer type. The UKLCC has consistently called for greater investment into lung cancer research and we welcome the huge investment made, for example, by CRUK, which has tripled its lung cancer specific research spend over the last decade or so.⁶

The UKLCC continues to support cutting edge research into new targeted therapies. However, it is with great concern that the UKLCC heard of the closure of the National Cancer Research Institute and its lung cancer sub-group. We will continue to lobby for lung cancer to be kept as a priority for research funding in lung cancer and push for the development of a suitable body to replace the NCRI as a driver of high-quality multi-centre research in lung cancer.

Engaging with MPs and policymakers

The UKLCC has drafted and coordinated numerous open letters, and personal letters, to secretaries and ministers of state on topics such as screening, CRGs, genomic hubs, public awareness initiatives and published to urge action or inform of the challenges and issues facing UK lung cancer. Senior clinical members of the UKLCC have spoken at a number of parliamentary events.

The coalition has also disseminated numerous written briefings on key lung cancer issues, which have resulted in the tabling of 10 parliamentary questions and a Westminster Hall Debate. Ministers and other high-profile parliamentarians have commented on, or quoted, UKLCC reports and activities, following direct parliamentary engagement or high-profile media coverage generated e.g., the UK and Welsh Secretaries of State for Health.



The former Health Secretary quotes details of the UKLCC's COVID-19 Matters report on BBC Breakfast.

UKLCC has engaged directly with **over 100 MPs** across the **4 UK nations** via UKLCC events, **desk-side briefings**, and invitations to **All Party Parliamentary Groups**.

Engaging with the Media

UKLCC media activities have reached millions of readers, viewers and listeners and helped to raise public and political awareness of this devastating disease. The UKLCC has also commented publicly on third party announcements such as clinical trials (e.g., SUMMIT), Government initiatives and policy. While it is not UKLCC’s policy to comment directly on individual drug treatments under evaluation, we continue to push for the introduction of new equipment, technology, and better and more effective therapies to improve patient outcomes.

UKLCC campaigns and reports have generated over

350 items of coverage

in the national, medical, regional, and broadcast media.

Governance and Funding

The UKLCC has successfully worked and collaborated with a wide range of organisations which have shared its aims of improving the diagnosis, care, and treatment of people with lung cancer in the UK. These have included commercial companies and government - as well as other professional societies, research groups and charities.

The UKLCC receives sponsorship to support its activities. Our primary consideration in any collaboration with sponsors is ensuring that our independence is not in any way compromised and we are free to act in the best interests of healthcare professionals, the lung cancer community and people with lung cancer. The current sponsors, AstraZeneca, Bristol Myers Squibb, Eli Lilly, Janssen Cilag, MSD and Roche, have had no input into the production of this report and editorial control rests exclusively with UKLCC.



Widespread coverage in national, medical & regional media for the Route back to 25 by 25' Report



UKLCC Website homepage

In 2022-23 alone, UKLCC social and digital media activities received over 80,000 and 26,000 views respectively.

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3. National Lung Cancer Audit annual report 2022 (for the audit period 2019 England, Wales, and Guernsey and 2020 England only). Page 18. Access October 2023: <https://www.rcplondon.ac.uk/projects/outputs/nlca-annual-report-2022>
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6. Cancer Research UK Research Dept

All UKLCC reports can be accessed at www.uklcc.org.uk/our-reports

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Email: info@uklcc.org.uk Website: www.uklcc.org.uk

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