



UNITED KINGDOM
LUNG CANCER COALITION

The route back to 25 by 25

November 2021

Membership and acknowledgements

The UKLCC's Clinical Advisory Group (CAG) is a panel of senior clinicians, each representing particular specialities involved in the care of lung cancer patients, from the time of first suspicion of the diagnosis through to palliative care.

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The CAG is also supported by leading patient and clinical group members, including:

- ALK Positive UK
 - British Lung Foundation
 - British Thoracic Oncology Group
 - British Thoracic Society
 - Cancer Black Care
 - Cancer Research UK
 - EGFR Positive UK
- Macmillan Cancer Support
 - Lung Cancer Nursing UK
 - Primary Care Respiratory Society
 - Roy Castle Lung Cancer Foundation
 - Ruth Strauss Foundation
 - Tenovus Cancer Care
 - Yorkshire Cancer Research

About the UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) – the country's largest multi-interest group in lung cancer – is a coalition of the UK's leading lung cancer experts, senior NHS professionals, charities and healthcare companies.

Through our campaigning activity we aim to:

- **Raise political awareness of lung cancer**
- **Raise the general public's awareness of lung cancer – and especially encourage earlier presentation and symptom recognition**
- **Empower patients to take an active part in their care**
- **Improve lung cancer services**

CONTACT DETAILS

The UKLCC is keen to work with all interested organisations and bodies to improve the quality and outcomes of lung cancer treatment and care. For more information about our work and our partners, please visit our website or contact our secretariat. www.uklcc.org.uk

The UKLCC is grateful to its corporate members including Amgen Ltd, Boehringer Ingelheim Ltd, Bristol-Myers Squibb, Merck Sharp & Dohme (UK) Limited, Lilly UK and Janssen Oncology.

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COVID-19 has had a devastating impact on lung cancer

Professor Robert Rintoul, Chair, UKLCC Clinical Advisory Group and Martin Grange, Chair, UKLCC



Clinical Advisory Group

COVID-19 has had a devastating impact on lung cancer pathways, treatments and survival. Previous hard-won gains in improving outcomes are now in jeopardy with thousands of additional lung cancer deaths anticipated as a result the pandemic.

While this backwards step is one of the saddening legacies of the last 18 months, as a lung cancer community we believe that we must refocus our efforts – rather than simply return to pre-pandemic levels – and we must look to improve outcomes to be the best in Europe and the world.

This report is based on the outcomes of a meeting of the UKLCC's Clinical Advisory Group and follow-up interviews

with clinical leaders in each of the four UK nations. Unlike our previous report, COVID-19 Matters (Nov.2020), it looks beyond the impact of the first wave of the pandemic and provides a series of recommendations which offer a 'route-back' to delivering on our original 2016 survival ambition: to drive up five-year lung cancer survival to 25 percent by 2025.

As we await the results of the recent Health Select Committee and All-Party Parliamentary Group inquiries into cancer and lung cancer services respectively, we believe there is the political will to address unwarranted variations in lung cancer both across and within the UK nations. We believe that if the Government's levelling up

agenda was applied to lung cancer, then we would be seeing many more patients accessing potentially curative treatments - which would transform survival outcomes and move us closer to our ambition of '25 by 25'. We urge all those responsible for management of lung cancer, whether policy makers, commissioners or clinicians, to consider the issues and actions outlined in this report.

It has been heart-breaking to see the hard work and achievements of those involved in lung cancer care impacted so enormously by COVID-19. However, we must rally together and ensure that the pre-pandemic progress in lung cancer outcomes was not in vain. We can fix UK lung cancer.

Martin Grange

Robert Rintoul

Summary of recommendations

Recommendation - 1

The UK National Screening Committee should recommend the establishment of a UK-wide lung cancer screening programme at the earliest possible opportunity. This should include smoking cessation support where appropriate

Recommendation - 2

Public awareness campaigns focused on lung cancer should be funded to run at least twice a year to realise their full impact. National campaigns should be run alongside bespoke regional and local campaigns to support improved understanding of signs and symptoms and where appropriate should focus on driving uptake of lung health checks

Recommendation - 3

A dedicated lung cancer telephone helpline should be set up to ensure that people who are worried about the signs and symptoms of lung cancer, which are highlighted through awareness campaigns, have access to support. This would provide a friction free process for patients to access advice while ensuring that additional burden is not placed on primary care

Recommendation - 4

All organisations should achieve the National Lung Cancer Audit standard of 85% of lung cancer patients with early-stage disease (stage I-II) and good performance status (0-2) being offered curative treatment. Areas lagging behind should receive targeted support from the relevant national body to level up with the outcomes of the best performing areas

Recommendation - 5

Alongside surgery, the NHS should invest in Stereotactic Ablative Radiotherapy (SABR) to enable widespread access to curative treatments for lung cancer patients

Recommendation - 6

NICE and NHS England should assess and approve molecular biomarkers and their associated diagnostic tests regularly to keep pace with the emergence of novel targeted therapies

Recommendation - 7

For patients with advanced disease, real life survival data should be monitored to gauge how access to immunotherapy is impacting on survival outcomes

Recommendation - 8

In the short term, the Government should invest in the training and upskilling of existing support staff and assistant practitioners to enable them to do tasks which they otherwise wouldn't be able to do in order to free-up other team members to undertake more specialised tasks

Recommendation - 9

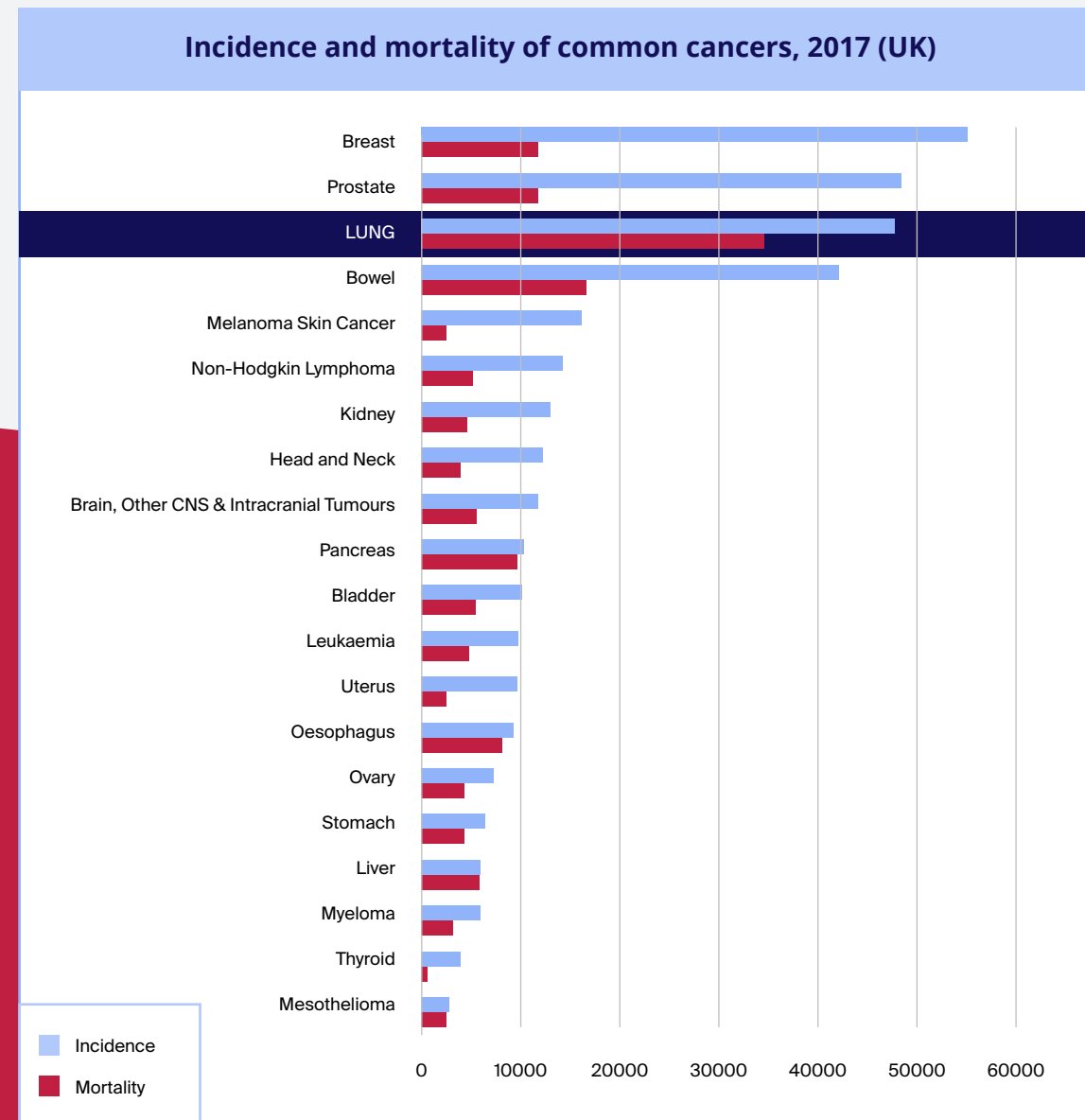
To address the workforce shortages, the Government should invest in all the disciplines of the lung cancer multi-disciplinary team, with targeted funding focused on training and research to ensure that lung cancer remains a dynamic field

Recommendation - 10

Work should be undertaken to determine how we can improve access to more near real-time data in lung cancer so that services can be monitored in a way that means action can be taken more quickly if data shows that key performance metrics are being missed

1. Introduction

Lung cancer has consistently been the UK's **biggest cancer killer**, accounting for 21% of all cancer deaths in 2018.



This equates to 35,100 lung cancer deaths in the UK every year, 96 every day¹. Despite improvements in treatment, lung cancer still has some of the worst outcomes of all cancers.²

Although outcomes have improved over the past decade, UK lung cancer survival rates continue to lag behind those of other European countries.³

This under performance on lung cancer outcomes is one of the reasons why lung cancer has been, and should continue to be, singled out by policymakers as crucial to efforts to improve overall performance on delivering world-class cancer outcomes.

Given the large numbers of patients, lung cancer has the potential to help achieve some of the most pressing policy ambitions of the day:

- **Lung cancer will significantly contribute to the Government's 'levelling up' agenda** – by ensuring that people who receive a diagnosis of lung cancer have outcomes which are pushed up to be in line with other cancers
- The *NHS Long Term Plan* for England has set an ambition of diagnosing 75% of all cancers at stage I or II, leading to 55,000 more people surviving cancer for five years or more each year, by 2028. **Lung cancer will have the biggest impact on this metric because it is the cancer with the largest percentage of diagnoses at stage III and beyond**
- One of the five 'tests' set out in The *NHS Long Term Plan* is 'The NHS will reduce unjustified variation in performance' – therefore, **focusing on unwarranted variations in access to curative treatment for lung cancer patients with stage I and II disease can help to achieve this test**

Since 2016, the UKLCC has been campaigning to raise lung cancer five-year survival rates to 25% by 2025 ('25 by 25'). Hard work from healthcare professionals, researchers, health service managers, policymakers, and governments of all four UK nations had made progress towards improvements across the whole lung cancer pathway, including:

INCREASING RATES OF SURGERY AND RADICAL RADIOTHERAPY FOR ELIGIBLE LUNG CANCER PATIENTS

NEW LUNG CANCER PATHWAYS BEING IMPLEMENTED IN ALL FOUR OF THE UK NATIONS

IMPLEMENTATION OF THE BAN ON SMOKING IN PUBLIC PLACES

RAPID DIAGNOSIS PATHWAYS BEING ESTABLISHED

PILOTING OF LUNG HEALTH CHECKS

ACCESS TO BIOMARKER TESTING AND PERSONALISED MEDICINES

This report sets out some of the key areas where the UKLCC believes urgent action needs to be taken to ensure that lung cancer outcomes continue on the pre-COVID trajectory of improvement.

2. Pre-pandemic progress & the subsequent impact of COVID-19

Lung cancer survival

Prior to the pandemic, good progress was being made in achieving the objective of raising five-year survival rates to 25% by 2025.

Five-year survival for lung cancer patients diagnosed between 2014 and 2018, followed up until 2019, stood at an estimated 17.6% in England.⁴

We know that stage of diagnosis is the most important factor in the prognosis of a patient. When diagnosed at its earliest stage, almost 9 in 10 (88%) people with lung cancer will survive their disease for one year or more, compared with around 1 in 5 (19%) people when the disease is diagnosed at the latest stage.¹ Data from the National Lung Cancer Audit (NLCA) found that in 2019 only 29% of lung cancers across England and Wales were diagnosed at stages I and II.⁵

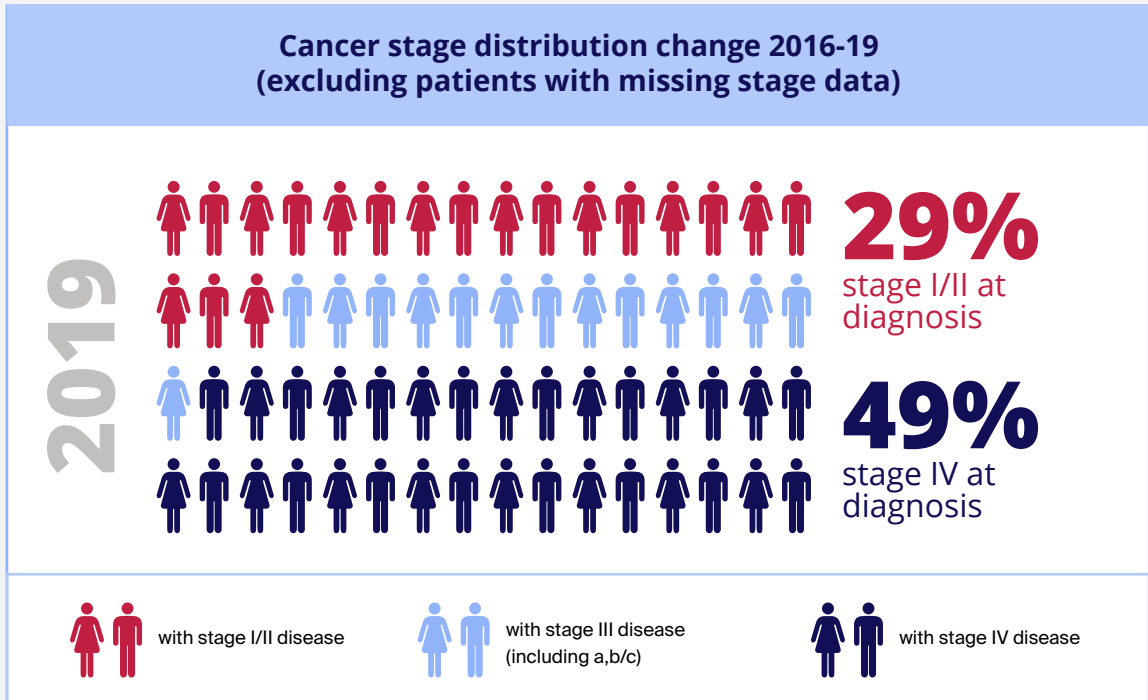
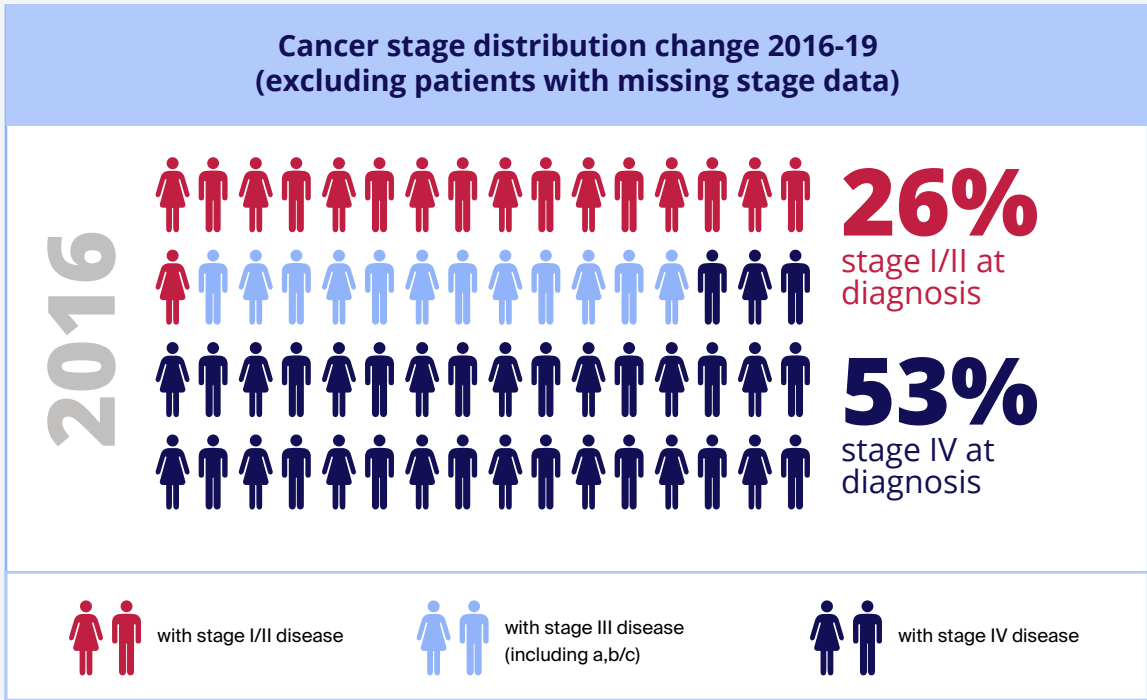
Comparing 2019 data with 2016, there has been an increase in diagnosis at stages I and II from 26% to 29% and a reduction in diagnosis at stage IV from 53% to 49%.⁵

Increasing diagnoses at the earliest stages of lung cancer and decreasing diagnoses at stages III and IV are important proxy indicators for improvements which signal that there should be an increase in five-year survival. However, it has been estimated that due to the delays in cancer diagnoses caused by the COVID-19 lockdowns in the UK alone, the increase in lung cancer deaths up to 5 years after diagnosis will be 4.8% - 5.3%.⁶ Therefore, it is even more important that the gains we have achieved over the three years prior to the pandemic are not only recovered but also accelerated.

The NLCA plan to publish their latest data in early 2022 revealing the effect of the pandemic has had on lung cancer. The UKLCC suspects that this will show that there has been an adverse impact on curative treatment rates for early-stage lung cancer. **We believe that the recommendations in this report provide clear solutions to improve lung cancer outcomes.**



Lung cancer five-year survival was 17.6% in England prior to the pandemic. It is estimated that the COVID-19 pandemic in the UK will increase lung cancer deaths up to 5 years after diagnosis by 4.8% - 5.3% "



Stage of diagnosis

In January 2019, the NHS set out challenging ambitions and commitments to improve cancer outcomes over the next ten years.

The NHS Long Term Plan for England has set a target of diagnosing 75% of all cancers at stage I or II, leading to 55,000 more people surviving cancer for five years or more each year, by 2028.⁷ We, as the UKLCC, support this ambition and call for at least 40% of lung cancers to be diagnosed at stage I or II by 2025 in order to reach five year survival of 25% as we previously set out to achieve.

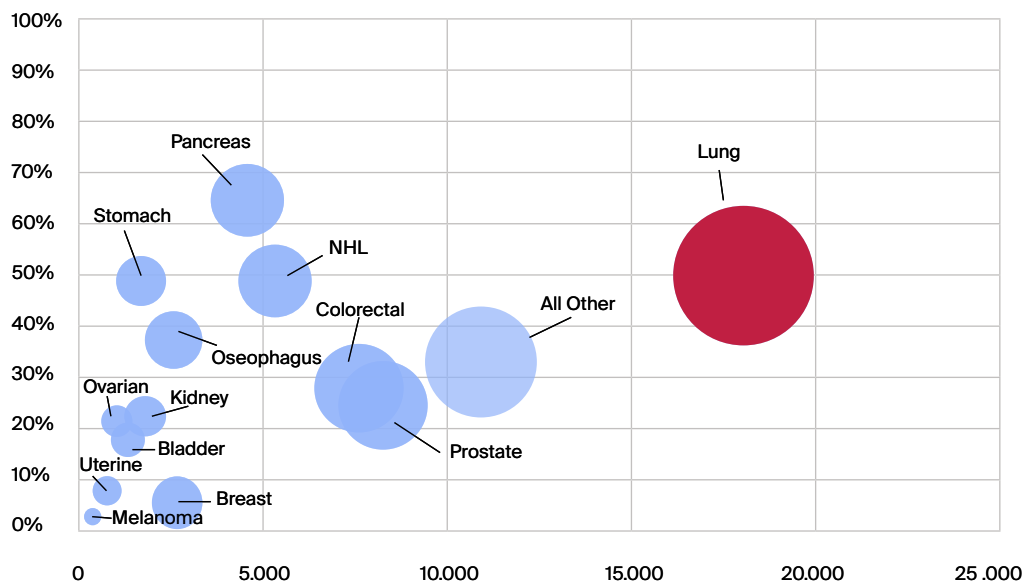


Lung cancer has the potential to be the key contributor to The NHS Long Term Plan commitment of diagnosing 75% of all cancers at stage I and II by 2028 ”

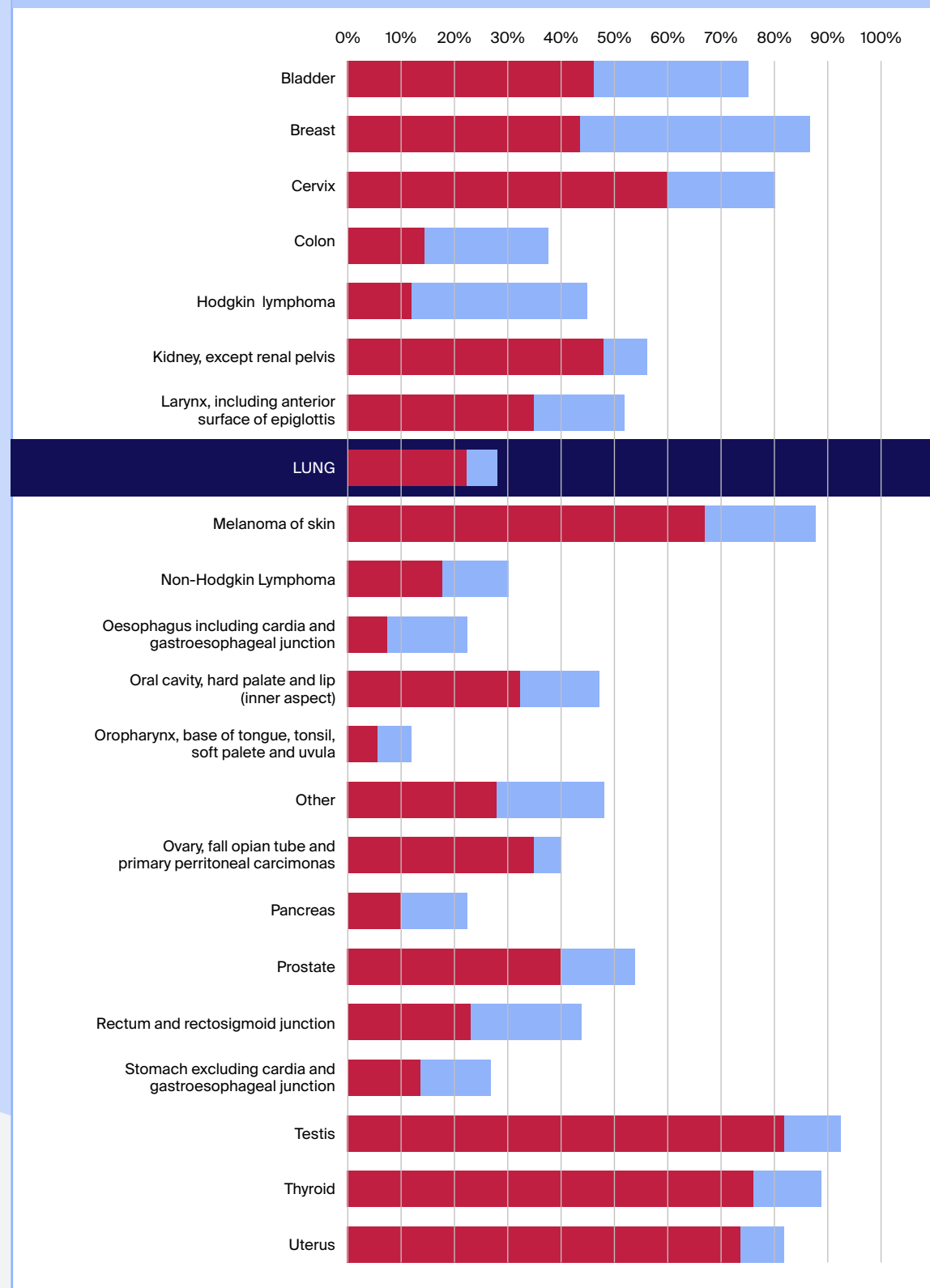
Lung cancer has the potential to be the key contributor to achieving this ambition, as it has a significantly greater number of people diagnosed at stage IV than any other cancer.

Making a major improvement in the early diagnosis of lung cancer will be a vital element in achieving many of the NHS’ ambitions with one cancer, given the high mortality rate.

Number and Proportion of Cancer Cases Diagnosed at Stage IV, ENGLAND 2017 ⁸



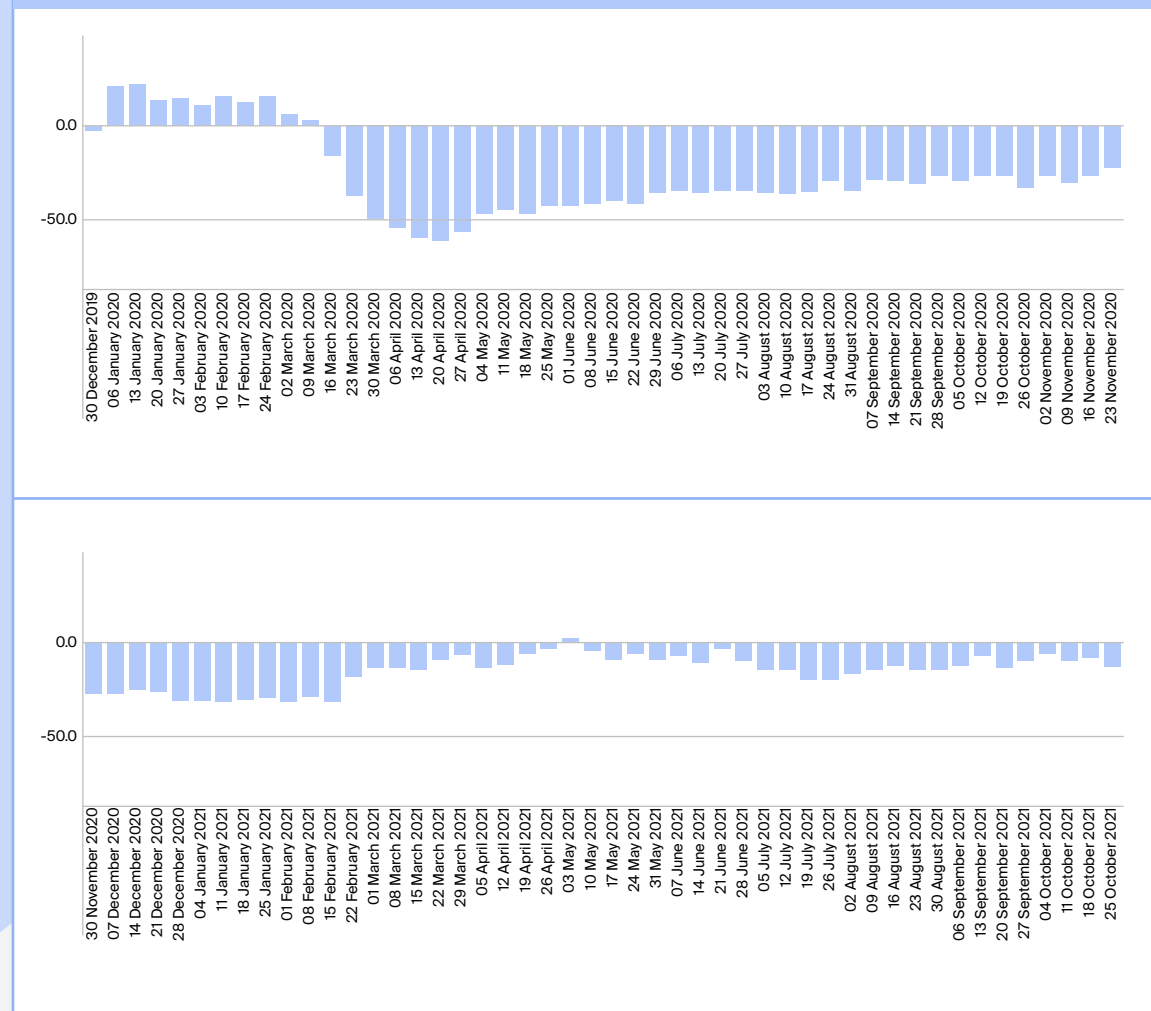
Percentage of stage I and II cancers diagnosed by cancer site in England, 2018⁹



However, COVID-19 has jeopardised achieving these ambitions, impacting the normal running of general practice and cancer services. During the first wave of the pandemic, many people with signs and symptoms of cancer were reluctant to seek medical advice,¹⁰ and as a result 40,000 fewer people started cancer treatment in 2020 across the UK.¹¹

Specifically in lung cancer, at the time of publication, urgent referrals are still being impacted, which may be in part because of the overlap of symptoms with COVID and lung cancer (cough, breathlessness and fatigue).

Lung cancer two week wait data - Percentage change of number of referrals from baseline *¹² (England only)



* Baseline is defined as the average number of referrals, bookings or appointment slot issues per week between 7 October and 29 December 2019. This period was chosen as it was unlikely to be affected by COVID-19

In England and Wales, urgent referrals for suspected lung cancer were 26% lower between March 2020 and August 2021 compared with the same months in 2019, which equates to around 25,900 fewer people being referred.¹³

In Scotland, 15% fewer patients started treatment for lung cancer following an urgent referral for suspected cancer between April 2020 and June 2021, compared with the same time-period in 2019.¹³

In Northern Ireland the number of patients starting treatment for lung cancer following an urgent referral between April and September 2020, compared with the same time-period in 2019, has fallen by 23.6%. This equates to 41 fewer people.¹⁴

As demonstrated above in the estimates of the impact of the pandemic on lung cancer survival, **reductions in referrals are leading to people receiving a delayed diagnosis. This leads to patients presenting with more advance disease as well as delays to treatment, both of which will have a significant impact on outcomes including one, three and five-year survival.**

3. Lung health checks and screening

Lung health checks were identified in *The NHS Long Term Plan* as key to meeting the ambition on early-stage diagnosis. Screening trials across the UK and Europe, including the NELSON Trial and UK Lung Cancer Screening Trial (UKLS), have demonstrated the value of proactively finding cases of lung cancer.

The NELSON Trial is a population based, randomised controlled trial initiated in 2000. The goal of the study was to assess the mortality reduction with volume-based, low-dose CT lung cancer screening in high-risk populations. The trial suggests a 24% lung cancer mortality reduction for men and 33% for women in comparison with no screening.¹⁵ Long-term results from the UKLS trial, although not statistically significant, have strengthened previous evidence from the NELSON trial by providing consistent and robust evidence on the reduction in lung cancer mortality with screening.¹⁶

Results from nine randomised controlled trials were included in the recent meta-analysis, which showed

that low-dose CT lung cancer screening was associated with a 16% relative reduction in lung cancer mortality when compared against a non-low dose CT control arm (RR 0.84 [0.76 – 0.92]).¹⁶

Together, these studies provide the evidence that a lung cancer screening programme is key to improving lung cancer outcomes.

Following initial success in pilot sites, NHS England introduced a scheme of 'lung health checks' in 2019, targeting those aged from 55-74 years with a smoking history. These pilots have added to the evidence base supporting the importance of lung cancer case finding through health checks or screening.



South Tyneside and Sunderland lung health check pilot¹⁷

South Tyneside and Sunderland introduced a primary care-based lung cancer targeted screening programme for those aged 55-74 years with a smoking history of more than 10 years.

Of the 2% (19 out of 925) of attendees who were discovered to have lung cancer, 66.7% had early-stage disease and 78.9% were offered treatment with curative intent.

When comparing the rates of lung cancer diagnosis before and after the implementation of the screening programme in South Tyneside and Sunderland, there was an evident rise in the percentage of stage I lung cancer detection and a fall in stage IV case. This demonstrates the role of targeted screening programmes in driving earlier diagnosis of lung cancer.



Greater Manchester lung health check pilot^{18,19}

In 2016, the University of Manchester NHS Foundation Trust introduced their lung cancer targeted screening programme for smokers and former smokers aged 55-80 years.

The results from the programme found that prior to the introduction of screening only 31% of patients were diagnosed at stage I and II. The post screening rates were 80.4% of stage I and II diagnoses. Of the patients identified to have lung cancer through the screening process, the surgical resection rate was 65% and treatment with curative intent was offered to 89.1%.¹⁹

As a result of the pandemic, the health check programme was temporarily paused which almost certainly played a role in the drop in referrals for diagnosis of suspected lung cancer.^{20,21} The NHS *Cancer Programme's Cancer services recovery plan*, published in December 2020, identifies restarting targeted lung health checks as one of the key elements in restarting activity from the *NHS Long Term Plan* that supports post COVID-19 recovery.²²

The lung health check programme has now resumed, but the speedy implementation of the lung health check programme is of vital importance to improve outcomes for lung cancer patients. The *Lung Health Check Wales – Scoping Report*²³ identifies a reduction in the prevalence of smoking and a screening programme as “the only strategies likely to lead to a significant reduction in lung cancer mortality”.

Variation between the four nations

In England, the lung health check programme has expanded from the original 10 sites established by NHS England in 2019 to 23 Clinical Commissioning Groups (CCGs) rolling out the programme in the second phase.

The footprint of lung health checks is now being expanded to 43 sites across all Cancer Alliances. This next phase of the lung health check programme is warmly welcomed, as it means that unwarranted variation in access to a lung health check in England will be improved.

In Scotland, the Scottish Government stated in Recovery and redesign: An action plan for cancer services²⁴ that:

“

We will appraise the options, opportunities, harms and benefits of targeted lung health checks in Scotland. This will begin with an exploratory piece of research by The University of Edinburgh to understand the feasibility of the introduction of lung health checks within Scotland ”

We understand that this piece of work is focussed on understanding barriers to screening uptake which are unique to Scotland, e.g., rurality, major socioeconomic gradients and lung cancer stigma. We hope that this will provide the evidence base to ensure that any lung cancer screening programme can be implemented effectively across the country.

The Lung Health Check Wales – Scoping Report²³ states:

“

The only strategies likely to lead to a significant reduction in lung cancer mortality are reducing the prevalence of smoking, and the introduction of a screening programme to detect more lung cancers at an early stage ”

The report recommends that given it is likely to be several years before a UK-wide screening programme is approved and implemented, it would be desirable for Wales to commence some pilot lung health check activity to prepare for the implementation of a future national programme. The Government are yet to agree to the establishment of lung health check pilots, but there are campaigns in support of such a programme. To date, at the time of publication, there has been no commitment from the Welsh Government to fund lung health checks.

Due to demographic differences the potential population in Wales who would be eligible for a lung health check, based on the NHS England programme over a two-year cycle is 25% higher in Wales than in England.²³

Northern Ireland is actively considering whether to roll-out a health check scheme, similar to the one running in England, from 2022. *The Cancer Recovery Plan 2021/22 – 23/24*²⁵ sets out the latest thinking on the implementation of lung health checks:

Year 1	Appraise the opportunities and benefits of targeted lung health checks elsewhere in the UK
Year 2	Commence development Targeted lung health checks for NI if recommended from year 1

Where you live in the four UK nations should not limit your chances of having lung cancer diagnosed at the earliest stage.

The need for a UK-wide national lung cancer screening programme

While the commitment to lung health checks is a welcome step in England, and the interest from the other nations is positive, this is not a replacement for a fully funded screening programme across all four nations of the UK. The high standards demanded of national screening programmes to ensure equitable access, clinical effectiveness and safety are not guaranteed via local programmes. A national lung cancer screening programme will maximise participation to ensure that everyone at a high risk of lung cancer is able to access the programme in all four of the UK nations.

One of the barriers to date for securing a UK-wide national screening programme is that a targeted screening programme would fall outside of the current remit of the National Screening Committee (NSC), which focuses on population-wide screening programmes. In October 2019, an

independent review of adult screening programmes in England was published.²⁶ The report recommended that a single advisory body be established, bringing together the functions of the NSC on population-based screening and NICE on targeted screening. This recommendation was accepted by Matt Hancock, then Secretary of State for Health and Social Care. It is currently uncertain whether this will be achieved by extending the remit of the NSC or by forming an entirely new body, but it is positive that the barrier of who would commission a lung screening programme is being tackled.

We believe that the roll-out of a full lung cancer screening programme across all four nations will do more to improve lung cancer survival than any other single intervention. Where appropriate, this should include smoking cessation support.

Recommendation - 1

The UK National Screening Committee should recommend the establishment of a **UK-wide** lung cancer screening programme at the earliest possible opportunity. This should include smoking cessation support where appropriate

4. Public awareness campaigns and easy access to diagnosis

Lack of awareness among patients and the public of the signs of lung cancer and when to see their doctor is still a significant barrier to earlier diagnosis.

This has been exacerbated by the pandemic given the similarities in symptoms between lung cancer and COVID-19, and because of the Government's messaging to "stay at home" when the pandemic began. Cancer Research UK found that a reluctance to attend hospital tests and come forward about symptoms could be contributing to the significant drop in lung cancer diagnoses. In England and Wales, urgent referrals for suspected lung cancer were 26% lower between March 2020 and August 2021 compared with the same months in 2019, which equates to around 25,900 fewer people being referred, with similar trends in Scotland¹³ and Northern Ireland.²⁷ Public awareness campaigns play an extremely important role in getting people with suspected lung cancer into services.



Be Clear on Cancer, Public Health England

The Be Clear on Cancer campaigns, aiming to encourage more people to recognise symptoms that might be an early indication of cancer and to see their GP sooner, were first commissioned in 2012.

One study examined the impact of one regional and one national large-scale intervention on raising public awareness using persistent cough as the target symptom. Amongst its findings was that there was a 31.8% increase in urgent GP referrals for suspected lung cancer during the campaign period, adjusted for working days. There was also a shift towards more patients being diagnosed at an earlier stage and more patients being treated.²⁸

The first major lung cancer 'Be Clear on Cancer' campaign was regional, running in the East and West Midlands in 2011 and (as has been the case for all subsequent campaigns) was targeted at people over the age of 50 and those in lower socioeconomic groupings. This campaign was the most effective of all four of the national campaigns and had the highest level of advertising spend per head of population reached. There is, however, evidence that the impact of such campaigns can lessen with time, with much less clear impact being seen in the latter two national campaigns. Part of the reason for this may have been reduced levels of media activity in the later campaigns.



Detect Cancer Earlier Programme, Scottish Government

Recovery and Redesign included the pledge that an additional £500,000 would be invested in developing a lung cancer awareness campaign as part of the Detect Cancer Earlier Programme. This awareness campaign ran across Q2 2021 highlighting the importance of early detection and prompting people with potential symptoms to seek help as early as possible.

Although there have been good examples of awareness campaigns that have been run in England and Scotland with promising results, there must be ongoing and sustained investment in lung cancer awareness campaigns.

In Wales, campaigns to raise awareness of the symptoms of lung cancer have been undertaken but have had little impact on outcomes.²⁹ This was based on a small scale, limited public awareness campaign, so further investigation into the value of this type

of campaign in Wales would be useful. A key learning from the work in Wales is that it is critical that public awareness campaigns are targeted at the specific population they are designed for.

In Northern Ireland, historically there have been no public awareness campaigns for lung cancer. It is good that the *Cancer Recovery Plan*³⁰ includes public awareness campaigns in its list of actions, but there is a need to ensure that they include lung cancer:

Year 1

- Digital/Press and pharmacy campaign to encourage those with worrying signs and symptoms to contact GP
- Strategic development and research for early detection public awareness campaign.

Year 2

- Deliver phase 1 of Detect Early/Be cancer aware campaign

Year 3

- Deliver phase 2 of Detect Early /Be Cancer Aware Campaign.

Public awareness campaigns, in light of COVID-19

It is important that awareness campaigns remain targeted and relevant to the external environment. For example, in the last year we have seen the introduction of high-profile campaigns which aim to address getting people with suspected lung cancer back into healthcare services.



'DO IT FOR YOURSELF'

MSD UK and leading cancer charities

The *Do It For Yourself* campaign was launched in December 2020 by MSD UK in collaboration with leading cancer charities including the Roy Castle Lung Foundation, Mesothelioma UK, Northern Cancer Alliance, Greater Manchester Cancer Alliance and Cancer Research UK.

The campaign was launched in response to the drop in the number of people with lung cancer symptoms presenting to healthcare services because of the COVID-19 pandemic.



'HELP US HELP YOU CAMPAIGN'

NHS England

In February – May 2021 the *Help Us Help You* campaign in England focussed on lung cancer. The aim of the campaign was to raise awareness of the key symptom of lung cancer – a cough which lasts more than three weeks. While this was an important campaign it is crucial that this is extended into a longer-term awareness campaign which goes beyond only highlighting cough as a reason to see a GP.



'GET CHECKED EARLY'

NHS Scotland and Scottish Government

Get Checked Early was introduced in Scotland in May 2021, focused on driving earlier detection of all cancers, in particular lung cancer. <https://www.getcheckedearly.org/lung-cancer>

The campaign was developed in response to the reduction in the number of people being diagnosed with lung cancer during the COVID-19 pandemic encouraging people to go and get checked. We look forward to seeing the impact of these campaigns in the coming years.

In light of COVID-19 and its impact on people presenting to health services, we need urgent action to address public awareness of lung cancer. However, while raising awareness of signs and symptoms of lung cancer is of critical importance to diagnose more lung cancers earlier, it is critical that people who think they need to seek advice based on an awareness campaign have somewhere to go. This additional burden shouldn't simply fall on general practice who are already stretched. It is essential that we explore new ways to make it easier for patients to be correctly triaged and get more direct access to diagnostic imaging tests, particularly around the time of awareness campaigns.

There are a number of different models which could be explored including ensuring that a process is in place

through individual GP practices or through Integrated Care Systems to deal with additional capacity demands created by awareness campaigns. This could also be coordinated through cancer diagnosis centres (CDCs). An additional approach, which the UKLCC is extremely supportive of, is the establishment of a direct telephone triage helpline for people who are worried that they have symptoms of lung cancer providing a friction free process for patients to access advice. This dedicated telephone helpline could link people direct to triage if necessary and then enabling direct access into diagnostic imaging tests.

Aligning awareness and access is a critical feature which will help to support all of the other initiatives which help facilitate early diagnosis.

Recommendation - 2

Public awareness campaigns focused on lung cancer should be funded to run at least twice a year to realise their full impact. National campaigns should be run alongside bespoke regional and local campaigns to support improved understanding of signs and symptoms and where appropriate should focus on driving uptake of lung health checks

Recommendation - 3

A dedicated lung cancer telephone helpline should be set up to ensure that people who are worried about the signs and symptoms of lung cancer, which are highlighted through awareness campaigns, have access to support. This would provide a friction free process for patients to access advice while ensuring that additional burden is not placed on primary care

5. Reducing variation in access to treatment – levelling up

Access to curative treatment – surgery

Beyond late diagnosis, geographical variations within the UK – particularly access to curative treatment – is a key contributing factor in poor lung cancer survival rates.

For example, studies have found that a person can be up to 51% more likely to receive thoracic surgery for lung cancer if they are first diagnosed in a thoracic surgical centre.^{32,33}

The National Lung Cancer Audit (NLCA) collects data on curative treatment rates. These rates have been steadily improving but in many parts of the country are much lower than they could and should be. In the latest edition of the NLCA (published March 2021 for the audit period 2018), 81% of patients with early-stage disease (stage I-II) and good performance status (0-2) received treatment with curative intent.⁵ This was the same result as the 2017 cohort. While this achieves the NLCA audit target of 80%, it still means that one in five such patients did not receive treatment with curative intent, which is not good enough given the need to diagnose more patients at this stage of disease.

Beyond these headline numbers, there is huge variation across England. NLCA data shows that treatment with curative intent, which captures surgery and radical radiotherapy, varied between 55% and 100%. In total 59 organisations failed to meet the audit target of 80%.⁵ While some variation is inevitable, more needs to be done to ensure that there is a consistent and better service offer across the country regardless of where a patient is diagnosed and treated for lung cancer. This is an unwarranted variation which needs to be addressed to improve outcomes for people regardless of where they live.

A new standard of 85% has been set by the NLCA for the next round of the audit, demonstrating that more needs to be done in this area.⁵ While it is understandable that the NLCA will increase the standard in an incremental fashion to support centres who are not yet achieving the previous standard, there is no reason why all centres should not be aiming for 90-95% on this metric.

“

Areas lagging behind on curative treatment targets should receive targeted support from the relevant national body to level-up with outcomes of the best performing areas ”

As a result, NICE added a new statement to Quality Standard 17 – Lung cancer in adults in 2019 – *“Adults with non-small-cell lung cancer stage I or II and good performance status have treatment with curative intent.”*³⁴

The NLCA has also published a toolkit to support MDTs who are not achieving the standard to review their processes for selection of patients for curative treatment in order to help them meet the new 85% standard.⁵

One of the five ‘tests’ set out in the NHS Long Term Plan is: *“The NHS will reduce unjustified variation in performance”*.⁷ Tackling geographical variation in treatment with curative intent would be a relatively easy way to deliver against this ‘test’ and improve the outcomes of many people with lung cancer. We need to ensure that those areas that are still lagging behind are supported to level up with the outcomes of the best performing areas.

Recommendation - 4

All organisations should achieve the National Lung Cancer Audit standard of 85% of lung cancer patients with early-stage disease (stage I-II) and good performance status (0-2) being offered curative treatment. Areas lagging behind should receive targeted support from the relevant national body to level up with the outcomes of the best performing areas

Access to curative treatment – SABR

We need to invest in curative treatment options for those patients who are not suitable for surgery.

The doubling of five-year survival in previous years was no doubt in large part due to an increase in surgical resection rates – but we now need to think ahead to the other treatments that can support us in driving further improvements in survival. In particular, we need to invest in curative treatment options for those patients who are not suitable for surgery.

Stereotactic Ablative Radiotherapy (SABR) – a technique to give high dose radiotherapy to a small portion of the lung – has been found to be as effective at curing or controlling early lung cancer as surgery.³⁵

In 2020, NHS England stated that SABR should be rolled out to all English radiotherapy centres by April 2021 for non-small cell lung cancer.³⁶ This roll out programme was accelerated during the pandemic as a result of the benefits

the treatment offered in reducing the number of hospital visits that vulnerable cancer patients would need to make. While this is a welcome move from NHS England, we need to ensure that similar access is offered across all UK nations.

In Wales SABR is only available at a single site, the Velindre Cancer Centre in Cardiff. Patients in North Wales who need to be treated with SABR are referred to Clatterbridge Cancer Centre in the Wirral. This means that there can be lengthy travel times for people in Wales to access both of these sites. Plans for local SABR services in Wales are in development.

In Scotland access to SABR and trials remain unequitable, with particular challenges relating to travel time for patients in the north of Scotland and rural communities.

Recommendation - 5

Alongside surgery, the NHS should invest in Stereotactic Ablative Radiotherapy (SABR) to enable widespread access to curative treatments for lung cancer patients

Access to treatments for advanced stage disease

- supporting the patients of today

We need to be realistic in our ambitions and acknowledge that we cannot cure all people living with lung cancer. However, based on major advances in the treatment of advanced disease, we are at a turning point with the treatment for lung cancer and we are beginning to see the first lung cancer patients who could call their condition a 'chronic disease', in other words living for several years with 'controlled' rather than 'cured' disease.

The use of immunotherapy is beginning to have a major impact for some lung cancer patients with advanced disease. Evidence from trials suggests that patients with advanced disease can survive 2-5 years or more with these types of treatments.³⁷ In addition, there is no doubt that the introduction of molecular targeted therapies has revolutionised the treatment of advanced lung cancer for some patients. These are huge steps forward for patients diagnosed with advanced stage disease who might previously have had a prognosis of a few months only. Numerically, advanced disease represents the largest group of lung cancer patients and therefore we

must not forget that there needs to be constant development in treatment and care for patients with advanced disease.

There is an imperative for lung cancer pathways to keep pace with the science, so that each patient is offered appropriate testing and can have the personalised treatment which their clinician thinks is best for them.

One of the potential barriers to patients having rapid access to medicines which require pathology or molecular diagnostics is that the National Genomic Test Directory is only reviewed annually. If this rigid review system remains in place, a medicine approved by NICE could have to wait up to a year to have its diagnostic test added to the Test Directory. This means that it would not be possible to make such medicines available to patients within the required standard timeframe of three months following NICE approval. We must ensure that steps are put in place to ensure that pathology and molecular diagnostics services are able to keep up and align with the changing treatment landscape.

Recommendation - 6

NICE and NHS England should assess and approve molecular biomarkers and their associated diagnostic tests regularly to keep pace with the emergence of novel targeted therapies

We know that cancer medicines are often used in advanced cancer patients and if proven to be effective, are licensed for earlier stage disease. Therefore, monitoring the impact of immunotherapies and molecular targeted therapies on lung cancer patients diagnosed with advanced disease will provide insights into how this could improve outcomes when immunotherapy becomes available for patients with earlier stage disease. Intermediate survival measures in people with advanced lung cancer often present trends in longer term survival.

Recommendation - 7

For patients with advanced disease real-life, survival data should be monitored to gauge how access to immunotherapy is impacting on survival outcomes



6. Other threats to achieving the 25 by 25 ambition

Workforce

The UK cancer workforce plays a vital role in fulfilling survival ambitions for lung cancer.

Yet without investment to address workforce shortages, these ambitions cannot be met. Workforce shortages across the entire pathway are a major limiting factor in improving lung cancer outcomes.

To ensure that we have an optimal lung cancer workforce the Lung Cancer Service Specification sets out how much specialist clinical capacity a Trust should have to look after their lung cancer patients. This specifies both the amount of time and the level of expertise / specialism a lung cancer clinician should have based on what proportion of their role is focused on lung cancer. Compliance with this standard was measured in the National Lung Cancer Audit – Organisational Audit Report ³⁸ to see how many Trusts are achieving the standards. Unsurprisingly, the results demonstrate that more work needs to be done to ensure that we have an optimal workforce across the country.

Overall, only 5% (8% in 2017) of sites had adequate levels of specialist staffing across all of respiratory medicine, medical/clinical oncology, radiology and specialist nursing. ⁴⁰

Recommendation	2019%	2017%
10 programmed activities respiratory physician for direct clinical care per 200 new diagnoses per year	16%	61%*
Radiologist with at least 1/3 of their job plan devoted to lung cancer	65%	83%
Medical oncologist with at least 1/3 of their job plan devoted to lung cancer	74%	60%
Clinical oncologist with at least 1/3 of their job plan devoted to lung cancer	83%	70%
1 whole time equivalent lung cancer nurse specialist per 80 new diagnoses per year	32%	19%

There is also significant variability across the UK. According to the Royal College of Radiologists UK Clinical Oncology workforce census 2020, whilst a quarter of cancer centres reported annual workforce growth of 6% or more per year over the last 12 years, one quarter reported no gain or a decline in their consultant workforce. ³⁹ Unfortunately, this workforce shortage is likely to be exacerbated because of COVID-19.

*In 2017 the survey asked for the number of WTE respiratory physicians who were involved in lung cancer care, whereas in 2019, the survey asked for the total number of direct clinical care sessions provided by these physicians (to enable closer alignment with the commissioning guidance). The result for 2019 (16%) reflects a much more accurate evaluation of respiratory physician staffing levels, while any deterioration in staffing levels should not be concluded

We need urgent action to identify efficient ways to provide quality care for those living with lung cancer today.

In addition, it is essential that we retain and invest in staff for the future to ensure trusts are able to meet the specialist staff levels outlined in the Lung Cancer Service Specification. All four governments of the UK need to recognise lung cancer as a priority area. Being a priority area will help with staff recruitment and retention.

Recommendation - 8

In the short term, governments should invest in the training and upskilling of existing support staff and assistant practitioners to enable them to do tasks which they otherwise wouldn't be able to do in order to free-up other team members to undertake more specialised tasks

Recommendation - 9

To address the workforce shortages, the Government should invest in all the disciplines of the lung cancer multi-disciplinary team, with targeted funding focused on training and research to ensure that lung cancer remains a dynamic field

Access to near real time data

Lung cancer is edging towards becoming a chronic disease and it is our ambition that the prognosis for people with lung cancer is greatly improved as we focus on improving early diagnosis and long-term treatments. This will ultimately have a positive impact on survival. One of the challenges in assessing improvements in cancer generally and lung cancer specifically is that it takes a long time to get data to measure long term survival. Historically there has been a lag in access to data for patient outcomes of about one to two years, meaning that critical time can be lost in making service improvement if we have to wait for data to become available to inform decision making.

It is extremely welcome that Northern Ireland are now able to contribute data to the National Lung Cancer Audit. This will help to ensure that data are collected and analysed in a standard way in England, Wales and Northern Ireland.

Recommendation - 10

Work should be undertaken to determine how we can improve access to more immediate real-time data in lung cancer so that services can be monitored in a way that means action can be taken more quickly if data shows that key performance metrics are being missed

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