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# EARLY DIAGNOSIS MATTERS

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MAKING THE CASE FOR THE EARLY  
AND RAPID DIAGNOSIS OF  
LUNG CANCER



UNITED KINGDOM  
LUNG CANCER COALITION

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## 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.

The members of the group are:

**Dr Andrew Wilcock**

Clinical Reader in Palliative Medicine and Medical Oncology, Nottingham University Hospitals NHS Trust

**Ms Carol Stonham**

MBE – Nurse Practitioner, NHS Gloucestershire CCG

**Dr Ian Williamson**

Consultant Respiratory Physician, Assistant Medical Director for Cancer Services, Aneurin Bevan University Health Board

**Dr Jason Lester**

Consultant Clinical Oncologist, Velindre Cancer Centre

**Professor Keith Kerr**

Consultant Pathologist, Aberdeen Royal Infirmary

**Ms Lavinia Magee**

Nurse Consultant, Thoracic Oncology, Papworth Hospital NHS Foundation Trust

**Professor Michael Lind**

Professor of Medical Oncology, University of Hull

**Dr Michael Snee**

Consultant Clinical Oncologist, Leeds Teaching Hospitals NHS Trust

**Professor Mick Peake (Chair)**

Clinical Director, Centre for Cancer Outcomes, Cancer Collaborative, UCLH; Emeritus Consultant and Honorary Professor of Respiratory Medicine, University of Leicester; Honorary Clinical Lead, National Cancer Registration and Analysis Service (NCRAS), Public Health England

**Mr Naidu Babu**

Consultant Thoracic Surgeon, Birmingham Heartlands Hospital

**Mr Richard Steyn**

Consultant Thoracic Surgeon; Deputy Medical Director, University Hospitals Birmingham NHS Foundation Trust; Honorary Associate Professor, University of Warwick and Chair of the UKLCC

**Dr Robert Rintoul**

Consultant Chest Physician, Department of Thoracic Oncology, Papworth Hospital NHS Foundation Trust

**Dr Steve Holmes**

General Practitioner, The Park Medical Practice, Shepton Mallet, Somerset

**Dr Wendy Anderson**

Consultant Respiratory Physician, Antrim; Northern Ireland Lung Cancer Co-Lead

**Miss Juliet King**

Consultant Thoracic Surgeon and Clinical Lead, Thoracic Surgery, Guys and St Thomas' NHS Foundation Trust

**Mr Doug West**

Consultant Thoracic Surgeon, University Hospitals Bristol NHS Foundation Trust

**Professor Denis Talbot**

Professor of Cancer Medicine and Consultant in Medical Oncology, Oxford University

**Dr Ian Woolhouse**

Consultant Respiratory Physician, University Hospitals of Birmingham NHS Foundation Trust

**Mr Martin Grange**

Patient representative, and member of the Lung Cancer Screening Advisory Group

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

- **British Lung Foundation**
- **British Thoracic Oncology Group**
- **British Thoracic Society**
- **Cancer Black Care**
- **Cancer Research UK**
- **Macmillan Cancer Support**
- **Lung Cancer Nursing UK**
- **Primary Care Respiratory Society**
- **Roy Castle Lung Cancer Foundation**
- **Tenovus Cancer Care**

## 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](http://www.uklcc.org.uk)

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## FOREWORD

The fact that – despite major advances in treatment and the quality of care are now available to lung cancer patients, the long-term prognosis remains poor for most of them – is well rehearsed. This is in contrast to a number of other cancers where significantly greater progress has been seen. The single most important reason for this is that, by the time patients are diagnosed, well over half of them have what is, using current technologies, essentially incurable disease. Hence the vital importance of efforts to diagnose more patients at a stage where potentially curative treatment is possible. In particular, it is a travesty that 'emergency presentation' is the most common route to diagnosing lung cancer when we know that patients diagnosed by that route are over five times as likely to be dead one year after diagnosis than those referred by their GP.

The fact that the UK diagnoses a smaller proportion of patients at an early stage of their disease than in a number of other comparable countries, is one of significant reasons why UK survival rates fall well below the best internationally.

In November 2018, the UK Lung Cancer Coalition (UKLCC) – with much-valued sponsorship from Cancer Research UK (CRUK) – convened a workshop focused on 'Making the case for the early and rapid diagnosis of lung cancer'. The workshop brought together key voices from across the cancer community to look at the evidence in this area and to better understand the effectiveness of interventions already tested aimed at tackling both the late and slow diagnosis of lung cancer.

This report explores the issues which were discussed at the meeting, as well as looking at the wider picture for earlier diagnosis in lung cancer and collating examples of best practice initiatives to prompt the development of innovative ways of achieving earlier and faster diagnosis.

If you are working in the any part of the health system, I hope that this report will inspire you to consider what concrete actions you can try to implement in your own area to support the earlier diagnosis of lung cancer. If, on the other hand, you are an advocate for improvements in healthcare, the detail in this report will hopefully encourage you to consider what changes need to be made to help bring lung cancer outcomes in the UK into line with its European and other international counterparts.

It is important to remember that there is no single 'silver bullet' when it comes to increasing rates of early diagnosis in lung cancer. Only through consistent, wide ranging and coordinated efforts from across the community can we see a difference in the outcomes achieved across the UK.

We need to act collectively and rapidly on these opportunities, working to give lung cancer patients across the UK the best chance of surviving this very common condition.

**Professor Mick Peake**  
*Chair, Clinical Advisory Group,  
UK Lung Cancer Coalition*

# INTRODUCTION

In 2016 the UK Lung Cancer Coalition (UKLCC) set an ambition for five-year lung cancer survival to be 25% by 2025. This was subsequently supported by the governments of each of the four UK nations.

Achieving this target would deliver much-needed improvements in care for those with lung cancer. However, making this happen isn't going to be easy and will require coordinated activity from everyone within the lung cancer community.

**Achieving the early diagnosis of lung cancer in a higher proportion of patients is a key enabler of meeting this ambition and improving survival. As such, the UKLCC workshop – with sponsorship from Cancer Research UK (CRUK) – brought together leaders in early diagnosis and lung cancer to:**

- Review the evidence relating to the late diagnosis of lung cancer
- Better understand the effectiveness of already tested interventions aimed at tackling both the late and slow diagnosis of lung cancer
- Share examples of good practice in this clinical area and to determine how best to spread and embed best practice to increase early diagnosis

Rather than present a formal written summary of that workshop, this report aims to distil the main issues and define some recommendations for future clinical and political action needed to make progress in this vital area of cancer care and outcomes. The workshop programme and a link to access the slides presented there are shown in the appendix. We would like to acknowledge and thank all those who contributed to that workshop for their freely given time and expertise, including our colleagues at CRUK.

The opportunity to improve survival through early diagnosis is clear. But to make improvements in this area there is an imperative to take action now, because progress to date on improving lung cancer outcomes has been desperately slow.

Much of what is discussed here is set in the context of policies of the English government and therefore of less direct relevance to the devolved nations of the UK, but similar principles will apply whatever the political context and some issues specific to the devolved nations are discussed later in this report.

The NHS Long Term Plan for England has set an ambition of diagnosing 75% of all cancers at stage I or II by 2028. In order to achieve this, making a major improvement in the early diagnosis of lung cancer will be a vital element.

The majority of lung cancer patients are diagnosed at a late stage of the disease. But we know that to make a significant impact on problems such as this requires transformative action and everyone with a stake in the lung cancer community – from national policy-makers and charities to local system leaders, academia and clinicians - must ensure that there is greater focus on improving the early diagnosis of lung cancer because it is so critical to improving patient outcomes.

What stood out from discussions at the workshop was the extent to which a real shift in lung cancer outcomes will only be possible through a whole-community effort. This report looks at various issues which were explored at the workshop – from awareness campaigns to the aim of establishing a national screening programme and improving primary care access to diagnostic tests.

The evidence base for action and the political will are both growing, so there is a huge opportunity to push forward on a range of fronts to improve outcomes. These are exciting times for the lung cancer community and for the patients we serve.

## EARLY DIAGNOSIS IN LUNG CANCER: A POLITICAL CALL TO ACTION

Lung cancer is still the most common cause of cancer death in the UK, accounting for 21% of all cancer deaths in 2016.<sup>1</sup> This is despite improvements in rates of surgery and systemic anti-cancer treatment in recent years.<sup>2</sup> Worryingly, the latest findings from the National Lung Cancer Audit report identified that only 37% of lung cancer patients will survive for one-year, which is unchanged from the previous year.<sup>2</sup> The most recent five-year net survival figures from the Office for National Statistics<sup>3</sup> for men and women in England diagnosed in 2012 (followed up to 2018) were 14% and 19% respectively. However, the most recent publication by the International Cancer Benchmarking Partnership (ICBP) showed the UK still had the lowest 5-year survival compared with the six other comparator countries.<sup>4</sup>

We also know that lung cancer disproportionately affects people living in socioeconomically deprived communities and, with these groups often being harder to engage, there are inequalities in outcomes across the UK.

Historically, lung cancer has been a condition with a low profile and less clinical, research and political interest than some other forms of cancer. However, as the evidence base for action accumulates, we need to capitalise on the increasing focus to make a real difference for lung cancer patients.

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### DIAGNOSIS AT STAGE I AND II

Diagnosing lung cancer at an early stage can lead to more treatment options and better outcomes for patients. Data for patients diagnosed in England between 2013 and 2017 show that 88% of lung cancer patients will survive for at least a year if diagnosed at stage 1 compared to 19% for people diagnosed with the most advanced stage of disease.<sup>3</sup>

Data from the National Lung Cancer Audit on the stage of diagnosis in England and Wales in 2017 showed that 57% of patients had stage IIIB or IV lung cancer at the point of presentation.<sup>5</sup> At this stage of disease progression, the cancer becomes harder to treat and patient outcomes are therefore a great deal poorer than when the disease is diagnosed at stage I or II.

## INTERNATIONAL COMPARISONS

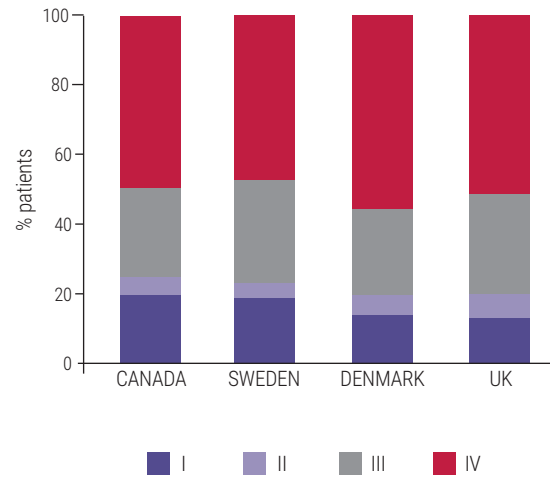
Beyond the regional variation which exists in the UK, we know that many other countries are performing better than the UK in diagnosing more lung cancers at an earlier stage – it is possible for us to improve early diagnosis.

As shown in figure 1, a study looking at the stage distribution between ICBP nations found that Canada is diagnosing just over 20% of patients at stage I, compared to the UK where only 13.5% of lung cancers were diagnosed at the earliest stage.<sup>6</sup> We also know that the mortality rate for lung cancer in the UK is the 11th highest in Europe.<sup>7</sup>

Similarly, in a study of patients aged 66 and over between 2008 and 2012, 30% were diagnosed at stages I & II in the USA, compared to 23% of patients in England<sup>8</sup> - more evidence that improving early diagnosis rates is possible.

Over the years, significant efforts have been made to improve the early diagnosis of lung cancer. Although the above data demonstrates that we are still a long way from routinely detecting and diagnosing the disease at a stage where curative treatment is more likely, there are some promising signs for the future.

**Figure 1: Stage at diagnosis for Non-Small Cell Lung Cancer patients by country between 2004-2007**  
Walters, et al. Thorax, 2013;68:551-5647

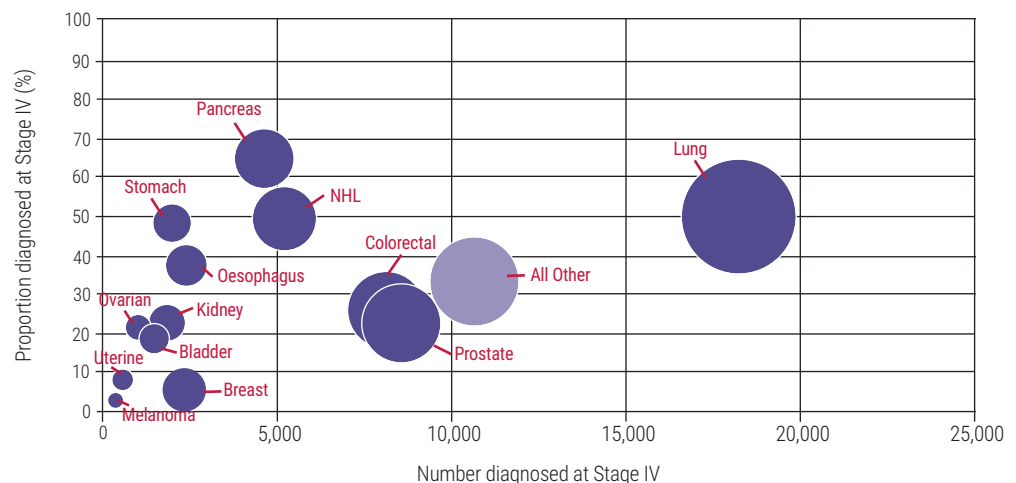


## LUNG CANCER AS A KEY ENABLER OF DELIVERING NATIONAL TARGETS IN ENGLAND

Currently, a little over half of all cancers are diagnosed at stages I and II. The NHS Long Term Plan (LTP) commits that by 2028, this proportion will increase to three-quarters of cancers being diagnosed at stage I and II.<sup>9</sup>

Data from the National Lung Cancer Audit reported that in 2017, 27% of lung cancers were diagnosed at stage I or II.<sup>10</sup> Given that this percentage is much lower than many other cancer types, earlier diagnosis of lung cancer offers an important contribution to achieving the ambitions of the LTP. It is therefore imperative that the whole community, including policymakers and local health leaders, is focussed on the role that tackling the issue of late diagnosis of lung cancer can play in delivering this national commitment – as shown in figure 2.

**Figure 2: Number and Proportion of Cancer Cases Diagnosed at Stage IV, England, Cancer Research UK (2017)**





Other commitments set out in the LTP will help to deliver the overarching target of significantly increasing the number of lung cancers diagnosed at stage I or II, including:

- **Lung health checks are being introduced in some parts of England** – people attending for a lung health check will be assessed as to their individual lung cancer risk and those identified as being at high risk of lung cancer will be offered a low-dose CT scan.
- **A 28-Day Faster Diagnosis Standard is being introduced** – this will mean that from 2020 most patients will receive a definitive diagnosis or ruling out of cancer within 28 days of an urgent GP referral for suspected cancer or from referral from an NHS screening programme.
- **Greater investment in diagnostic equipment** – the NHS will use its capital settlement negotiated in the 2019 Spending Review in part to invest in new equipment, including CT and MRI scanners, to deliver faster and safer tests.
- **The National Optimal Lung Cancer Pathway (NOLCP)** – the NOLCP is currently being implemented across England and, whilst focussed on the issue of Rapid Diagnosis after referral, is likely to have some impact on patients receiving treatment at an earlier stage of their disease
- **Rapid Diagnostic Centres will be rolled out** – to achieve the new 28-Day Faster Diagnosis Standard a radical overhaul of the way diagnostic services are delivered is required for patients with symptoms that raise suspicion of cancer but aren't suitable for a site specific pathway, or vague symptoms. From 2019, new Rapid Diagnostic Centres (RDCs) will begin to be rolled out across the country to upgrade and bring together the latest diagnostic equipment and expertise.
- **Use of molecular diagnostics will be extended** – the NHS will routinely offer genomic testing to all people with cancer for whom it would be of clinical benefit, and expand participation in research in the next ten years. This will increase our understanding of cancer which, in the future, may enable more rapid identification of those at highest risk of lung cancer.

It is pleasing to see this range of commitments set out in national policy, but we must not forget that changes in the wider political landscape could impact on speedy access to the most innovative medicines and technologies. There is no one 'silver bullet' in improving early diagnosis of lung cancer. What is critically important is that we push forward with a range of complimentary actions which, in their own ways, all support improvements in the early diagnosis of lung cancer and ultimately deliver better patient outcomes.

## LOCAL SYSTEM LEADERS

Local health system structures, including Sustainability and Transformation Partnerships (STPs), Integrated Care Systems (ICSs), Cancer Alliances and the new Primary Care Networks, have been established to bring local health leaders together to plan around the long-term needs of local communities. These organisations provide a strong platform to support improved outcomes in lung cancer but they cannot do this on their own and will need help.

The NHS Long Term Plan Implementation Framework<sup>11</sup> (Implementation Framework) outlines the ways in which STPs and ICSs will progress their five-year strategic plans to deliver on the provisions of the LTP. The Implementation Framework commits that by 2023/24 £400 million of additional funding will have been distributed to Cancer Alliances to support delivery of the LTP ambitions for cancer.

The Implementation Framework states that systems should engage with their Cancer Alliances to set out practically how they will deliver the LTP commitments, while improving operational performance through interventions such as improving access to diagnostics and addressing unwarranted variation.

It is important that local areas can focus on the needs of their individual communities, as a 'one size fits all' approach is unlikely to deliver the best outcomes across the country. However, as we have learnt from the past, taking a regional/local approach can mean that some areas perform better than others.

It is critical that learning is shared between these local system leaders to ensure that best practice can be spread and embedded as efficiently as possible. It is also important to share experiences of what isn't working so that time and resources aren't wasted by trying to implement things which aren't going to deliver the desired outcomes.

An additional area of support set out in the Implementation Framework is that the National Cancer Programme Team and NHS England and NHS Improvement regional teams will support Cancer Alliances and their system partners by, among other things, providing a tool to better understand variation in early diagnosis rates.<sup>12</sup>

It is essential that the National Cancer Board, regional teams and local system leaders work together effectively to deliver transformational outcomes for lung cancer patients. But this will require a lot of hard work, collaboration and determination to be successful.



## USE OF DATA

Since it began reporting, the National Lung Cancer Audit has been the catalyst for improving standards and outcomes. Vitally, it has helped to understand and therefore tackle unwarranted regional variations in care and outcomes.

The National Lung Cancer Audit Annual Report 2018 was the first time that the data for diagnosis at stage I and II was broken down by Clinical Commissioning Group.<sup>13</sup> This is an important tool for local commissioners so that they are aware of how their area is performing on this critical measure. It also means that they can compare their performance with other CCGs and take action to improve. The CADEAS (Cancer Alliance Data, Evidence and Analysis Service), a partnership between NHS England and Improvement and Public Health England, supports Cancer Alliances' analytical needs and the Service provides data on lung cancer stage distribution by Alliance and CCG via the CancerStats2 portal (<https://cancerstats.ndrs.nhs.uk/>).

A great deal of effort is expended collecting data as part of the National Lung Cancer Audit and also into other datasets such as SACT (Systemic Anti-Cancer Therapy), RTDS (RadioTherapy Data Set) and DIDs (Diagnostic Imaging Dataset). It is vital that we maintain the monitoring of services and lung cancer patient outcomes to ensure that we are making progress and to continue to strive to reduce unwarranted variation. However, the speed of access to these data needs to be increased and the raw data needs to be analysed and converted into clinically relevant intelligence to help drive improvements in standards of care. It is therefore imperative that the work of the Audit continues uninterrupted.

One of the limiting factors in having better intelligence in lung cancer is a lack of analyst capacity to find more detailed insights from data which is already collected. There are a lot of unanswered questions in lung cancer like *why are so many lung cancers diagnosed as an emergency?* Having more analyst time (e.g. in the National Cancer Registration and Analysis Service or the NLCA teams) devoted to some of the big questions in lung cancer is one of the tools we must use to help tackle late diagnosis.

## WHAT IS THE ROLE OF PUBLIC AND CLINICAL AWARENESS IN IMPROVING OUTCOMES?

In order to achieve the LTP's early diagnosis ambition, specifically in lung cancer, we need a radical shift in both public and clinical awareness around the symptoms of lung cancer and the timely referral of patients where there is any suspicion of lung cancer. This also means 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.

### BARRIERS TO IMPROVING AWARENESS

There are multiple barriers to improving awareness of symptoms and driving early diagnosis. Kate Brain, Professor of Health Psychology Division of Population Medicine Cardiff University, has spoken of these barriers including:

- Low awareness of signs and symptoms
- Fear and fatalism associated with poor outcomes
- Stigma and shame around smoking
- Mistrust in relation to engaging with GPs, due to a fear of judgement and blame
- Social influences
- Limited access to specialised assessment, treatment and care

The perception that lung cancer is exclusively a 'smokers' disease' – despite 10-15% of patients having never smoked,<sup>14</sup> in combination with historically poor clinical outcomes has led both to stigmatisation of the condition and a sense of fatalism. The UKLCC has heard anecdotally that people often avoid seeking help, both in terms of a potential diagnosis and treatment, because they believe an early diagnosis will not make a difference to their outcomes.

Recent campaigns, such as Roy Castle Lung Cancer Foundation's 'Face your Fear' campaign, have focussed on challenging the idea that 'nothing can be done', with the aim of encouraging people to engage with their GP in order

to increase the number of lung cancer cases diagnosed at an early stage. Interactions at a primary care-level are central to driving up rates of early diagnosis. Educating people on the potential signs and symptoms of lung cancer and encouraging help-seeking behaviour by tackling a range of barriers are key to reducing late stage diagnosis.

Problems around public awareness and fear and fatalism are compounded in deprived areas and within harder to reach groups. Professor Brain has also spoken of research on how to encourage people to seek help in deprived communities found that it is important to remove any practical barriers, making services:<sup>15</sup>

- **Easy to access** – with immediate access via a lung health check, clinical trials of screening (e.g. UCLH and Yorkshire), where they are available, or through better access of GPs to diagnostics and rapid access diagnostic clinics<sup>16</sup>
- **Proactive and personal** – for those in areas where lung health checks or screening programmes are underway, making sure that personalised invitations are sent out and that reminders for appointments are used
- **Flexible and inclusive** – enabling people who may have lower levels of literacy, and for whom English is not their first language, to engage with services

It is also important to reduce any psychosocial barriers by:

- **Building trust** – through creating a supportive environment and being non-judgemental
- **Normalising help seeking** – to foster a positive belief in the NHS / health-care professionals and the benefits of timely diagnosis
- **Building relationships** – by showing compassion, and having continuity of care and support<sup>17</sup>

Focussing on strategies designed to mitigate practical and psychosocial barriers is important in facilitating people from deprived communities and other hard to reach groups to engage with the NHS and detect lung cancers earlier. One way to do this is by co-producing interventions, as this has been shown to be a transformative way to engage these groups. Bringing the voice of those who will be targeted by such interventions into the planning process helps to ensure the activities are as impactful as possible. Professor Brain argues that, while building community partnerships take time, but it is crucial that this work is undertaken in order to see a real impact when it comes to symptom presentation and therefore, early diagnosis.

## THE IMPORTANCE OF PUBLIC AWARENESS CAMPAIGNS

Public awareness campaigns are central to what has been described by the members of the lung community as a 'whole system response'.<sup>18</sup> This response ideally starts with increased public recognition of the campaign messages and attendance at GP practices, translating into increased use of diagnostic tests and urgent suspected cancer referrals to secondary care going on to greater numbers of patients receiving active treatment. The cumulative effect of interventions coming via different routes over time creates a 'drip effect' potentially amplifying the impact on earlier diagnosis.

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 increase in urgent GP referrals for suspected lung cancer by 31.8% for the campaign period,<sup>19</sup> adjusted for working days (as set out in the table below).

There was also shift towards more patients being diagnosed at an earlier stage and more patients being treated.

The first major lung cancer 'Be Clear on Cancer' campaign was regional, running in the East and West Midlands in 2011 and (as was the case for all subsequent campaigns) was targeted at people over the age of 50 and those in lower socio-economic 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 was, however, evidence that the impact of such campaigns can lessen with time, with much less clear impact being seen in latter two national campaigns.<sup>20</sup> Part of the reason for this may have been reduced levels of media activity in the later campaigns. The future of such public awareness campaigns is uncertain as a result of a reduction in budgets for this work.

It is also important that awareness programmes are targeted towards the characteristics and needs of local populations and interventions should be developed which best respond to these challenges and are therefore as effective as possible in 'hard to reach' groups. Targeted, sustained campaigns can be highly valuable, with a symptom awareness campaign in Leeds resulting in a stage shift regardless of deprivation level.<sup>21</sup>

**Figure 3: First national lung cancer awareness campaign: number of urgent GP referrals and conversion rate for suspected lung cancer for the campaign and control periods<sup>18</sup>**

Control period					Campaign period					p value control vs campaign
Month	2011	2012	% Change (adjusted <sup>a</sup> )	p value	Month	2011	2012	% Change (adjusted <sup>a</sup> )	p value	
<b>Referrals</b>										
February	3416	3802	+6.0 <sup>b</sup>	0.015	May	3472	4817	+26.1 <sup>b</sup>	<0.001	-
March	3993	4149	+8.6	<0.001	June	3694	4072	+27.6 <sup>b</sup>	<0.001	
April	3523	3580	-3.7	0.114	July	3338	4960	+41.8 <sup>b</sup>	<0.001	
February-April total	10,932	11,531	+3.8	0.006	May-July total	10,504	13,849	+31.8 <sup>b</sup>	<0.001	
<b>Conversion rate</b>										
February-April average	24.3%	22.3%	-2.0 <sup>d,e</sup>	<0.001	May-July average	24.0%	21.5%	-2.5 <sup>d,e</sup>	<0.001	0.479

<sup>a</sup> Adjusted for a 5-day working week excluding bank holidays (e.g. includes Easter, Early May, Spring bank holidays and Queen's Diamond Jubilee Bank holiday for 2012)  
<sup>b</sup> Statistically significant difference between 2011 and 2012 (likelihood ratio test  $p < 0.05$ )  
<sup>c</sup> Statistically significant difference for the percent change for the control period compared with the campaign period (interaction term of Poisson regression model  $p < 0.05$ ) adjusted for working days  
<sup>d</sup> Statistically significant difference between 2011 and 2012 (two-sample proportion test  $p < 0.05$ )  
<sup>e</sup> Percentage point change

## THE ROLE OF CLINICAL AWARENESS IN IMPROVED OUTCOMES

The importance of improved clinical awareness, especially in primary care, must not be underestimated. Being able to identify the signs and symptoms of lung cancer and to know when a person should be referred for tests is an essential part of improving outcomes.

Anecdotally, we have heard that patients are only able to talk about one symptom per consultation. This is problematic from the perspective of diagnosing lung cancer, because many of the symptoms that could raise suspicion of lung cancer are non-specific and may not be raised by patients if they have what appears to be a more pressing medical problem. GPs must be able to treat patients holistically and therefore it is imperative that they are always able to talk to a person about a range of different symptoms which, when considered together, may indicate that lung cancer is suspected.

There needs to be a systematic but practical approach to GP education, which must involve all GPs in a practice. One approach might be to produce a brief standard set of information relevant to the diagnosis of lung cancer for use in continuing medical education events in primary care. This should set out the practical steps which a GP can take either in terms of the use of diagnostics in primary care or referral to a rapid access lung cancer clinic. The National Cancer Diagnosis Audit is also a very useful tool for use as the basis for a focussed discussion within a practice.<sup>22</sup> The emergence of Primary Care Networks creates an opportunity to expand and perhaps systematise educational programmes of this sort.

Better, intelligent clinical decision support tools need to be developed to support GPs in this process and the use of Artificial Intelligence in this space needs to be explored.

Incentives also need to be considered, like the Quality and Outcomes Framework (QOF) or other similar schemes, to ensure that primary care is incentivised to deliver high quality cancer care. It is certainly important that no financial barriers are

placed on them having easy access to chest X-rays and, where appropriate, CT scans. As GPs are generalist by their very nature, focussing their attention on helping to diagnose lung cancers at the earliest stage has the potential to make a significant difference in both the route to diagnosis and in supporting earlier diagnosis.

### The GP perspective in Leeds

While we know that GPs understand cancer detection to be a core part of their role, diagnosis in this setting is complex and more must be done to ensure GPs are 'brought in' to early diagnosis programmes grounded in a robust evidence base.

Symptoms for lung cancer are usually vague and non-respiratory, and might only be mentioned as an afterthought at the end of a consultation. These challenges are compounded by the fact that no two GPs are likely to take exactly the same diagnostic approach.

We must be careful that GPs' concerns around workload and issues relating to over-referral are appropriately addressed. Innovation in early diagnosis is essential, but primary care brings its challenges. In order for new interventions to be successful, it is highly important that GPs on the ground are brought along in this journey.

We know this works. The 'Be Clear on Cancer' campaigns have led to increased work load for GPs, but evaluation of the programme shows additional demand is manageable (six extra consultations per practice per week) and 80% of GPs are supportive of the programme.

**Professor Richard Neal and  
Dr Stephen Bradley**

# WHAT IS THE CURRENT PICTURE OF DIAGNOSIS?

What it means to be diagnosed with lung cancer has changed significantly over the past decade. Huge progress has been made in challenging the stigma connected to the disease and it is no longer a ‘death sentence’ for patients who are given a diagnosis. However, it is still by far the biggest cancer killer in the UK<sup>1</sup> and more must be done to give people the best possible chances of survival.

## DIAGNOSIS TAKING PLACE AS PART OF EMERGENCY ADMISSIONS

Analysis from the National Cancer Registration and Analysis Service looked at routes to diagnosis for lung cancer by CCG in England between 2006-2016. This shows that far too many cases of lung cancer are diagnosed during an emergency admission and that survival for those diagnosed in this context is very much worse than those diagnosed via an elective route,<sup>23</sup> once symptoms have worsened and the disease has progressed. However, as illustrated in Fig 4, there has been a fall in emergency admission diagnoses and a reciprocal increase in elective referrals via the 2ww route over the 10 years in which the routes to diagnosis have been reported.<sup>24</sup>

There is limited evidence as to why so many people are being diagnosed via an emergency admission.<sup>25,26</sup> But we do know that when people are diagnosed as an emergency their survival is worse. There are likely to be some local operational policies which are contributing to this, such as GPs sending patients with suspected lung cancer directly to A&E, but this does not explain all of these people.

If we were able to better understand why so many lung cancers are diagnosed through the emergency route, then it may be possible to work out which parts of the pathway or what behaviours from the public and healthcare professionals need to be changed to reduce the number of emergency presentations. For example, as our knowledge around tumour biology advances – and we learn more about how to identify which tumours are growing more rapidly than

others – it is important that we have the technology in place to support applying that knowledge into earlier diagnosis. There is huge variation between CCGs in the proportion of lung cancer patients

who are first diagnosed via an emergency admission (see fig 5 below) and it is likely that if these rates could be reduced to those of the best, survival would also improve.

Figure 4: NCRAS, Routes to diagnosis for lung cancer 2006-2016

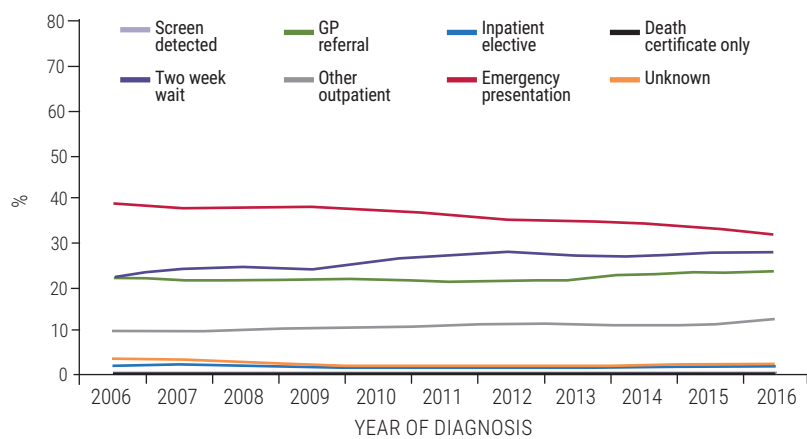
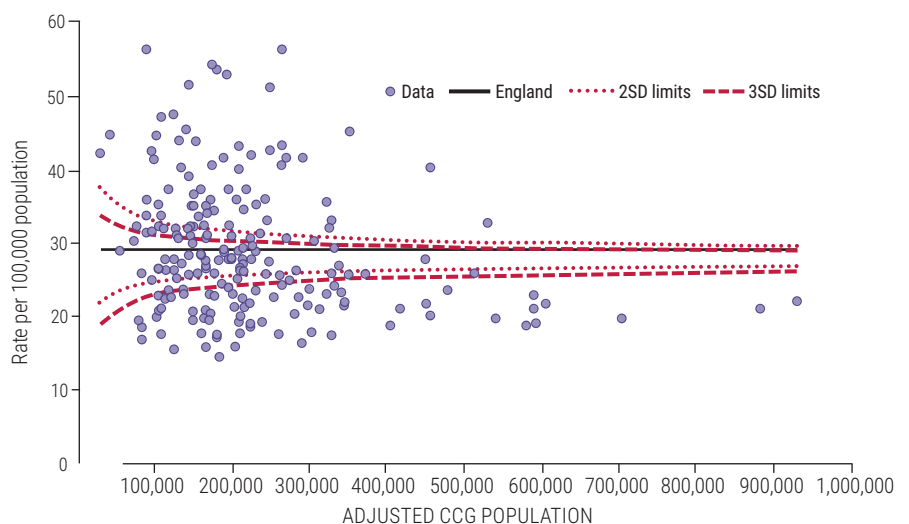


Figure 5: NCRAS, Age-standardised rate of Emergency route to diagnosis for lung cancer by CCG in England, 2006-2015<sup>27</sup>



## PATHWAY DESIGN

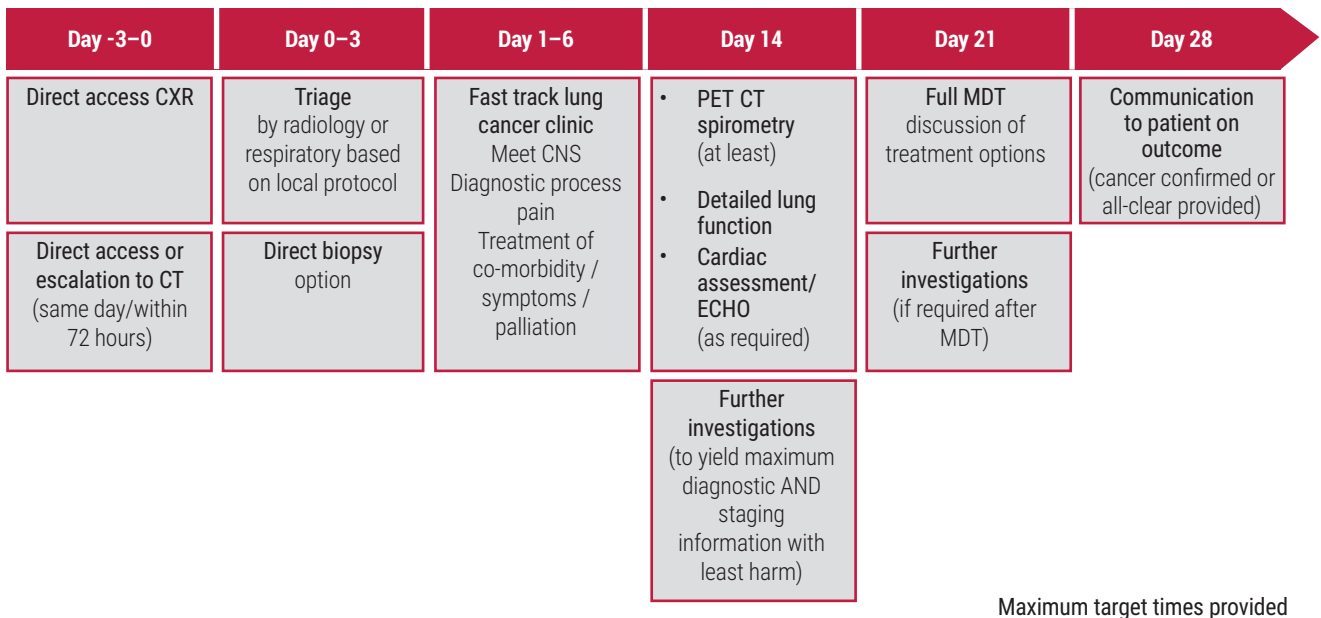
It is also important that the diagnostic pathway is designed in such a way that reflects how critical time is. The National Optimum Lung Cancer Pathway provides a road map for service providers and commissioners in England who are aiming to improve their local lung cancer services, to help ensure patients start treatment within 49 days. Though challenging, the time-lines in the pathway are achievable.

Even in the early stages, the growth of a tumour during a typical patient’s wait for treatment can be hugely significant, with the smallest of increases in the size of the tumour and/or lymph node involvement impacting on treatment options and outcomes. Studies show the direct link between shorter pathways and improved survival.<sup>28</sup>

The 28-day Faster Diagnosis Standard, due to be rolled out across England by 2020, is designed to ensure that every patient referred with suspected cancer is given a diagnosis, or told that cancer has been ruled out, within 28 days. Steps to shape the pathway in a way that reflects the importance of time must be implemented and abided by if the current picture of lung cancer diagnosis is going to change.

More information on the lung cancer pathway can be found in the UKLCC report, Millimetres Matter.<sup>29</sup>

Figure 6: NHS England, Implementing a timed lung cancer diagnostic pathway, 2018<sup>26</sup>





## THE NEED FOR IMPROVEMENTS IN DIAGNOSTICS

The threshold for a healthcare professional to refer a person with a suspicion of lung cancer for a chest X-ray needs to be very low and access made as easy and rapid as possible. Where a chest X-ray is suggestive of a diagnosis of lung cancer there needs to be very rapid referral for a CT Scan to achieve the ambitions set out in the National Optimal Lung Cancer Pathway and the 28-day Faster Diagnosis Standard.

Delays to diagnosis can be worsened by widespread logistical problems in relation to blood tests. The ability for all patients to obtain urgent blood tests to assess renal function can be very challenging (for example, due to delays in scheduling). These issues could be overcome if there was a move to install simple strategies, such as point of care blood testing, which can help to provide pragmatic solutions.

There also needs to be a move to ensure that the wider healthcare community, including nurses, pharmacists and dentists can signpost people to GPs they suspect of being at-risk of lung cancer for a chest X-ray. This is especially important for hard to reach groups who may not engage with their GP on a regular basis.<sup>30</sup>

### Spotlight on community-ordered chest X-rays in Leeds

In Leeds, an early diagnosis campaign for lung cancer commenced in 2011 comprising a public-facing marketing campaign and primary care education campaign. These were linked to setting up a self-request chest X-ray service for people with persistent respiratory symptoms. Chest X-ray rates across the city rose by 80%, and this increase has sustained over the 8 years the campaign has run. Alongside this there has been a significant stage shift in lung cancer cases (9% increase in early stage disease with a corresponding reduction in the absolute numbers of patients with late stage cancer) and an 8% reduction in deaths from lung cancer in Leeds over the last 5 years (approximately 40 fewer deaths per year compared to pre-campaign levels). These changes (stage shift and mortality reduction) have not been seen in national figures.

To make sure that demand for chest X-rays and other diagnostic tests can be met, a comprehensive capacity and training review needs to be conducted in diagnostics. Reviewing the capacity and organisation of staff involved in the process is key to ensuring that tests are managed efficiently.

With the increasing need for precise pathological and molecular diagnosis to guide the appropriate personalised treatment, the demands on pathologists and their technical support staff become greater all the time, yet staff numbers have not changed to reflect this. For example, The Royal College of Pathologists Histopathology Workforce Census, published in September 2018, found that only 3% of departments who responded had enough staff.

More must be done to ensure there is enough diagnostic capacity and that departments are properly equipped to meet the early diagnosis ambition in lung cancer.

There is evidence that, in some areas, some chest X-rays either go unreported or reporting is delayed by several weeks. Anecdotal evidence suggests that there are also a number of missed diagnoses on chest X-rays that are reported by less experienced radiologists. It is critical that radiologists are sufficiently supported and resourced to be able to report on potential cases of lung cancer as swiftly and accurately as possible.

## LUNG HEALTH CHECK AND SCREENING

The publication of the *Implementation Framework* reaffirmed NHS England's commitment to establishing lung health checks during 2019 in ten cancer alliances with some of the worst mortality rates from lung cancer. The *Framework* sets out that, from April 2020, health checks will continue to be rolled out in areas with higher mortality rates. Alongside supporting early diagnosis, lung health checks can also act as an intervention point for changing behaviour (encouraging those at-risk to stop smoking) and evidence-based smoking cessation support should be embedded throughout the lung cancer pathway, through initiatives such as the Yorkshire Enhanced Stop Smoking Study (YESS), - trialling a personalised smoking cessation intervention embedded in the Yorkshire Lung Screening Trial.

While the commitment to lung health checks is a welcome step, it is not a replacement for a fully-funded national screening programme. The high standards demanded of national screening programmes to ensure equitable access, clinical effectiveness and safety are not guaranteed via such roll out approaches. It is therefore vital that as the health checks are rolled out, they have safe and standard effective processes with robust, nationally centralised data collection, collation and evaluation. This is central to maximising patient benefit and to support the availability of high-quality evidence to inform future policy and practice.

The establishment of such a national screening programme rests on the publication of the findings from the NELSON trial into low-dose CT screening. Once published, the UK National Screening Committee (UKNSC) should review the results to consider whether recommending a national programme is appropriate.

The recent publication of Professor Sir Mike Richards's review into screening in cancer, which includes the recommendation that should the lung health check pilots succeed, the programme should be rolled out nationally, should be welcomed as a positive step towards the establishment of such a national screening programme. However, fundamental questions remain as to who is responsible for delivering this, specifically whether the UKNSC considers lung screening to be within its remit (because lung screening focuses on individuals at increased risk rather than the population as a whole).

It is therefore not yet clear whether the UKNSC will itself make a recommendation on a national lung screening programme, nor how to proceed if they do not. This issue should be resolved as a matter of priority and, if a recommendation is made to implement a national lung screening programme, it should be implemented across the UK as quickly as possible. The implementation of a targeted national screening programme is an important intervention in terms of achieving a positive stage shift – with the potential for an additional increase in the number of cancers diagnosed at an early stage through further optimising of screening, including risk stratification.

# A LOOK AT THE DEVOLVED NATIONS

## WALES

Lung cancer has been a specific priority in Wales for several years now. This reflects the fact that Wales has poorer outcomes in lung cancer than other UK nations.<sup>31</sup> *The Cancer Delivery Plan 2016-20* sets out a vision where the incidence, mortality and survival rates from cancer are comparable with the best.<sup>32</sup>

There are several areas where Wales is taking a positive approach, which are explored below.

### Smoking cessation

The *Tobacco Control Action Plan for Wales* was published in February 2012. The Plan set an overall vision of a *smoke-free society for Wales, in which the harm from tobacco is eradicated*. This is supported by the specific aim to *drive down adult smoking prevalence levels in Wales to 16% by 2020*.<sup>33</sup>

Progress is being made against this target with smoking rates among adults being at a low of 19% in 2016/17.<sup>34</sup> But it is acknowledged that it is going to be challenging to achieve this target and that a range of support and services are needed to help get smoking rates down in Wales.

### Single Cancer Pathway

In 2018, the Welsh Government took the decision to implement a Single Cancer Pathway in Wales from June 2019.<sup>35</sup> This was a key ambition in the *Cancer Delivery Plan for Wales 2016-2020*.

Until now there have been two cancer pathways:

- **Urgent Suspected Cancer Pathway** – where a patient is referred from primary care for treatment within 62 days
- **Non-Urgent Suspected Cancer Pathway** – where a patient must be treated within 31 days of when the ‘decision to treat’ was made

It was identified that those patients who were being investigated through the Non-Urgent Suspected Cancer Pathway were being put at a disadvantage because of the clock starting when the ‘decision to treat’ was made, not when cancer was suspected.

The Single Cancer Pathway will see all patients measured from the point of suspicion of a cancer through to treatment within 62 days.

### Spotlight on delays in the lung cancer pathway

During 2016, the NHS and Novartis funded a lung cancer project in Cardiff and Vale University Health Board that looked at delays for patients in the lung cancer pathways and solutions to those delays with the aim of making the diagnostic pathway more efficient and effective. The work included testing the benefits of ‘straight to CT’, developing a computer-based risk assessment tool and community pharmacy access to chest X-Ray (CXR).

The project secured Welsh Government funding for the introduction of routine genetic testing, using next generation sequencing, as part of the lung cancer diagnostic process, to ensure that more patients can get the most appropriate treatment and also be potentially identified for participation in clinical trials.

This issue has now been adopted by the Wales Cancer Network with the learnings being utilised within their Lung Cancer Site-specific Group.

## Direct access to diagnostic tests

Health Boards have been asked to provide primary care with wider access and timely reporting of diagnostic interventions for suspected cancers and a lower threshold for suspicion of cancer.

A survey was conducted by the Wales Cancer Network in 2017 and repeated in 2018 to understand and monitor progress in primary care access to diagnostic investigations.

The 2017 survey found that 100% of GPs reported open access to chest X-ray where lung cancer was suspected and 79% of GPs reported direct access to CT following an abnormal chest x-ray.<sup>36</sup>

The 2018 survey reported that all Health Boards are now providing direct access to CT following an abnormal chest x-ray for suspected lung cancer.<sup>37</sup>

Having this direct access to diagnostic tests is critically important to improve early diagnosis rates. Now that this has been successful for GPs we would encourage that other healthcare professionals, including nurses, dentists and pharmacists, are able to refer people with suspected lung cancer directly for diagnostic tests too.

## SCOTLAND

Scotland and Northern Ireland sitting outside of the National Lung Cancer Audit (NLCA) risks a lack of alignment with regards to driving forwards improved standards in this area. Scotland and Northern Ireland should consider how they audit lung cancer services, to ensure that there is comprehensive information available which can be used to better understand lung cancer in these countries. They should consider whether to adopt all or parts of the NLCA.

In 2012, the Scottish Government announced the launch of the Detect Cancer Early programme, with the stated aim of increasing the proportion of people diagnosed at stage one and improving the five-year survival rate for those with lung cancer.<sup>38</sup>

In response to the Government's HEAT target (Health Improvement, Efficiency, Access to treatment and Treatment) for health boards to increase the number of breast, colorectal and lung cancers detected at an earlier stage, NHS Fife ran a lung health programme across the Health Board in 2014. It ran what it described as an 'inequalities-focussed lung cancer suspicion screening pilot',

targeting people attending Stop Smoking clinics who demonstrated signs and symptoms of lung cancer, such as a persistent cough and unexplained weight loss. Identified patients were referred for an X-ray at an open access clinic and GP appointment if necessary.<sup>39</sup> This screening pilot is a step in the right direction and further indicates the need for a more comprehensive programme.

As a result of the pilot there was an 8.4% increase in the percentage of people diagnosed at stage 1 for breast, colorectal or lung cancer (combined) between the baseline (calendar years 2010 & 2011 combined) and Year 6 (calendar years 2016 & 2017 combined).<sup>40</sup>

## NORTHERN IRELAND

Northern Ireland is the only country within the UK without an up-to-date specialised Cancer Strategy, although a strategy is currently being developed. The current strategy dates back to 2008 and is in the form of a regional framework aimed at reducing disease burden including that posed by cancer.<sup>41</sup>

In Northern Ireland, screening currently takes place for cervical, bowel and breast cancer. Given the lateness of diagnosis for some cancer types, in a recent major report, CRUK has stated that there is scope to detect and diagnose cancer earlier in Northern Ireland.<sup>42</sup>

Geographical inequalities are an issue in cancer diagnosis in Northern Ireland, with cancer incidence 15% higher in the most deprived communities compared to the Northern Ireland average, and 8% lower in the least deprived communities.<sup>43</sup>

Lung cancer patients deserve to be afforded the professional and political attention that is seen in many other cancer types. One major step forward would be the implementation of a screening programme. The Department of Health, Social Services and Public Safety (DHSSPS) has previously suggested that they see merit in a lung cancer screening programme in Northern Ireland.<sup>44</sup>

## HOW TO MAKE IT HAPPEN – RECOMMENDATIONS

No one single action listed below will solve the problem of the late diagnosis of lung cancer, but these are the ten recommendations that we believe will see maximum impact. If the Long Term Plan ambition for a major shift in the number of cancers diagnosed at an early stage is to be realised, a significant impact in lung cancer is likely to be of great importance in contributing to achieving this.

Therefore, sufficient focus must be given to lung cancer, and a whole community effort is required – as well as ongoing evaluation – to see action alongside the implementation of the individual commitments in the Plan.

- 
- 1 Local health leaders should continue to prioritise efforts to achieve a stage shift and improved outcomes for the lung cancer patients in their area, developing local programmes and adopting a range of interventions to address different points along the diagnostic pathway and sharing and embedding good practice
  - 2 The National Lung Cancer Audit (NLCA) must continue uninterrupted and with sufficient analytical capacity to better define the nature and potential causes of variation at regional and local level. CCGs should dedicate time to reviewing data from the NLCA and other sources such as CADEAS so they can compare their performance with other CCGs and consider what actions are required to improve outcomes in their areas
  - 3 Public awareness and action campaigns focused on lung cancer should be funded annually, alongside regional and local campaigns to support improved understanding of signs and symptoms
  - 4 Smoking cessation services should be encouraged to use their contact with smokers to increase awareness of the symptoms of lung cancer and the value of early detection
  - 5 High quality GP education programmes - with impactful content focused on the early recognition, investigation and referral of lung cancer - should be rolled out and embedded in new and existing platforms
  - 6 The adoption of incentives in primary care for effective referrals in cases of suspected lung cancer should be examined to drive forward high quality cancer care; this should include encouragement to participate in, and use the results of, the National Cancer Diagnosis Audit
  - 7 The 28-day Faster Diagnosis Standard and NOLCP must be comprehensively rolled-out across England by 2020. Trusts and primary care – with the support of their local Cancer Alliance – must work together to ensure their referral pathways are fit for this purpose
  - 8 Patients who, on clinical and/or radiological grounds, are highly likely to have lung cancer should be referred directly to a specialist lung cancer diagnostic clinic and the use of RDCs should be limited to those with vague and less specific features where a diagnosis of lung cancer is much less likely
  - 9 The wider healthcare community, including nurses and pharmacists, must be able to refer someone who they suspect might have lung cancer for a Chest X-ray
  - 10 Further to the publication of Professor Sir Mike Richards's review into screening, clarity should be provided as to whose remit a lung cancer screening programme should fall under. The roll out of lung health checks must also be supported by effective processes with robust, nationally centralised data collection, collation and evaluation programme

# EXAMPLES OF BEST PRACTICE

## CASE FINDING IN SOUTH TYNESIDE

### 1. What problem were you trying to solve?

South Tyneside has a two-fold higher age-standardised incidence of lung cancer compared to the national average in the UK.

Diagnosis is often delayed and this has an impact on prognosis. Nearly 40% of diagnoses are made following an emergency presentation. National lung cancer screening trials have shown detection of earlier stage lung cancers and a relative reduction in lung cancer mortality. There has been a participation bias in screening trials with fewer patients from a lower socioeconomic status (SES). Lower SES is a risk factor for lung cancer after adjusting for smoking status. Patients with lower individual income have been found to have a poorer prognosis from lung cancer. We were keen to establish a case finding model that addressed these issues.

### 2. What was your approach to tackling this?

South Tyneside Clinical Commissioning Group (CCG) and South Tyneside NHS Foundation Trust agreed a case finding service targeting patients seen at the annual COPD review in general practice. It is felt that airflow obstruction and emphysema have been neglected as potential selection for lung cancer screening. They are an independent risk factor for development of lung cancer.

A feasibility assessment was done with a pilot project and then this was rolled out to all 16 practices in the CCG. Practice nurses and General Practitioners (GPs) were given face to face education on implementing the project and written guidance produced. A patient information leaflet was produced. Smoking cessation was further emphasised. Patients could then be counselled and consented for a low dose CT (LDCT) scan. This is then requested electronically under a specially created option and the LDCT is performed out-of-hours. The cost per LDCT is £91.

Images are reported by the lung cancer multidisciplinary meeting thoracic radiologist with access to previous imaging, and a standardised template report is provided to GPs with volumetric measurements when needed. This gives clear instructions for report outcomes and action required. If a lung cancer is detected this is then referred directly by radiology to the one-stop lung cancer clinic.

### 3. What challenges did you encounter along the way, and how were you able to solve them?

Agreeing funding through the CCG. A business case was submitted for CCG funding and this was approved.

Establishing GP and practice nurse agreement to the project. Face to face discussion and education aided this.

### 4. What were the outcomes, and what impact did this have on patients and staff?

The feedback from GPs and practice nurses has been very favourable and they have engaged well. GPs found the requesting system and reports easy to use and interpret. Practice nurses felt comfortable counselling patients.

812 patients have been screened to date since February 2017. 14 lung cancers have been found in the first round of LDCT; a prevalence of 1.7%. 43% (n = 6) were stage I, 7% (n = 1) were stage II, 43% (n = 6) were stage III and 7% (n = 1) were stage IV. Curative intent treatment was offered in 79%. 59% of patients are from the deprivation quintile 5 (lowest) and 21% from deprivation quintile 4. Improving participation from the lowest SES was a primary objective and is being met with this targeted approach.

### FOR MORE INFORMATION ON THIS WORK, PLEASE SEE THE DETAILS BELOW:

Dr Helen Grover – helen.grover@stft.nhs.uk

Dr Liz Fuller – liz.fuller@stft.nhs.uk

Fuller E, Athey S, Hunter J. M14 Implementing a low dose CT screening programme for lung cancer into routine NHS practice – The South Tyneside Model. *Thorax* 2018;73:A253.

Ross T, Athey S, Hunter J, Fuller E. Implementing a low-dose CT screening programme for lung cancer into routine NHS practice: the South Tyneside Model. *Lung Cancer*, Volume 127, S23



## ESTABLISHING WORKSTREAMS TO SUPPORT IMPLEMENTATION OF NOLCP IN NOTTINGHAM UNIVERSITY HOSPITAL (NUH)

### 1. What problem were you trying to solve?

At NUH waiting times for lung cancer were recognised as being very poor and compared unfavorably against national figures (lowest quartile for 62 day target). The 62 day national target had not been met for several years.

There is an increasing body of evidence that faster pathways result in better outcomes for patients.

In response to this the lung cancer service formed a formal project team in August 2016 to begin implementation of the NOLCP which was a ready-made solution to poor cancer waiting times.

In parallel with this there was recognition of poor governance and inefficient processes within the service, so implementation of the new pathway presented an opportunity to improve efficiency and governance.

### 2. What was your approach to tackling this?

Detailed analysis was undertaken for data collection including review of every breach RCA for over 2 years, discovery meetings, demand and capacity analyses, process mapping, audits and benchmarking exercises with peer trusts. This informed changes required to implement the new streamlined pathway.

Five workstreams were set up to systematically address the whole of the pathway with a multi professional, cross discipline approach: administrative, tertiary, referrals (referral or CXR to first OPA), diagnostics (first OPA to DTT) and treatment (DTT to treatment).

Specialty specific action plans were developed with the aim of achieving the key waiting time milestones set out in the NOLCP. For each specialty frequent meetings took place with clinicians and specialty general managers or service managers. The question posed to each specialty was always 'What would you need to achieve this turnaround time?'. This helped to expand the potential solutions as we were keen to explore all options and not be limited by the status quo.

Monthly steering group meetings with each specialty were chaired by the clinical lead for lung cancer.

Communication was key – within specialties and across disciplines - to achieve a robust approach to achieving rapid turnaround times across the pathway. Advocacy work was undertaken to raise the profile of the lung cancer service and to improve clinical and corporate engagement within the trust.

Whilst we have addressed all parts of the pathway in parallel, we have prioritised the front end as this would benefit the greatest proportion of patients.

### 3. What were the outcomes, and what impact did this have on patients and staff?

- Partial implementation of the NOLCP, although key milestones not yet met.
- Sustained improvement in performance against the 62 day target.

#### Radiology

- CT waiting time target 10d reduced to 5d
- New CXR to CT pathway 'straight to CT' (median 8 days saved, 43% conversion rate) - joint primary care, radiology and respiratory pathway
- Same day/ next day USG neck node bx
- Ambulatory lung bx
- X 1 WTE cons – Sept 2018
- Job planning – protect specialist work

#### Respiratory

- Daily triage – 1/3 off pathway, scheduling of consultant rota
- Daily new patient clinics (+ lung function support)
- Trial 'cancer hour': daily escalation of results, preserve MDT and clinic capacity
- Endoscopy: additional scopes, 2 extra lists (7.25/ week), reconfigure consultant staffing to match skill mix to procedure demand
- Introduction of deep sedation endoscopy lists for poorly tolerant patients
- X1 WTE cons (to be recruited)
- Virtual attendance at regional mesothelioma MDT (clinician, LCNS, MDT Co)
- Appointment of clinical data lead

#### Respiratory/ admin

- In-house management of clinic space
- Use of partial waiting lists to reduce demands on MDT and cancer clinic
- Expansion of band 3 & 4 admin teams
- Admin SOPs – improved efficiency, visibility and governance
- Integration of upgrade decision into MDT
- New MDT outcome, MDT referral and lung cancer upgrade forms
- Cancer clinic letters sent within 2 working days

#### Respiratory/ LCNS

- X2.5 WTE (total 6.4)
- 3 pre-treatment meetings: pre diagnosis, at diagnosis, eHNA (comply with national guidance)
- X2 WTE Oncology CNS
- Job plans for nurses

- Reintroduction of in-patient cover for emergency presentation October 2018

#### Pathology

- Extended transport and lab hours
- 0.4 WTE cons Jan 2018
- In-house PDL 1 and ROS 1 testing

#### PET

- Increase daily capacity, prioritise lung cancer, expand ARSAC cover

#### Surgery

- X1 WTE 5th thoracic surgeon recruited – start Dec 2018
- Consultant cross cover for referrals
- Direct interspecialty handover
- Introduction of high risk surgical MDT for complex cases
- Introduction of robotic surgery

#### Oncology

- Clinical oncologists using pooled lists for SABR ('next available')
- Reconfiguration of clinical oncologist job plans to release additional capacity
- CHART weekly start rather than fortnightly
- X1 WTE med onc (mix lung, sarcoma and germ cell)
- nurse led clinics, advanced clinical practitioner clinics to release consultant capacity

#### Palliative Care

- Both NUH MDTs now have specialist palliative care attendance
- Introduction of Enhanced Supportive Care (ESC) - >80% of all stage 4 patients now offered access to specialist palliative care services
- >90% of patients offered ESC have accepted care
- Offer to discuss prognosis and to be involved in decision making about their management
- All patients admitted as an emergency with stage 4 disease at QMC are seen by specialist palliative care

**Data quality** to inform and monitor pathway changes and for submission to the NLCA has improved significantly

**Governance:** a separate task group was set up to address clinical incidents in the service. Far fewer Datix incidents have been reported in 2017-2018 compared with 2016-2017 due to the introduction of admin SOPs, improved admin staffing, improved radiology processes and integration of upgrade decisions into the lung MDT. Many of these improvements are being rolled out to other tumour sites at NUH.

#### Conclusions:

- The NUH lung cancer team have made substantial progress with respect to cancer waiting times, clinical governance and data quality
- Significant improvement in national cancer performance against the 62 day standard (see table)

- Significant reduction in number of patients untreated over day 104
- Improved job satisfaction where service delivers high quality care for patients

#### NUH 62d performance %

2016	2017	2018	2019*
58.1	57.9	69.4	74.9

#### 4. What challenges did you encounter along the way, and how were you able to solve them?

- **Data quality** – a constant issue and one that is still a challenge to date in all areas of the NOLCP. For certain focussed parts of the pathway (eg, radiology and resp med) we have ensured local data is validated and robustly collected at source by the specialty to help establish baselines and monitor progress.
- **Resource limitations** – staffing (eg, radiologists), equipment, diagnostic capacity and treatment capacity. We attempted to mitigate these by close cross-specialty working and a flexible approach to solving problems – designing a system that relied on the weakest point as little as possible and negotiating compromise wherever possible.
- **Advocacy** – i) within the service there was understandable concern that the NOLCP would overburden hard pressed members of the team; it was important to reassure colleagues that this was not the case and any solution had to be fair and sustainable ii) outside the service it was important to convey why the lung cancer service needed to be prioritised for clinical reasons.
- **Tertiary referrals** – local cancer centre processes are complex, not standardised or efficient. This has not been addressed.
- **Complex patient pathways with multiple inter-specialty handovers** – Admin SOPs to clarify lines of responsibility, improved cancer tracking and closer clinician-admin team working relationships.

#### FOR MORE INFORMATION ON THIS WORK, PLEASE SEE THE DETAILS BELOW:

sadia.anwar@nuh.nhs.uk (Lead Clinician for Lung Cancer - Nottingham University Hospitals)  
fiona.bakewell@nuh.nhs.uk (Respiratory Specialty General Manager - Nottingham University Hospitals)

## APPOINTMENT OF A PATHWAY COORDINATOR IN BARTS HEALTH NHS TRUST

### 1. What problem were you trying to solve?

Achieving the various time targets set by the NOLCP.

### 2. What was your approach to tackling this?

The Barts Thorax Centre pioneered a new patient coordinator role in order to facilitate the outcomes of their new, daily, virtual MDT. The role included ensuring CTs and PETs are booked, imported and reported in a timely manner, arranging blood tests and scheduling EBUS and bronchoscopies.

Building on this work, the North Central and East London (NCEL) Cancer Alliance allocated transformation funding for patient Navigators at 6 of our trusts.

The Alliance allowed local flexibility around duties however the vision for the Navigators was in line with the Barts Thorax Centre, i.e. that a dedicated patient facing Navigator would help deliver a fast, joined up service that would help us achieve targets and improve patient experience.

### 3. What challenges did you encounter along the way, and how were you able to solve them?

The role was offered as a secondment. This meant the recruitment pool was largely restricted to those already working within a lung service; in some cases this meant that when they were appointed, Navigators continued to do elements of their previous role. Conversely, recruiting staff with a background in lung cancer services meant Navigators were able to quickly make an impact in their new role once their time had been protected.

As Navigators would need to track elements of the patients' pathway some overlap with MDT coordinators was anticipated. However some sites reported that duplication of roles was an issue. The NCEL Alliance gathered evidence suggesting that the sites at which Navigators were most successfully implemented had one or more of the following elements in common:

- The Navigator's workspace was physically placed with the lung teams, i.e. alongside MDT coordinators and CNS'.
- The position was valued and thus protected by engaged clinical and managerial leads. The risk is that the role is absorbed within the day to day running of the service or that the Navigator becomes an additional CWT tracker.
- The Navigator and MDT coordinator worked closely to ensure their jobs complement rather than replicate each other.
- The patient facing aspect of the role was fully embraced; at our most successful site the Navigator was introduced to relevant patients in clinic.

### 4. What were the outcomes, and what impact did this have on patients and staff?

The Barts Thorax Centre coordinator role helped to achieve:

- Reduced time to first appointment.
- All patients now have upfront CTs all of which are reported prior to their appointment.

In terms of the Navigators;

- At one of our trusts the proportion of patients treated within 49 day target increased by 20% and within 62 days by 19% (the 15-month period before the Navigator and post Navigator were compared). This was achieved despite an increase of 62% in referrals to the lung service. Other trusts also documented improvements.
- Following success of the lung role, the above mentioned trust has also successfully introduced a Navigator for its urology cancer pathways.
- Our data suggested that at the sites with a Navigator, 88% of patients were informed of diagnosis within 28 day target.
- 94% of patients at sites with a Navigator had a CT before first outpatient appointment and 86% of patients had a formal CT report by said OPA. This suggests that our hospitals have been successful in implementing up-front CT.
- 80 patient experience surveys were sent to patients, 16 responses were received, 15 of which were fully complete.
  - 14/15 patients said the time in which they received their CT was 'about right'. 1 said the CT was 'too fast'.
  - 15/15 said the time of their follow up appointment and the overall speed of the service was 'about right'.
  - 15/15 patients said they felt fully informed before each appointment.
  - 3 patients rated the organisation of their appointments as 'satisfactory', 12 stated that it was good or very good. None chose the unsatisfactory option.

### FOR MORE INFORMATION ON THIS WORK, PLEASE SEE THE DETAILS BELOW:

william.ricketts@nhs.net for the Barts Thorax Centre coordinator work.

Simon.evans15@nhs.net for the Alliance Navigator work.

One of our trusts is due to present data at this year's BTOG Conference.

The Alliance is writing up a full evaluation with case studies covering our services' experiences of implementing a Navigator. This will be published on our website. Please contact Simon Evans for further details.

## THE LIVERPOOL HEALTHY LUNG PROGRAMME

### 1. What problem were you trying to solve?

Liverpool has one of the highest cancer mortality rates in England, particularly within lower socioeconomic groups. Lung cancer death rates have a significant effect on the poor health outcomes and years of life lost in these groups, and contribute to the health inequalities within the city.

For men Liverpool's lung cancer directly age-standardised registration rate (incidence) was 74.2 per 100,000 populations in 2009-11, which was almost double the England rate of 38.0 per 100,000. For women, the age-standardised rate in Liverpool of 56.6 per 100,000 was statistically significantly higher than the national rate of 28.5 per 100,000

### 2. What was your approach to tackling this?

Through the Liverpool Healthy Lung Programme, we aim to reduce Liverpool's cancer mortality rates, narrowing the health inequalities gap with the rest of England, and to:

- Increase knowledge and understanding in communities, promoting positive messages around lung health, thus recognising and starting to tackle fear and fatalism in the city surrounding lung cancer
- Define and find people at higher risk of lung cancer (the 'case finding' programme) and offer these patients intervention. For some people, this will include an offer of low dose non enhanced CT
- Engage people about lung health through a lung health check at a 'teachable moment'
- Signpost patients to lifestyles support services where appropriate
- Raise awareness of other cancer screening programmes, promoting uptake where possible
- Via the case-finding programme, identify a number of lung cancers at an earlier stage to enable early treatment and improve patient outcomes.
- Identify previously undiagnosed COPD (there are currently over 6,000 people with undiagnosed COPD in Liverpool: Long Term Conditions Programme Report: COPD, April 2014, Liverpool City Council)
- Contribute to the developing national policy and evidence around the early diagnosis of lung cancer.

The Liverpool Healthy Lung Programme has been running since April 2016. The programme is currently targeted at people aged 58-75, who have ever smoked or who are in this age group and have COPD.

The Liverpool Steering Group has agreed that Liverpool will:

- Finish the final areas of the city (1st full round of the city) by March 2020 as planned (according to the existing programme protocol and governance arrangements) to ensure that the original programme is completed equitably across the city.
- Use the next few months to work up a business case and plan to move to the national specification starting from 1st April 2020.
- Link with the Cheshire and Merseyside Cancer Alliances and NHS England to investigate funding opportunities/support, and how Liverpool can contribute data from April 2020 as part of the national evaluation which is being commissioned.
- In the meantime, we will undertake a further local independent evaluation to report on the full original programme, building on the previous two independent evaluation reports and utilising additional funding which has been provided to Liverpool via the Cancer Alliance.

Here is more information about the Liverpool Healthy Lung Programme:  
<https://www.liverpoolccg.nhs.uk/health-and-services/healthy-lungs/>

### 3. What challenges did you encounter along the way, and how were you able to solve them?

One of the biggest challenges is around increasing uptake (people who take up the invite of coming to the first appointment with the lung nurse). Average uptake remains at around 40% from the invited population. To try to address we are:

- Revamping communication and engagement materials available to the public, i.e. people who are potentially eligible for the programme. And also materials available to GP practices and other community healthcare staff/settings such as pharmacies, who are key partners in helping to promote and raise awareness about the programme in target patient groups. Part of designing these materials will include liaising with GP practices to ask what they may find useful.
- We are also undertaking an audit of uptake between two GP practices located in close proximity and who had quite different uptake (one practice around 30% uptake, the other around 50% uptake) to see if there is anything to be learnt.
- Invite letters have also recently been updated to include a pre-invitation, followed by an invite letter (in line with learning from other sites and screening programmes).

There are various other challenges which have been documented in the project lessons learned log and we can share other learning on request.

#### 4. What were the outcomes, and what impact did this have on patients and staff?

Two independent evaluation reports have been provided to-date (a third report will be delivered in March 2020) which showed:

- More than 80% of people attending the lung health checks are in the most deprived socioeconomic quintile, indicating that the programme is reaching deprived populations
- 10% of those without a pre-existing diagnosis of COPD will in due course be diagnosed with and treated for COPD following attending the lung health checks. The programme is detecting mild stages of respiratory disease in people who are likely to respond to treatment, which will help to improve their quality of life and prognosis.
- 2% of those scanned were found to have lung cancer. Stage I and II cancers comprised over 75% of the lung cancers diagnosed.
- The stage distribution of lung cancer indicated a reduction in mortality with 26% five-year survival in the cancers diagnosed in the programme, compared to the 10% which would be expected without the programme, more than a doubling of the five-year survival rate in cancers detected as a result of CT scans in the programme. This translates to an absolute prevention of 1 lung cancer death per 264-330 CT scans.
- The programme observed a rate of around 9% of nodules requiring further workup. This is a considerably lower rate than was observed in the randomised trials USA.
- A health economic evaluation undertaken as part of the ACE Proactive Lung Cluster report suggested that the programme was on the borderline of cost-effectiveness [9], at around £13,000 per quality adjusted life-year (QALY).
- There is considerable patient satisfaction from the programme, with enthusiasm that it continues and a willingness to encourage others to take part.

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#### FOR MORE INFORMATION ON THIS WORK, PLEASE SEE THE DETAILS BELOW:

Michelle Timoney  
Rachel Arvanitis

HealthyLung@liverpoolccg.nhs.uk

August 2019 Journal Lung cancer:  
<https://www.sciencedirect.com/science/article/abs/pii/S0169500219304702?via%3Dihub>

September 2018 mentioned in the Vision Film for the European Respiratory Society.

Independent evaluation report 2017/18:  
<https://www.liverpoolccg.nhs.uk/media/3245/final-lhlp-2nd-year-report-10-july-2018-with-logos.pdf>

Lancet oncology Dec 2017: [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(17\)30861-6/fulltext](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(17)30861-6/fulltext)

BMJ thorax 2017: [https://thorax.bmj.com/content/72/Suppl\\_3/A10.2](https://thorax.bmj.com/content/72/Suppl_3/A10.2)

Journal of Practice Nursing Sept 2017 (copies available on request). Also Nursing Times Magazine August 2017. GP Pulse Magazine August 2017. GP online magazine Aug 2017.

Posters have been presented, and some verbal presentations given at British Thoracic Society conferences over the years, and also the World Lung Conferences and also CRUK conference 2018 and NCRI 2017.

# APPENDIX

## JOINT NATIONAL WORKSHOP ON PROMOTING THE EARLY AND RAPID DIAGNOSIS OF LUNG CANCER

Friends' House, Euston, London, Wednesday 28th November 2018

### PROGRAMME

TIME	TOPIC	SPEAKERS
10.00am	Registration, coffee and morning refreshments	
10.30am	Morning session – Chair <b>Sara Hiom</b> : welcome and introduction	
	<i>'Rapid fire' presentations</i>	
	- Making the case for early and rapid diagnosis	<b>Prof Mick Peake</b> , UCLH
	<i>Practical aspects of lung cancer screening and 'targeted high risk case-finding' studies.</i>	
	- Introduction, including output of CRUK screening workshop and the NELSON Trial	<b>Prof Mick Peake and Dr Emma O'Dowd</b> , Nottingham
	- Examples from Manchester and Liverpool	<b>Dr Phil Crosbie</b> , Manchester <b>Dr Martin Ledson</b> , Liverpool
	- Engaging high risk populations	<b>Prof Kate Brain</b> , Cardiff
	Discussion: 'Next steps' screening and case finding	Chair – <b>Sara Hiom</b> with speakers, plus <b>Matthew Legg</b> , Programme Manager for early diagnosis, NHS England
11.20am	<i>Examples and impact of public awareness campaigns for lung cancer across the UK</i>	
	- Symptom Awareness Campaigns – so last season	<b>Dr Matt Callister</b> , Leeds
	- The Detect Cancer Early programme in Scotland	<b>Valerie Doherty</b>
	- What's been happening in Wales	<b>Dr Gareth Davies</b>
11.50am	Coffee	
12.10pm	- The primary care perspective: how, and how not, to diagnose lung cancer earlier	<b>Prof Richard Neal &amp; Dr Steve Bradley</b> , Leeds
	- Direct access to CT scans in primary care	<b>Dr Sadia Anwar</b> , Nottingham
	- Is there anything lung cancer can learn from the experience of Multi-Disciplinary Diagnostic clinics?	<b>Karen Fitzgerald</b> , ACE programme lead, CRUK
	- Rapid diagnosis: Rationale for, and progress in the implementation of, the NOLCP	<b>Dr Neal Navani</b> , UCLH
12.45pm	Discussion and introduction to afternoon workshop	<b>Sara Hiom</b> , CRUK



TIME	TOPIC	SPEAKERS
13.00pm	Lunch	
13.45pm – 15.15pm	Workshop sessions (with coffee)	
15.15pm	Feedback and discussion	
15.45pm	Summary and priorities for future strategies	Sara Hiom, CRUK
16.00pm	Meeting closes	

## AFTERNOON WORKSHOP SESSIONS

### Aims of the workshop:

- 1) to identify and define common problems and consider which, if tackled, would be likely to have the greatest impact on achieving earlier diagnosis and reducing inequalities, variation and outcomes in lung cancer
- 2) to hear about any new ideas or initiatives – delegates will be encouraged to come prepared to share details of initiatives in their own areas
- 3) to hear of experiences about what HAS already worked and what HAS NOT worked
- 4) to identify 3-4 actions that delegates are going to take back to their own teams for possible action

### Workshop topics:

**Group 1) Promoting earlier diagnosis:** covering public and primary care awareness and action; how to identify those most at risk and change behaviour, influencing positive action; engagement of the wider community health community (e.g. pharmacists, nurses, dentists, health centre staff); opening access to CXR by the public.

**Group 2) Promoting rapid diagnosis:** earlier identification of high risk patients in, and referral from, primary to secondary care, covering access to diagnostics in primary care, how better communication and collaboration regarding diagnostic pathways between primary and secondary care can reduce time to diagnosis; how to handle the increased workload that comes with lowering the risk threshold for referral; handling the need for very rapid access to reported CT scans.

*Where permission has been given, slides from the meeting can be accessed at [bit.ly/2NBCokX](https://bit.ly/2NBCokX)*

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**The UK Lung Cancer Coalition (UKLCC) is calling for a doubling of five-year lung cancer survival rates to 25% by 2025.**

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**UKLCC 25 x 25 Report - <http://bit.ly/2tzainA>**

In November 2016, the UKLCC published a ground-breaking report entitled '25 by 25: a ten-year strategy for improving lung cancer survival rates' which generated widespread UK media and political interest. The report calls for a drastic improvement in lung cancer care across the four UK nations in order to raise five-year survival rates to 25 percent by 2025



**UKLCC Millimetres Matter Report <http://bit.ly/2TGRyJI>**

The report provides information on the outputs of a one-day workshop held in 2018 around the National Optimal Lung Cancer Pathway and its implementation. It sets out:-

- The evidence base for why rapid diagnosis and the NOLCP is important
- What we already know works, which can support implementing the NOLCP
- Where the major remaining problem areas are in the pathway and what needs to be done to address those issues
- Some practical examples of best practice in implementing elements of the NOLCP



**UKLCC Molecules Matter Report - <http://bit.ly/368T3Tr>**

This report features the outputs of a workshop which brought together a select group of highly qualified experts in molecular diagnostics to try and define the issues that need to be addressed, and to propose a set of actions to ensure that every lung cancer patient in the UK has timely access to all the pathological detail of their tumour so that they can access whatever treatment is most likely to have a beneficial impact on their outcomes. If the UK wants to achieve the best cancer outcomes in the world, 4 then these issues must be addressed, and urgently

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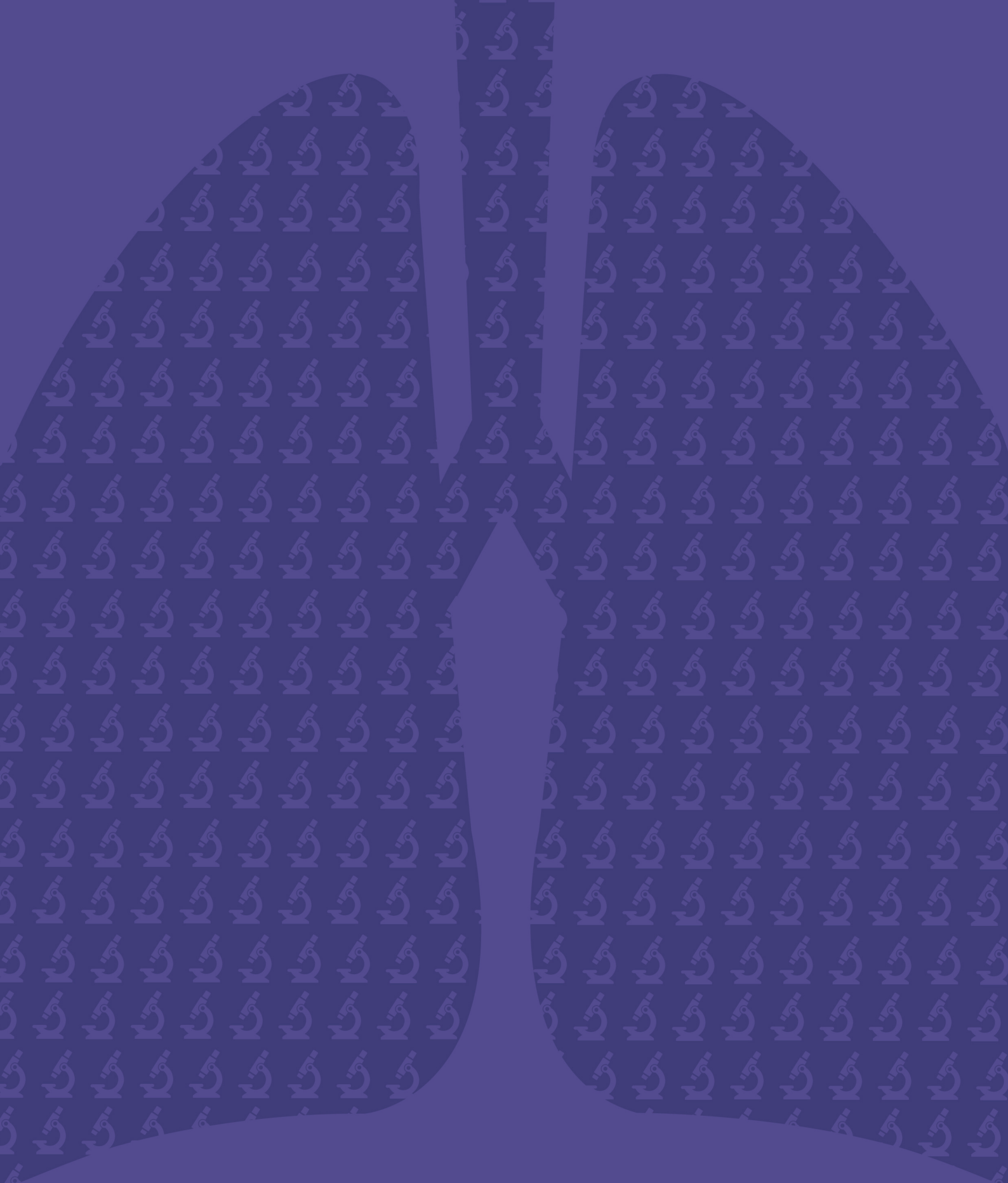
**Pathways Matter** - <http://bit.ly/3aqCxBA>

According to *Pathways Matter* – the first report to track uptake of NHS England’s National Optimal Lung Cancer Pathway [NOLCP] guidance and identify barriers – the appointment of a patient pathway navigator can help to more than double the number of lung cancer patients receiving treatment by day 49. However, securing funding for the role remains ‘challenging’, according to interviews among 17 of the 19 Cancer Alliances.<sup>1</sup>









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