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UNITED KINGDOM
LUNG CANCER COALITION

JANUARY 2020

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:

- 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

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FOREWORD

There is wide geographical variation in many aspects of lung cancer care, particularly in rates of treatment and survival.¹ This variation exists not only between the UK and many other countries with comparable economies, but also within the UK itself. If every patient diagnosed with lung cancer received the level of care that is apparent in the very best areas of the country, there would be a significant increase in the number surviving five-years or more.^{2,3}

The diagnosis and treatment of lung cancer has become more complex and is changing rapidly. This makes it impossible for every patient to have access to the full range of specialist clinical and technical skills available on his or her 'street corner'. Accessing more distant care poses both the clinical and organisational challenges of working across healthcare organisations and the logistical challenges of getting the patient and the specialist clinical team together. There is evidence that patients who are more deprived and/or who live further from a specialist surgical centre are around 40% less likely to have potentially curative surgical treatment.^{4,5} It is highly likely that variation in ease of access to specialist care is one of the major drivers of the regional variation in treatment and survival referred to above.

The UK Lung Cancer Coalition (UKLCC) has been calling for 'Universal Access to Specialist Care' for many years in different ways, including its '*Dream MDT*'⁶ and '*25 x 25*'⁷ reports. In the first of these it was argued that we should strive to establish clinical teams of the quality and range that we would wish for ourselves and our loved ones should we be unfortunate enough to be diagnosed with lung cancer; in the second, we set out a portfolio of actions that we believe could lead to an improvement in five-year survival rate to 25% by 2025.

In July 2019, the UKLCC held its annual Clinical Advisory Group meeting and this brief report highlights some of the

issues which were identified by our expert group at that meeting. They range from local organisational and clinical issues including patient communication and support, to how local and more distant clinical teams should work to ensure every patient is properly assessed and managed wherever they live. This brings in issues such as support for patient travel and accommodation, and the innovative use of digital communication technologies, but also raises the pervasive and perennial issue of workforce limitations.

To achieve our aim and the result that patients should expect and demand, there needs to be a response from the whole healthcare community, from clinicians and technical staff through to local trust managers, commissioners and those who are responsible for the NHS at its highest level. Too often, suboptimal care is leading to missed opportunities and poorer outcomes for patients. We must work together to make this a thing of the past, as quickly as we can.

Professor Mick Peake

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INTRODUCTION

We know that there is too much unwarranted variation in lung cancer care which is leading to sub-optimal outcomes for patients. The UKLCC is committed to the ambitious vision for a drastic improvement in lung cancer survival. In October 2016, the UKLCC published the report *25 by 25* which set out a 10-year strategy to raise five-year survival rates to 25% by 2025.⁷

Since this ambition was set, it is positive that several national level policy documents have been published to support local commissioners and clinicians to improve many parts of the lung cancer journey and deliver the *25 by 25* ambition:

- Lung Cancer Commissioning Guidance⁸
- National Optimal Lung Cancer Pathway⁹
- NICE NG122 Lung cancer: diagnosis and management¹⁰

These are excellent documents which will support service redesign at the local level and, if they were to be fully implemented, would transform the care provided to people with lung cancer. But we know that full implementation can be challenging and slow.¹¹ To consider these issues, the UKLCC convened a meeting of its Clinical Advisory Group (CAG) to identify some of the biggest barriers to the delivery of universal access to optimal lung cancer care across all four nations of the UK which could be tackled now.

This paper sets out the four themes which were identified by the CAG as priority areas for action. This is not an exhaustive list, but rather the output of a prioritisation exercise:

1. Service configuration – specialist vs local
2. Patient fitness assessment
3. Models of follow-up
4. Workforce issues

Each of these themes makes up a section of this paper. In these sections we have provided the context and evidence to demonstrate that actions or activities are contributing to unwarranted variations in treatment, care and outcomes for people with lung cancer. We have then set out what we see as the challenge, a proposed solution and a suggestion of how to make this happen.

This document is intended to provide some simple, practical ideas which clinicians, commissioners and policymakers could implement to help ensure that consistent and equitable treatment and care options are being offered to patients who present with similar profiles, regardless of where they live. This paper is primarily aimed at the clinical and support staff who work in lung cancer services, because this is the community of practice who can act now. However, some of the issues raised in this paper require action and support from commissioners and national policymakers.

The UKLCC is calling on all members of the lung cancer community to review this paper and assess if any of the ideas could be piloted or implemented in their service to help us achieve the ambition of achieving universal access to timely and optimal lung cancer care.

1. SERVICE CONFIGURATION - SPECIALIST VS LOCAL

The management and treatment of lung cancer is complex and therefore it is agreed that it is best for people with lung cancer to be managed by a specialist team.⁸

The benefits of centralising services include:

- a concentration of experts in one place
- easy access to specialised equipment and treatment techniques
- simpler inter-departmental communication and streamlined administration, which supports more rapid progress through the pathway

The benefits of a local service include:

- high standards of delivery of certain types of surgery, chemotherapy and radiotherapy
- more convenient and accessible, especially for people with lung cancer who have multiple appointments, are less fit and who are less able to afford transport costs

As discussed in a previous UKLCC report,¹² *Millimetres Matter*, centralising services can help to support faster diagnosis and treatment of lung cancer. The fragmentation of diagnostic tests, treatment and other services in local centres can mean that patients are more likely to experience delays. These unwarranted delays can allow the tumour to grow by just a few millimetres which can have a dramatic effect on the success of treatment.

While the need for specialists to care for every person with lung cancer is an important ambition, making this a reality is challenging. Making sure that a patient's disease and the services they require are appropriately matched, alongside considerations of convenience and patient preference is complex.

More effective hub-and-spoke relationships need to be developed to make decision-making as consistent and effective as possible. It has been suggested that one way to ensure that all patients get access to specialist services at a convenient location is for clinicians from specialist centres to hold clinics in local centres. The challenge with this approach is that clinical staff would waste valuable time travelling between sites, which could otherwise be spent with patients.

SOME OF THE KEY FACTS FROM ENGLAND

- Two thirds of people with lung cancer are seen at more than one hospital during their cancer journey¹³
- Specialist centres only give 30% of lung cancer treatment and smaller units give 70%¹⁴
- People with lung cancer are twice as likely to receive active anticancer treatment if they are seen by a lung cancer clinical nurse specialist (CNS)¹⁵
- People with lung cancer are 50% more likely to undergo surgical treatment if they are first seen in a thoracic surgical centre¹⁴
- 31% of MDTs discussed more than 30 patients in a single meeting¹⁶
- Only 43% of providers have a separate diagnostic MDT¹⁶
- People who are seen in a centre which has more people in clinical trials are more likely to get anti-cancer treatment¹⁷
- People who live a long way from a surgical centre or are deprived, are less likely to get surgery. This is compounded if the person is both far away and deprived⁵
- Centralisation of service provision increases geographical distances that are likely to further widen this deprivation gap⁵

Technology could be used to enable the input from clinicians in specialist centres to support the treatment of patients being managed in a local centre. There are already examples of specialists providing real-time clinical advice via video link. This is part of the solution, but eliminating unnecessary stages in diagnostic pathways, ensuring early senior assessment and fine-tuning communication systems all have a part to play.

At the very least, the Commissioning Guidance must be implemented by every lung cancer team. Evidence demonstrates that while national variation in the provision of services and workforce remain, adherence to the national lung Commissioning Guidance has the potential to improve patient outcomes within the current service structure.¹⁸

MAKING IT HAPPEN

Identified challenge	Proposed solution	Making it happen
The commissioning process is not working effectively. Commissioning Guidance (a Service Specification) has been developed by the Lung Cancer Clinical Expert Group. The guidance is for commissioners of specialised and non-specialised services. It includes details of the expertise and time commitment of the MDT members and priorities for healthcare improvement, what to commission and what to measure. The guidance was signed off by NHS England in August 2017 and sent to Trusts, STPs and Cancer Alliances for implementation. However, the guidance is not being followed in many areas of the country.	<p>Commissioning guidance to be recirculated to ALL commissioners, so that there is a clear expectation that there will be equal expertise available for all people with lung cancer.</p> <p>This communication should also reiterate the critical importance of strong communication to enable different services to work together efficiently and effectively to ensure that unwarranted delays are eliminated.</p> <p>Centres need to understand the areas where they are performing well, so that they can build on these successes. This information is captured in the National Lung Cancer Audit.</p>	<p>UKLCC will request that NHS England remind all commissioners of the Commissioning Guidance with a call to action to fully implement this in their local area.</p> <p>The <i>Getting it Right First Time</i> (GiRFT) programme should assess the expertise and time local MDT members commit to lung cancer care and red flag where this is not at least in line with the Commissioning Guidance.</p> <p>The GiRFT programme should assess the communications between different lung cancer services and teams, to ensure that resource is available to help 'join the dots'.</p> <p>Lung cancer teams should use the results of the National Lung Cancer Audit as a coaching and quality improvement tool.</p>
Processes and logistics are creating inefficiencies in the system and patient delays. ¹⁹	<p>The <i>National Optimal Lung Cancer Pathway</i> (NOLCP) has been developed to help provide a framework to create a more efficient up-front part of the pathway.</p> <p>The GiRFT programme for Lung Cancer will be examining the local implementation of the NOLCP but it is unclear the extent to which it will deal with issues of inter-trust referral.</p> <p>Standards of Care have been developed by the CEG for bundles of diagnostic tests. They are also in the process of producing SoC documents for surgery, complex radiotherapy and systematic treatment to ensure that there is a more standardised approach.</p> <p>The ACE Programme works collaboratively to support innovation across cancer pathways. The ACE3 work stream is focussed on identifying service design solutions to factors driving unwarranted variation in access to optimal standards of diagnostics and treatment, for patients diagnosed with lung cancer. The programme is supported by Cancer Research UK.</p>	<p>All those delivering lung cancer care should implement the NOLCP. The UKLCC's reports '<i>Pathways Matter</i>' and '<i>Millimetres Matter</i>' are useful resources containing ideas and examples of good practice.</p> <p>GiRFT should assess different approaches to inter-trust referral and determine which approaches are most successful. This should be used as a lever to introduce the organisational resources required to deliver world class services.</p> <p>The UKLCC CAG will support the CEG in disseminating these SoCs with the lung cancer community.</p> <p>The ACE3 case study portfolio (which is in development) should help to resolve some of the identified root causes of unwarranted variation in lung outcomes. The team can be contacted on ACEteam@cancer.org.uk</p>
Some patients would like the option of accessing specialist services and expertise closer to home when they don't live near a specialist centre.	<p>Technology could be utilised to allow staff from specialist centres to be involved in the treatment and care of patients at local services, without having to travel to the centre, wasting valuable time.</p> <p>The ACE3 programme are looking for case study examples of how teams have used digital technology to overcome issues. For example, how the use of video-conferencing to help manage the requirements of smaller centres and reduce professional travel time, and how 'virtual' appointment arrangements can meet patients' needs.</p>	<p>Local centres should identify what support it would be useful to access from specialist centres. Specialist centres should determine how they may be able to support local centres.</p> <p>Lung cancer teams who are using digital technology to create an effective hub and spoke model should contact the ACE3 team at Cancer Research UK to share their experience and ensure that learnings are spread.</p>

2. PATIENT FITNESS ASSESSMENT

One of the most important issues when determining if a patient is eligible for radical treatment, is assessing their fitness for that treatment. This is of particular importance in patients with early stage NSCLC who are considered of borderline fitness for surgery. However, the way that fitness is assessed is not standardised, meaning that the local approach to fitness assessment can impact on a patient's care and treatment plan, and be another factor leading to unwarranted variation in patient treatment and outcomes. Also, not all centres have the ability to offer a joint assessment with both a thoracic surgeon and a clinical oncologist with expertise in stereotactic ablative radiotherapy (SABR) which may also add to variation in access to such an alternative, potentially curative, therapy.

Pre-habilitation is of great value in many patients of borderline fitness, in making surgery possible and safer, but again timely access to a high quality pre-habilitation programme is not universally available.

AGE

Anecdotal evidence suggests that in some services/MDTs the age of a patient can influence whether they are offered active treatment or not, regardless of how well they are. There is evidence to suggest that we should have higher active treatment rates²⁰ and that unconscious bias based on a patient's age might contribute to patients not being properly assessed and therefore receiving sub-optimal treatment.^{21,22}

In February 2012, the Department of Health produced a report looking at *The impact of patient age on clinical decision-making in oncology*.²¹ The study explored clinical attitudes to age as a factor in approaches to cancer treatment, and the extent to which age influences clinical recommendations about the intensity of treatment which should be offered to patients. The study found that age was a significantly bigger factor than either comorbidities or social support in determining the intensity of treatment a clinician would recommend. Anecdotally, our CAG reported that, seven years on from this work, these challenges still exist.

For some people, radical treatments are not going to be appropriate because they would not be able to withstand them, but decisions should be based on an assessment of the patient's fitness or frailty not on their age.

DISEASE STAGE

The stage of disease – specifically for patients with stage IIIA NSCLC – also leads to a variation in approach. As treatment protocols have changed over time, it is now possible to treat more of these patients if they have a good performance status.

However, the National Lung Cancer Audit, Annual Report 2018 found that in England, in patients with non-small cell lung cancer *"For stage IIIA patients with good performance status (PS 0–2), 34% receive multi-modality treatment with chemotherapy and either surgery or radical radiotherapy, with a further 20% receiving surgery or radical radiotherapy alone. Although these results have improved compared with last year (31%), it still means that 46% of patients in this group are only given palliative treatments or supportive care."*²¹

PATIENT CHOICE

Patient choice is clearly a very important factor in treatment decisions. The 2018 Spotlight Audit conducted by the National Lung Cancer Audit examined reasons why patients with early stage disease and good performance status were not being offered surgery or other potentially curative treatment; patient choice was recorded as the reason why 31% of people did not receive such radical therapy.²³

While some of the decisions not to have surgery will be entirely appropriate and will have been made with informed decision-making, we know that patient choice can be strongly influenced by the way that care options are presented to patients by their clinical team or an individual clinician. Better understanding of the extent to which there is a relationship between the expertise of a clinical team or an individual clinician and the likelihood of a patient accepting a more radical diagnostic and therapeutic pathway warrants further investigation. As survival is often used as a surrogate marker for efficiency and effectiveness of the health service, a focus on ensuring that patients make an informed choice about potentially curative treatment is even more crucial.

MAKING IT HAPPEN

Identified challenge	Proposed solution	Making it happen
There is no standard way of performing a fitness assessment. This means that there may be variation between centres as to which patients do and don't get offered active treatment.	A common approach to assessment should be used, and, for older patients, should include some assessment of frailty such as the Comprehensive Geriatric Assessment tool, to determine how well a patient may tolerate treatment. All appropriate clinical staff should be trained in how to undertake the assessment so that variation between centres is reduced.	Appropriate fitness assessment frameworks should be agreed (ideally with more research to make them properly evidence-based). A survey of current practice is under development by the CRUK ACE3 team in collaboration with the Society for Cardiothoracic Surgery. The findings of such a survey, combined with expert opinion and examples of best practice, could then be used in the ACE3 programme to help reduce variation in how patients are assessed as fit for surgery. Once a common approach to the fitness assessment has been agreed upon, training and coaching should be rolled out to the whole networked team.
If a clinician is managing a patient remotely, they do not have the opportunity to assess their mobility, such as walking from the waiting room to the consulting room or up a flight of stairs. This can be an important informal assessment and is a key indicator of a patient's fitness for treatment.	Where possible, first consultations should take place face-to-face so that a clinician can see the patient perform routine tasks, which help to inform a fitness assessment. 'Real time' video consultations with distant experts may allow for some aspects of frailty to be assessed.	Clinicians should determine if it would be preferable to see a patient face-to-face for their first appointment. The benefits of this should be communicated to the patient. Lung cancer teams should be identified to experiment with live video-linked patient consultations.
Clinicians may make some treatment decisions based on a patient's age rather than their fitness. This means that some patients who are well enough to have treatment may be missing out.	Remove information about the age of a patient from MDT meeting notes so that unconscious bias based on age is reduced.	UKLCC to write to all MDTs, suggesting that they consider removing the age of patients from MDT meeting presentations to mitigate unconscious bias based on an individual patient's age.
Many patients pose particularly difficult problems where very high levels of specialism are required; these include: - patients with early stage disease who are of borderline fitness for surgery - patients with stage IIIA NSCLC where the delivery of concurrent combination chemo-radiotherapy may be the optimal treatment - patients with stages IIIB and IV NSCLC whose tumours exhibit mutations or translocations or where immunotherapy is being considered	On second opinions, the lung cancer commissioning guidance and NICE guidance states: <i>"People with resectable lung cancer who are of borderline fitness and not initially accepted for surgery are offered the choice of a second surgical opinion, and a multidisciplinary team opinion on non-surgical treatment with curative intent."</i> ²⁴ The ACE3 programme is in the process of developing case studies based on patients who present with complex problems, often classed as borderline for radical therapies. These case studies will be evidence-based, practical solutions. These will be available later in 2020.	All lung cancer teams should be implementing the service specification and offer patients a second opinion if their case is borderline. The ACE3 programme should publicise the case study compendium once it has been published. All lung cancer teams should review these case studies and examples of best practice to a) assess the extent to which they could enhance the quality of their own care and b) publicise any local successful innovations which could usefully be shared at other sites.

3. MODELS OF FOLLOW-UP

One of the biggest worries for patients during their lung cancer journey is not knowing what their next step is. Having a clear follow-up plan is essential in making sure that patients are appropriately engaged and supported, and that precious clinical time is not lost by such issues as non-attendance or missed appointments. As suggested in our report *Millimetres Matter*,¹² “no patient should be allowed to leave a clinic without knowing what their next step is and having appointments booked if possible. All patients should have a designated key worker (usually a lung cancer CNS) whom they can contact with any queries or concerns.”

Follow-up is an important step in every part of the lung cancer pathway. We heard from our CAG that there is no consistency in the way that longer-term follow-up is provided across the lung cancer teams and that this may ultimately impact on clinical outcomes and patient experience, in particular the early detection of recurrence. This is made even more important because there is evidence to demonstrate that it is important to manage the possibility of second primary cancers. To begin contemplating ‘curing’ lung cancer patients for the long term we need to be thinking about long term follow-up from the very beginning of the cancer journey.²⁵

NICE guidance on *Lung cancer: diagnosis and management*¹⁰ recommends:

- Offer all people with lung cancer an initial specialist follow-up appointment within 6 weeks of completing treatment to discuss ongoing care. Offer regular appointments after this, rather than relying on the person requesting appointments when they experience symptoms
- Offer protocol-driven follow-up led by a lung cancer clinical nurse specialist as an option for people with a life expectancy of more than 3 months
- Ensure that people know how to contact the lung cancer clinical nurse specialist involved in their care between their scheduled hospital visits

While the NICE guidance is a useful starting point, it doesn't provide any detail about how follow-up should be delivered and how patients should be stratified to ensure that they receive the specific follow-up support that they require (both from the clinical team and through self-management).

We heard from our CAG that in certain circumstances follow-up is being organised which doesn't use clinical resources efficiently. A specific example was described where in England thoracic surgeons hold follow-up appointments with their patients which means precious clinical expertise and time is taken away from surgery. It was reported that this follow-up does not need to be delivered by the thoracic surgeon specifically and could be delivered by another member of the lung cancer team, such as a CNS. In Wales, thoracic surgeons don't do any follow-up as this is delivered by local lung cancer teams, usually by nurses. This demonstrates the crucial role of team work. Nurses are highly skilled and surgeons respect their nursing colleagues to take forward this important part of the care package. Patient reported outcome measures (PROMs) and patient experience measures (PREMs) are being introduced to assist with these assessments.

Alternatives to face-to-face clinical follow-up are being investigated to ensure that patients receive the follow-up that they need and to ensure that clinical time is being optimised. For example, a study which was presented at ASCO in 2017 looked at the use of electronic self-reporting of symptoms for patients undergoing chemotherapy.²⁶ This study was made up of patients with different cancer types, but 26% of participants had lung cancer. The study compared ‘usual care’ for patients receiving chemotherapy vs ‘web-based symptom monitoring’ with patient-reported outcomes, over a seven-year period.

The patients in the 'web-based symptom monitoring' arm of the study self-reported 12 common symptoms via a tablet or computer. Patients could report these symptoms from home and a healthcare professional would respond when the system alerted them to problems which required actions to alleviate suffering and to improve outcomes. In the 'usual care' group, patients discussed their symptoms during appointments and had the option to call the doctor's office between visits if they were worried about symptoms. The study found that doctors and nurses were unaware of severe symptoms up to half of the time.

The study reported that the patients in the 'web-based symptom monitoring' arm lived approximately five months longer than those assigned to the usual 'care arm'. The lead investigator concluded that a web-based approach to symptom monitoring should be "considered for inclusion as a part of standard symptom management, as a component of high-quality cancer care."²⁷

Self-monitoring using technology may, in certain circumstances, be an appropriate way for patients to self-care and to ensure that follow-up is targeted, and intervention can happen at the right moment.

MAKING IT HAPPEN

Identified challenge	Proposed solution	Making it happen
Face-to-face follow-up with clinicians may not be effective or necessary for every patient. This takes time and resources away from the delivery of active treatment and care of other patients who may benefit more.	Further work should be done to understand what research and evidence exists around different types of follow-up to better understand how to stratify patients.	Lung cancer centres should share examples of different follow-up protocols and their impact on clinical services and patient outcomes.
In several thoracic surgical centres follow-up is regularly done by thoracic surgeons themselves, diverting them from their primary skills of conducting complex surgery.	Where appropriate, nurses should lead on a patient's follow-up. This mirrors what happens in Wales.	Thoracic surgery sites should evaluate how much time is devoted by surgeons to follow-up and how to appropriately move this workload to other members of the team.
Early detection of recurrence is important in ensuring patients have access to second and subsequent lines of treatment.	Ensure patients understand what symptoms they should be aware of which might indicate recurrence and have rapid access to their key worker (usually a CNS) to trigger clinic review where appropriate.	<p>Lung cancer services who are delivering symptom-led access to clinics and piloting innovative ways of detecting recurrence should publicise this work so that the learnings can be spread.</p> <p>Where possible, resource – time and small amounts of money – should be allocated to help so that teams can get together to learn from one another and share learnings.</p> <p>The ACE3 programme is seeking examples of where lung cancer teams are using digital technology to overcome issues, so lung cancer teams using web-based symptom monitoring should contact the ACE3 programme.</p>

4. WORKFORCE ISSUES

Workforce shortages are a major limiting factor in achieving universal access to optimal lung cancer services. There are a range of different issues at play and the UKLCC intends to do further work on this in 2020.

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.⁸ Compliance with this standard was measured in the *National Lung Cancer Audit – Second Organisational Audit* 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.

RECOMMENDATION	2017 n (%) ¹⁶
1 whole time equivalent respiratory physician (10 programmed activity) per 200 new diagnoses per year	79 (60%)
Radiologist with 1/3 of their job plan devoted to thoracic imaging	107 (81%)
Medical oncologist with 1/3 of their job plan devoted to lung cancer	77 (58%)
Clinical oncologist with 1/3 of their job plan devoted to lung cancer	90 (68%)
1 whole time equivalent lung cancer nurse specialist per 80 new diagnoses per year	24 (18%)

The worryingly low attainment against the standard for CNSs is a sign that these posts are not being as highly valued as they should be. CNSs have a critical role to play in helping patients to navigate the pathway and help members of the clinical and administrative team to communicate and work effectively together.

In addition to the results of the Audit our CAG has identified some of the workforce challenges that they see in their clinical practice. This is not an exhaustive list, but it helps to contextualise some of the workforce challenges we are facing.

Radiology

Radiology is a specialism which is busier than ever and where a significant number of posts are currently unfilled both in England and Wales.²⁸ This shortage of radiologists impacts not only on the timeliness of tests and their reporting, but also on the quality of the reports. With more complex tests being introduced these take more time to report. Capacity constraints also impact on timely access to image-guided biopsy.

Chest X-ray reporting by radiographers has been shown to be an effective and efficient way to create additional capacity within imaging and shorten the time to diagnosis of lung cancer if implemented as part of the national optimal lung cancer pathway.²⁸

From a lung cancer perspective, it is important to remember that imaging touches every urgent pathway, not just lung cancer. Therefore, demands on the radiology workload comes from many different specialities.

CNSs

The CNS role is currently threatened in two different ways. The first wave of CNSs is rapidly reaching retirement age. This means that many of the experienced and talented nurses who have been in these roles since they were established are likely to retire around the same time as each other.

We are also aware that some CNS posts are being down-graded or the CNS role is not being replaced when individuals leave. This is reducing the overall number of experienced CNSs.

Pathology

Pathology (and the associated molecular pathology) is of ever-increasing importance in the diagnosis of lung cancer. The Royal College of Pathology conducted a workforce census in 2018 which found that only 3% of histopathology departments have enough staff to meet clinical demand.²⁹ The census also shows that staff retirement could make this problem worse, with a quarter of all histopathologists aged 55 or over.

Clinical trials

Clinical trial entry requires additional time from medical and nursing staff. Clinical Trials Units report that recruitment to trials is falling and increasing demands on clinical time is a major factor in this decline.

It is important to remember that not only do workforce shortages have an impact on clinical outcomes and patient experience, they can have a huge effect on job satisfaction for clinicians.

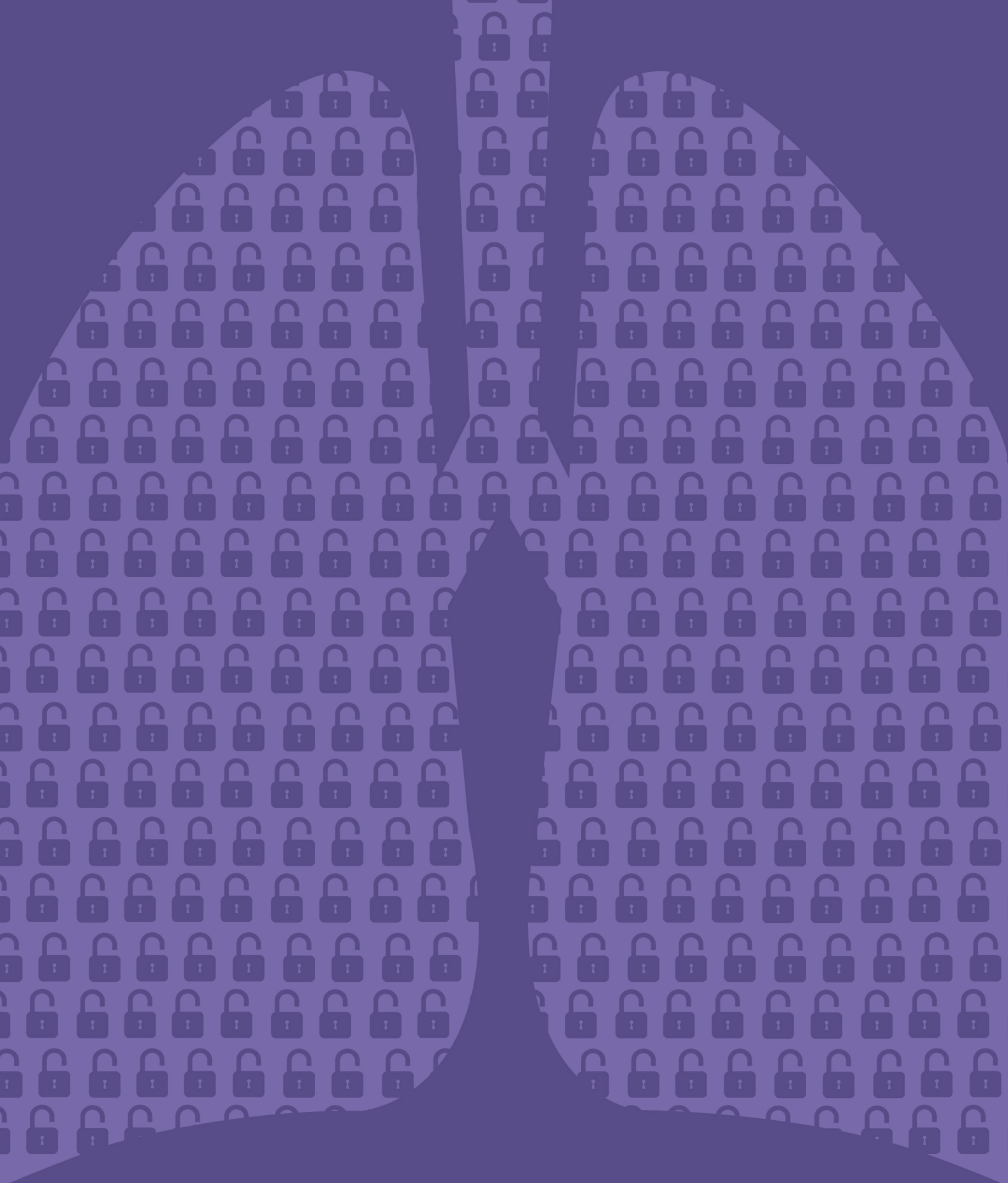
To better understand services, the GIRFT programme is conducting a national review into services for people with lung cancer. The review will focus on making improvements in line with the roll-out of the National Optimal Lung Cancer Pathway. The first element of its work will be to compile data packs for 133 individual trusts in England, as well as six tertiary centres. This will then be followed up with deep dive visits to all trusts and centres which are scheduled to be completed in by July 2020.³⁰ A national level report will follow this which will include data, GIRFT's findings, examples of best practice and an action plan of proposed changes and improvements. It is not clear if this piece of work will consider the workforce, but we would urge the GIRFT team to take this in to account in their investigations as it is a critical element in implementing the National Optimal Lung Cancer Pathway.

MAKING IT HAPPEN

Identified challenge	Proposed solution	Making it happen
Issues related to the lung cancer workforce are complex and manifold. Without acting, things are likely to get worse in the short term, so action needs to be taken.	<p>Detailed work is required to look at each speciality in the lung cancer workforce, to review the existing data on workforce numbers and defining the scale and impact of shortages on lung cancer care, together with suggesting some possible solutions.</p> <p>Different specialities have conducted their own workforce census, but these have not been brought together to give an overview of the full lung cancer workforce situation.</p> <p>National Commissioning Guidance sets out how much clinical capacity each service should have.</p> <p>The NLCA organisational audit could be expanded to collect more information about the workforce in different services and if there is a hub and spoke model between different trusts.</p> <p>ACE3 are developing case study analysis on network solutions to diagnostics in constraint, for example looking at how pooling manpower resources can help resolve individual trust capacity and expertise issues.</p>	<p>To be included as a significant part of the UKLCC's work programme for 2020.</p> <p>The GIRFT team should consider workforce in their investigations as it is a critical element in implementing the National Optimal Lung Cancer Pathway.</p> <p>Trusts should review the report from the GIRFT team, providing feedback on their lung cancer service and implement recommendations.</p> <p>Lung cancer teams should assess their capacity compared to the Commissioning Guidance and propose an action plan to achieve the levels if they are not achieving these.</p> <p>The UKLCC will engage with the National Lung Cancer Audit team to determine if there is an opportunity for the UKLCC to support and enhance a future organisational audit to ensure that it captures workforce issues within their scope of work.</p>

REFERENCES

1. Royal College of Physicians, National Lung Cancer Audit – Annual Report 2018 (for the audit period 2017), May 2019
2. Riaz SP, Lüchtenborg M, Jack R, Coupland V, Linklater K, Peake MD, Möller H. Variation in radical resection for lung cancer in relation to survival: population-based study in England 2004-2006. *Eur J Cancer*, 2012;48:54-60
3. Möller H, Coupland VH, Tataru D, Peake MD, Mellemgaard A, Round T, Baldwin DR, Callister ME, Jakobsen E, Vedsted P, Sullivan R & Spicer J. Geographical variations in the use of active cancer treatments are associated with survival of lung cancer patients in England: national cohort study. *Thorax*, 2018;73(6):530-7
4. Crawford SM, Sauerzapf V, Haynes R, et al. Social and geographical factors affecting access to treatment of lung cancer. *Br J Cancer* 2009;15; 101(6):897-901
5. Peake MD. Deprivation, distance and death in lung cancer. *Thorax* 2015;70:108-10
6. UKLCC, The dream MDT for lung cancer: Delivering high quality lung cancer care and outcomes, November 2012
7. UKLCC, 25 by 25 – A ten-year strategy to improve lung cancer survival rates, October 2016
8. Lung Clinical Expert Group, Commissioning Guidance for the Whole Lung Cancer Pathway, April 201
9. Lung Clinical Expert Group, National Optimal Lung Cancer Pathway, August 2017
10. NICE, NG122 - Lung cancer: diagnosis and management, 28 March 2019
11. UKLCC, Pathways Matter: A review of the implementation of the National Optimal Lung Cancer Pathway, October 2019
12. UKLCC, Millimetres matter: Implementing the National Optimal Lung Cancer Pathway, November 2018
13. Personal communication from Prof Mick Peake, based on National Lung Cancer Audit Data
14. Rich AL, Tata LJ, Free CM, et al. Inequalities in outcomes for non-small cell lung cancer: the influence of clinical characteristics and features of the local lung cancer service. *Thorax* 2011;66: 1078–84
15. Health and Social Care Information Centre, National Lung Cancer Audit Report, 2014
16. Royal College of Physicians, National Lung Cancer Audit – second organisational audit, January 2018
17. Rich AL, Tata LJ, Free CM, Stanley RA, Peake MD, Baldwin DR, Hubbard RB. How do patient and hospital features influence outcomes in small cell lung cancer in England? *Br. J Cancer*, 2011;105: 746-752
18. Adizie JB, Khakwani A, Beckett P, et al. Impact of organisation and specialist service delivery on lung cancer outcomes. *Thorax* 2019;74:546-550.
19. Lung Clinical Expert Group, Standards of Care for Lung Cancer, 2019 <https://www.roycastle.org/for-healthcare-professionals/clinical-expert-group/>
20. Arnold M, et al. Progress in cancer survival, mortality, and incidence in seven high-income countries 1995–2014 (ICBP SURVMARK-2): a population-based study. *Lancet Oncol* 2019; 20: 1493–505
21. Department of Health, The impact of patient age on clinical decision-making in oncology, February 2012
22. M D Peake, S Thompson, D Lowe and M G Pearson. Ageism in the management of lung cancer. *Age and Ageing*, 2003; 32, 171 - 177
23. Royal College of Physicians, National Lung Cancer Audit – Annual Report 2017 (for the audit period 2016), January 2018
24. Lung Clinical Expert Group, Service Specification for Lung Cancer, 2015 http://documents.roycastle.org/Lung_Service_SpecificationV8DRAFT.pdf
25. Barclay ME, Lyratzopoulos G, Walter FM, et al. Incidence of second and higher order smoking-related primary cancers following lung cancer: a population-based cohort study. *Thorax* 2019;74: 466-472.
26. Ethan M. Basch MD, et al. Overall survival results of a randomized trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *Journal of Clinical Oncology* 35, 2017 (suppl; abstr LBA2)
27. Oncology Pro, Simple web-based tool to self-report chemotherapy side effects helps extend overall survival of patients with metastatic solid tumours, 7 June 2017
28. Royal College of Radiologists, Clinical radiology: UK workforce census 2018 report, April 2019
29. Royal College of Pathologists, Meeting pathology demand – Histopathology workforce census, September 2018
30. GIRFT, GIRFT starts work on lung cancer review, 12 August 2019



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