



# Lung Cancer GIRFT Programme National Specialty Report

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I am delighted to recommend this Getting It Right First Time (GIRFT) review of lung cancer, led by Paul Beckett, Sarah Doffman and Liz Toy.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The unprecedented events of 2020/21 – and the extraordinary response from everyone working in the NHS – add greater significance to GIRFT's recommendations, giving many of them a new sense of urgency.

Actions in this report, such as optimising lung cancer pathways and streamlining diagnostic pathways to minimise patient visits and appropriately order investigations, can help the NHS as it faces the substantial challenge of recovering services, while remaining ready for future surges, by operating more effectively and safely than ever before.

Paul, Sarah and Liz, alongside lung cancer nurse specialists Victoria Anderson and Monica Hugh, have brought the GIRFT approach to NHS lung cancer services. Nearly 50,000 people per year in the UK are affected by a new lung cancer diagnosis, and sadly only around 16% of patients diagnosed with lung cancer will survive for five years or more. Earlier diagnosis and treatment, and the development of new therapies in the past decade, offer opportunities for better outcomes, or improved quality of life and reduced symptom burdens for people living with lung cancer.

The recommendations and findings in this report are based on visits to 71 trusts and deep-dive meetings with many lung cancer multidisciplinary teams. This report is the first GIRFT review to address a whole cancer pathway, with a focus on the diagnostic pathway but also including aspects of treatment, palliative and end of life care. The report sets out 33 recommendations which, if implemented, will support the NHS to deliver more rapid and precise diagnosis and reduce variation in treatment rates and options.

I am pleased to hear that the GIRFT clinical leads have seen so many examples of innovation in their deep-dive visits, some of which are featured in this report.

Like clinical leads before them, Paul, Sarah and Liz were impressed and humbled by the dedication and hard work of all involved in lung cancer care, their honesty in discussing unwarranted variation and their enthusiasm to tackle it.

This is essential to the GIRFT programme, which cannot succeed without the backing of clinicians, managers and everyone involved in delivering services.

With the recommendations and actions set out in this report, and the urgency added by the COVID-19 pandemic, I hope that GIRFT will provide further support and impetus for all those involved in lung cancer services to work together, shoulder to shoulder, to improve treatment, care and outcomes for our patients.



#### Professor Tim Briggs CBE

**GIRFT Programme Chair and National Director of Clinical Improvement for the NHS** Professor Tim Briggs is Consultant Orthopaedic Surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs. He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs. Professor Briggs is also National Director of Clinical Improvement for the NHS. We are delighted to publish our review of NHS lung cancer services, which was commissioned jointly with the NHS England National Cancer Programme. We are grateful to NHS England, the National Cancer programme and the Cancer Alliances for their partnership and support in the planning and delivery of this, the first Getting It Right First Time (GIRFT) review of a whole cancer pathway. We are also grateful to the entire GIRFT team for their support and hard work through this most challenging of times.

The GIRFT methodology has already been established as an effective model to highlight, challenge and reduce unwarranted clinical variation, and so by bringing together a wide range of data sources, this was an exciting opportunity for us to engage with lung cancer teams across England and to gain a much richer understanding of the reasons for variation in outcomes from lung cancer across the country.

From an initial expectation that we would focus on the diagnostic pathway, the project expanded significantly to include aspects of care from diagnosis to treatment, and through to supportive, palliative and end of life care or cure. Subsequently in March 2020, the emergence of the COVID-19 pandemic became the most dramatic focus of the NHS, profoundly affecting not only how cancer services were delivered but also how patients interacted with them. It was incredibly humbling to see how hard teams worked through the pandemic and fought to preserve and protect their lung cancer services and patients from the effects of COVID-19. We are grateful for teams enabling our visits to continue, albeit remotely, in between the peaks of pressure encountered.

Currently only around 16% of patients diagnosed with lung cancer in the UK will survive for five years or more. For many years, the lung cancer clinical community has been aware of variation in outcomes for patients, both within the UK and between other countries with similar healthcare systems. Although these outcomes have been steadily improving over the past decade, the pace of change has been relatively slow. There are now a wide variety of treatments available for patients, and this complexity means that a high level of expertise is needed within lung cancer clinical teams in order to appropriately characterise the type and the stage of the tumour, to assess a patient's fitness for treatment and to deliver these therapies with maximum effect and minimal toxicity. Ensuring that all patients have equitable access to this expertise, as well as to all the available diagnostic and therapeutic modalities, is a consistent theme of our report. Likewise, we have maintained a strong focus on support of patients and their carers throughout their cancer journey, and highlighted ways in which experience of care and quality of life can be improved.

A criticism of this report may be that it is overly long; we make no apology for this. We were able to access a number of detailed datasets which, along with the deep-dive visits to teams, told a comprehensive story of the variability in lung cancer care across England.

We have reflected deeply on the reasons for this variation in order to determine our recommendations. During our visits, we were inspired by the honesty shown by teams of clinical and non-clinical staff to recognise problems and their enthusiasm to engage with colleagues to address them.

We resisted the urge to distil the recommendations down to a shortlist of a handful only, as we felt strongly that this would undermine the integrity of the GIRFT process in truly determining the complex reasons behind variability in care, and the need for collaboration to address this across the entire healthcare system. However, we reached a consensus in the team that a keen and urgent focus on a smaller number of universal themes is pertinent to all stakeholders responsible for the care of patients with lung cancer, as follows:

- Rapid national roll-out of risk-based lung cancer screening to detect early stage disease and, in time, lead to a
  reduction in late and emergency presentations. This would require an accompanying increase in access to CT scanners
  and radiologists to report the scans to facilitate its implementation.
- Improving access to treatment and increasing overall radical treatment rates with all treatment modalities (surgery, radiotherapy including SABR, multimodality treatment for stage III disease and thermoablative techniques).
- Uniform access to prehabilitation (including smoking cessation support), rehabilitation and specialist palliative care from the point of referral to end of life.
- Respiratory teams moving to a system of proactive management of patients from the point of first abnormal radiology report, and rapid implementation of daily triage to drive forward the diagnostic pathway.
- A standard of seven calendar day positron emission tomography (PET) turnaround (with measures taken to address services not adherent) moving to five calendar day turnaround as soon as national contracts can be renegotiated, given the need for early, upfront PET and the subsequent impact of delays on the remaining diagnostic pathway.

We recognised a strong desire to deliver the highest quality care and saw many examples of innovative practice, some necessitated by COVID-19, that have the potential to make widespread and meaningful improvements to patient outcome and experience, as well as to the cost and efficiency of NHS services. We remain hugely impressed by the dedication and care we bore witness to in all of our visits and discussions.

Throughout our visits and in this report, we have endeavoured to ensure that patients are at the heart of our recommendations, and to not allow structural issues within the NHS to affect our judgement. These recommendations must not remain as ink on a page, but must be considered and implemented at local, regional, and national level by those responsible for commissioning and delivering services. GIRFT implementation managers are already working with those trusts we have visited to assist in addressing action points. Cancer Alliances have a critical role in monitoring this implementation, and in co-ordinating a regional approach to managing capacity and demand, and to ensuring equitable access to expertise across their regions.

We are confident that our colleagues will rise to the challenge, but we do recognise that there are important considerations for national bodies as well. The NHS has significantly lower access to diagnostic testing capacity (such as CT and CT-PET) than other countries. Similarly, there are widespread gaps in the workforce, particularly in radiology, pathology and oncology, which need to be addressed if timely, expert care is to be delivered to all.

We would like to thank all the individuals and organisations who have supported our work and the stakeholders whose comments have been invaluable in producing this report.



#### **Dr Paul Beckett**

Dr Beckett is consultant respiratory physician at University Hospitals of Derby and Burton. He has been a clinical lead for the National Lung Cancer Audit for more than 10 years. He is a member of the Royal College of Physicians Quality Improvement Faculty, combining both theoretical and practical experience in delivering service improvement.



#### Victoria Anderson

Victoria is a lung cancer nurse specialist at the Newcastle upon Tyne Hospitals NHS Foundation Trust. She has been an LCNS for ten years and is an elected committee member for Lung Cancer Nursing UK.



#### **Dr Elizabeth Toy**

Dr Toy is a consultant clinical oncologist based at the Somerset NHS Foundation Trust. Currently she serves on the National Lung Cancer Expert Reference Group and has previously been a member of the Chemotherapy Clinical Reference Group.



#### Monica Hugh

Monica is a lung cancer nurse specialist at the University Hospitals of Derby and Burton NHS Foundation Trust. She has been an LCNS for ten years and is an elected committee member for Lung Cancer Nursing UK.



#### **Dr Sarah Doffman**

Dr Doffman is a respiratory physician and former divisional lead for medicine, and a past Chair of the Sussex Cancer Network Lung Tumour Group.





A new diagnosis of lung cancer affects nearly 50,000 people per year in the UK and lung cancer is the largest contributor to cancer-related death in both men and women, responsible for 35,000 deaths per year. Outcomes for lung cancer in the UK lag behind those for many comparable countries.

Sadly, many people have symptoms for some time before seeking medical attention despite numerous public campaigns to raise awareness of the early features of the disease. Furthermore, the symptoms of lung cancer are non-specific and very common in many people without the disease. This leads to the challenging situation of the majority of newly diagnosed cases being diagnosed at an advanced stage of disease. The armamentarium of treatment options has expanded considerably over the last ten years and continues to do so, which opens up options for treatment which can impact on survival even for advanced disease.

The imperative to reach a diagnosis and subsequent treatment cannot be underplayed, both in improving survival but also the quality of life and symptom burden for those living with lung cancer. There is much evidence to demonstrate better outcomes from reaching a diagnosis and subsequent treatment rapidly. This led to the development of the National Optimal Lung Cancer Pathway (NOLCP) with key targets of 28 days to communication to the patient of their diagnosis and 49 days to commencement of the first treatment from the point of an abnormal chest X-ray report or urgent referral.

However, there remain obstacles to achieving the goal of a faster diagnosis and earlier treatment in access and service configuration in primary, secondary and tertiary care.

### About this report

This was an ambitious programme of work, with visits planned to 137 NHS trusts, many of whom hosted two or more lung cancer multidisciplinary teams, all within a relatively short timeframe. Additionally, our work was interrupted and subsequently made considerably more difficult by the onset of COVID-19.

We were not resourced to examine healthcare delivery within primary care, living with and beyond lung cancer; the quality of and access to community and hospice services; nor how best to optimise follow-up after treatment, beyond what we had access to within our datasets and discussed with local teams at GIRFT deep-dive visits. This is not because these aspects of a person's journey are less important; simply a reflection of the enormity of that task. Since those aspects are common to many cancer sites, they would lend themselves better to a separate in-depth analysis.

Using the datasets available to us, informed further by our discussions with teams on deep-dive visits across England, we have made a series of recommendations for local, regional and national prioritisation, focusing particularly on the following aspects of lung cancer care which offer the most significant opportunities for improvements in outcome:

- making a rapid and precise diagnosis;
- delivering effective treatment;
- effective multidisciplinary working;
- improving data and information;
- resources, organisation and accountability.

### Making a rapid and precise diagnosis

The diagnostic pathway in lung cancer is complex, involving a number of investigations which may or may not be delivered on site at the base hospital, are influenced by the results of other steps in the pathway and are dependent on service configurations which are not designed with a faster pathway in mind. To achieve a more rapid diagnosis within the mandated 21 calendar days of the NOLCP, trusts need to ensure:

- Increased ownership and accountability by lung cancer teams to accelerate the diagnostic pathway for patients from the point of an abnormal chest X-ray onwards.
- Triaging new referrals with a suspected cancer diagnosis and reviewing results of completed investigations is carried out daily, with space in respiratory medicine cancer clinics available on at least three days across the working week.
- Scheduling of endoscopic bronchoscopic ultrasound (EBUS) lists (and indeed other diagnostic procedures such as CT-guided biopsy) should be more frequent than weekly to avoid rollover delays to the following week, with capacity meeting or exceeding demand.

- A navigator is in place within each lung cancer team to co-ordinate each step of the pathway and ensure results are available where tests are interdependent.
- Unnecessary delays in PET-CT imaging are eliminated and the ability for a clinician to directly book an available slot should be facilitated where possible. Images and a detailed report containing all the key required information should be available to the lung cancer team within seven calendar days of the request to enable next steps in the pathway to proceed.
- Job plans should enable adequate clinical administrative time to allow for daily actions or decisions by members of the lung team to review results and act on them accordingly. An overreliance on the multidisciplinary team meeting (MDM) for decision-making is inefficient and inappropriate.
- Turnaround times for a comprehensive cytology or histopathological report are improved by working collaboratively and innovatively across Cancer Alliances or regions, and alongside the genomic laboratory hubs (GLH).
- The considerable workload of the investigation and follow-up of lung nodules is resourced separately from the lung cancer service, using an appropriately skilled workforce and administrative support, and is not merely subsumed into the workload of an already overstretched team.

### **Delivering effective treatment**

To improve outcomes from lung cancer in the UK, a focus on ensuring patients are offered timely access to the most effective treatments is required. Throughout our visits we found evidence of significant variation in treatment rates between trusts, not only in patients being treated with curative (also known as radical) intent, but also in the utilisation of multimodality treatment techniques, access to palliative treatments including specialist palliative care, and to clinical trials. This is despite the variation having been highlighted over many years of national audit and the lung cancer community being highly engaged in delivering high quality care. Based upon our deep dives, where we discussed extensively the reasons contributing to variation, we identified a number of contributory causes and made recommendations to improve treatment rates and therefore outcomes:

- More patients with early-stage disease and good performance status should receive curative-intent treatments, with a benchmark of 85% to be expected from all providers. We set out a series of actions required to achieve this including roll-out of stereotactic radiotherapy (SABR) provision, an increase in surgical resection, use of 'high-risk' multidisciplinary teams (MDTs), increased use of local and regional audit, and through peer support.
- All MDTs should have access to a variety of techniques to optimise patients prior to curative-intent treatment, including prehabilitation and smoking cessation.
- Consultations with patients and carers should ensure that the full range of options are discussed. Ideally joint
  consultations with an oncologist and surgeon should be facilitated either in person or utilising remote consultation to
  ensure truly shared decision-making.
- The MDT should ensure that they have access to all available specialists and treatments through their core membership 52 weeks per year and that implementation of best practice surgical techniques (e.g. minimal access approaches) and radiotherapy techniques (e.g. intensity-modulated radiation therapy (IMRT)) is standard.
- Treatment should commence within 21 days from the decision to treat for surgery and within 16 days for radical radiotherapy, in line with the NOLCP and radiotherapy consensus guidelines, to avoid the risk of disease progression and the need for repeat staging.
- All MDTs should consider carefully their use of multimodality treatment in stage III non-small cell lung cancer (NSCLC) and in future this should be recorded and reported in the National Lung Cancer Audit (NLCA). The Cancer Alliances should keep this high on the agenda for regional discussions and review.
- MDTs should be able to achieve systemic anticancer treatment (SACT) rates in fit patients of good performance status (PS) (0-1) of over 70% for both advanced NSCLC and small cell lung cancer (SCLC), and this should commence within 14 days for at least 80% of patients. Additionally, flagging systems to speed up referral to oncology for small cell lung cancer should be implemented more widely.
- Early access to effective symptom control through enhanced supportive care and specialist palliative care enhances outcomes and should be core to all lung cancer services.
- All patients should have access to clinical trials, yet this was striking in its variability across organisations. Cancer Alliances have a valuable role to play in ensuring equitable access to the latest research and innovation in lung cancer.

### Effective multidisciplinary working

Multidisciplinary working is at the heart of lung cancer care, crystallised in the multidisciplinary team meeting (MDM), where treatment options are agreed. We found evidence in our deep dives of exemplar patient-centred team working, with many teams embracing the rapid rollout of improved digital technology (as a result of COVID-19) to hold MDMs remotely, thereby improving overall attendance by core members particularly those based at a distance from the relevant trust. However, MDMs are a costly and limited resource and we identified ongoing challenges which require attention to maximise their effectiveness.

- A diagnostic MDM should be held more than once weekly (ideally daily triage should be implemented), in order to avoid delays of several days.
- Treatment MDMs are an important means of discussing potential options for a patient based on all available results and should be attended by all core members and held at least once weekly, ideally at a point in the week to dovetail with the results of investigations and timings of diagnostic lists.
- Streamlining of the MDM should be undertaken as standard, enabling greater efficiency of the meeting and appropriate time for decision-making regarding patients with more complex disease. This requires dedicated time within job plans to prepare the list for discussion and allow prioritisation of cases. The list can be separated into sections to allow for certain clinicians to attend only for the sections of the meeting relevant to them.
- The MDT should take action to ensure that the MDM is not used inappropriately as a means of chasing up results, reviewing unreported scans, or discussing non-cancer cases.
- Communication of outcomes from an MDM should be rapid and comprehensive, both to patients and to primary care or other relevant clinicians.

### Improving data and information

Clinical teams working within lung cancer services have long committed to submit data to a high-quality national audit (the NLCA) and it has helped many services to focus on areas to improve or challenge practice. We saw evidence in deep dives and in the data sets we reviewed of the commitment of clinical teams to engage with data to drive improvements.

- We recommend that this commitment to maintain the NLCA continues and that it extends to focus on some areas where the UK performs less well than other countries, such as multimodality treatment for stage III NSCLC, adjuvant treatment and second/third line therapies.
- Data on an individual service's performance against key indicators should be available much closer to real time, making
  it more useful and applicable. The NLCA and National Cancer Registration and Analysis Service (NCRAS) should work
  together to look at ways to achieve this.
- A dataset to measure the speed of processing patients through the diagnostic and treatment pathway should be developed and implemented to allow trusts and Cancer Alliances to monitor and manage performance against NOLCP standards.
- Having seen wide variation in standards of delivery of EBUS services across our deep dives, we recommend that all providers collect and publish an agreed dataset aligned to performance metrics and standards.
- The routine use of patient reported outcome measures (PROMs) has not extended into lung cancer services and we would strongly advocate for their value in ensuring these services are responsive to patients' needs.

### Resources, organisation and accountability

Throughout our visits and review of data sets, we questioned why, after 20 years of audit and focus on outcomes, the UK continues to lag behind other countries in improving survival from lung cancer. We considered factors around service configuration and commissioning, resources available to teams in reaching a diagnosis and delivering treatment, alongside workforce challenges and potential solutions. A unifying theme we encountered across all areas of the workforce was that of clinical vacancies, the recruitment challenge and the bureaucratic processes that impede innovation and collaboration.

• The employment of novel roles and responsibilities traditionally held by the medical workforce, for example, reporting radiographers and extended pharmacist prescribing, offers an attractive means of improving career development opportunities and enhancing workforce retention and job satisfaction.

- Streamlining MDMs, process mapping inefficient pathways and enhanced investment in important administrative roles such as pathway navigators will all lead to the existing workforce being able to work more efficiently, which reaps its own rewards both financially and in improved morale. Innovative methods of facilitating cross-organisational contracts and the development of networks in crucial functions, such as radiology and pathology, would go some way to address immediate pressures.
- We saw many examples of clinicians carrying out vital clinical administration in their own time, without job planning support to truly reflect activity. Recognising the time needed to develop the service is also not universally reflected in job plans, which hampers development and impacts negatively on a person's perception of the ability to affect change.
- There remain constraints in physical space within hospitals (e.g. outpatient clinics, recovery space following biopsy), and trusts should look at creative solutions that may require regional collaboration. Likewise, there remains variability in access to equipment required (such as a CT scanners, radiotherapy equipment and software) which impacts on patient care.
- The mainstay of GIRFT's success is in addressing unwarranted clinical variation. This variation importantly extends to how pathways are configured and commissioned between and within regions. Standardising referral pathways built on examples of best practice would reduce considerable delays encountered by patients at the very first steps of their diagnostic pathway.
- We saw some great examples of executive engagement in the GIRFT lung cancer deep dives and felt confident that these organisations would seize the opportunities offered to improve their services for patients benefit.
- National programmes of work such as lung cancer screening need to be rolled out widely and standardised from the outset. Likewise, nationally commissioned contracts, such as those for PET scanning, should not be subject to regional variation.
- The implementation of the National Genomic Screening programme through a series of laboratory hubs is ambitious but we saw widespread concern and a lack of communication with regard to its rollout and of understanding how this service will integrate into existing pathology pathways. It is important that the new service will provide results in the clinically required timeframe and sit alongside, but not stifle, the innovation of local pathology services.

### **COVID-19 and lung cancer**

The emergence of the COVID-19 pandemic affected all areas of healthcare, but the lung cancer pathway was particularly badly affected for a variety of reasons. Rapid guidance produced by the lung cancer Clinical Expert Group sought to assist primary care teams to distinguish between COVID-19 and lung cancer to mitigate the risk of missed diagnosis and subsequent late presentation. Further guidance for secondary care recommended changes in the diagnostic and treatment pathways where capacity was reduced, and gave support for risk assessment in patients undergoing systemic treatments. NHS England was able to make previously unfunded treatments available as well as endorsing treatment schedules outside their pre-existing license.

To reduce the risk of COVID-19 exposure to both patients and staff there was a general move to virtual working, including MDMs and patient consultations. Undoubtedly the greater use of IT will continue into the future, but a careful balance must be struck to ensure communication and support of both patients and colleagues is optimised.

Despite these changes, data suggests that many lung cancer diagnoses have been delayed as a result of the pandemic, and the impact on patient outcomes is likely to be felt for some years to come. We got a strong sense that those trusts which had already implemented the principles of the NOLCP in their pathways were better able to react to the pandemic and maintain their services with less disruption. This reinforces the need to continue to redouble efforts to ensure that pathways are optimised in all lung cancer services across the country. Furthermore, as we move out of the pandemic and into a recovery phase, these streamlined diagnostic pathways which minimise patient visits and appropriately order investigations should be urgently implemented to maximise capacity within the system.

### **Financial implications**

While implementing efficient pathways to streamline diagnosis, treatment and multidisciplinary working may yield cost savings, our overwhelming conclusion is that significant investment in staffing and infrastructure is required to deliver the improvements in outcome envisioned within the NHS Long-Term Plan that our patients deserve.

The following list of recommendations provides an overview of the six areas of key importance. They are presented in full in the recommendations tables (see Findings and recommendations, pages 22-89) of this report.

- Making a rapid and precise diagnosis.
- Delivering effective treatment.
- Effective multidisciplinary working.
- Improving data and information.
- Resources, organisation and accountability.
- COVID-19 and lung cancer.

### Making a rapid and precise diagnosis

- 1. Respiratory teams to immediately move to providing proactive management of unexpected abnormal chest radiology and work with radiology departments to implement pathways that deliver a three working day turnaround from abnormal chest X-ray or referral to CT scan report.
- 2. Key diagnostic investigations should be completed within 21 calendar days of the start of the pathway by adopting best practice recommendations on service configuration and pathway planning.
- 3. Renegotiate the national PET-CT contract to include a five calendar day turnaround from request to report and available imaging for initial investigations of new diagnoses of lung cancer.
- 4. An image-guided biopsy service should be available for all patients 52 weeks of the year, with appointments for the procedure being available (notwithstanding issues such as anti-coagulation or anti-platelet therapy) within five working days of the request.
- 5. EBUS for lung cancer should be available within five calendar days of request and must comply with the national service specifications, with regular monitoring of performance by local commissioners.
- 6. Ensure a diagnostic and therapeutic ambulatory pleural service is available for all lung cancer patients, accessible within five working days, 52 weeks of the year.
- 7. Pathological services should provide a maximum ten calendar day turnaround time for molecular profiling according to the national test directory of lung cancers to meet the requirements of the NOLCP.
- 8. Commission a specific, robust and predominantly virtual nodule pathway which is separate from the lung cancer MDT/MDM.

### **Delivering effective treatment**

- 9. All trusts should have an overall radical treatment rate of 85% or more in those patients with NSCLC stages I-II and of performance status 0-2. This includes all treatment modalities (surgery, radiotherapy including SABR, multimodality treatment and thermoablative techniques).
- 10. All trusts should have an overall surgical resection rate for NSCLC of over 20%.
- 11. All trusts that treat lung cancer with radiotherapy should be able to deliver SABR in line with the clinical commissioning policy.
- 12. All trusts should deliver radiotherapy in line with the Royal College of Radiologists consensus statements.
- 13. Where a patient has early stage disease but is declined for radical treatment, or does not have access to the full range of radical treatment options, more effective mechanisms should exist for a second opinion.
- 14. Trusts should monitor rates of post-surgical adjuvant and neoadjuvant treatments and this data should be available for national benchmarking.
- 15. Trusts should record and monitor multimodality treatment in stage IIIA disease and offer radical intent treatment as standard in fit patients.

- 16. Radical intent treatment should commence by day 49 of the overall NOLCP pathway. Furthermore, for surgery, thermoablation or radiotherapy, treatment should commence by day 16 after the decision to treat in line with NOLCP.
- 17. All trusts should improve their treatment rates with SACT to achieve greater than 70% treatment for fit patients with advanced NSCLC, and greater than 70% chemotherapy rates in small cell lung cancer.
- 18. Ensure that all patients with lung cancer have access to enhanced supportive care and/or specialist palliative care. Inpatient specialist palliative care provision should be available seven days per week.
- 19. Produce and implement protocols for follow-up pathways following radical therapies.
- 20. Clinical trial recruitment should be considered a focus for prioritisation, with MDTs collaborating to offer a wider regional portfolio.

### Effective multidisciplinary working

- 21. Review operational arrangements for multidisciplinary working to ensure it is as timely, efficient, and effective as possible and meeting the needs of patients.
- 22. Improve timeliness and effectiveness of communication from the MDT to lung cancer patients and primary care.

### Improving data and information

- 23. Continue the NLCA in the long-term in order to quality assure and improve services and bring the clinical community together with a shared purpose.
- 24. Monitor and performance manage trusts according to the key time points within the NOLCP.
- 25. Collect, analyse and publish an agreed EBUS dataset aligned to agreed performance metrics and standards.
- 26. Improve the annual review of data within lung cancer services.
- 27. Develop more relevant and generalisable methods of collecting data on patient-reported experience and outcomes.

### Resources, organisation and accountability

- 28. Ensure all lung cancer MDTs have a named clinical lead for the service, with job planned time for the role to allow for service development and management.
- 29. Ensure all lung cancer MDTs have appropriately skilled practitioners across the whole range of medical, nursing and allied health professions and healthcare scientists, able to give the same levels of high-quality care to all patients in all areas of the country 52 weeks of the year.
- 30. Review the process for funding allocations to ensure that transformation funding is used as effectively as possible.
- 31. Roll out national implementation of risk-based CT screening for lung cancer.
- 32. Ensure that a clinical reference group continues to be available to provide strategic and clinical advice.

### **COVID-19 and lung cancer**

33. National bodies and local lung cancer services should continue to respond to the challenges presented by the COVID-19 pandemic.

Lung cancer is the second most common cancer in men (after prostate) and women (after breast) with around 48,000 patients diagnosed with the condition each year in the UK<sup>1</sup>. Moreover, it is also the most common cause of cancer death (35,000 annually) in the UK<sup>1</sup>. Although lung cancer services also deal with rare thoracic malignant diseases involving the trachea, pleura and thymus, this report focuses on the common malignant tumours arising from the bronchus and lung, classified as C34 in the International Classification of Diseases, version 10.

#### Lung cancer types

There are three main types of lung cancer:

- 1. Non-Small Cell Lung Cancer (NSCLC) accounts for approximately 85% these tumours are further subclassified with the predominant types being squamous and adenocarcinoma. These tumours can harbour genetic mutations that drive the growth of the tumour and can be targeted with specific medication.
- 2. Small Cell Lung Cancer (SCLC) accounts for about 13% this tumour type is rapidly growing and the disease is usually relatively advanced by the time the patient presents to medical services.
- 3. Carcinoid tumours (2%) are relatively uncommon and often more slow growing with a lesser tendency to spread than the other tumour types.

Lung cancer incidence is strongly related to age, with around 44% of cases in people aged 75 and over. It affects more men than women, reflecting exposure to risk factors with 1 in 13 men and 1 in 15 women in the UK developing lung cancer in their lifetime. It has been estimated that about 80% of lung cancer cases are preventable, with the main modifiable risk factor being exposure to tobacco smoke, although workplace exposures and air pollution also contribute significantly to the risk. Furthermore, incidence of lung cancer is related to socioeconomic status and it is estimated that there are around 14,300 more cases of lung cancer each year in England than there would be if every deprivation quintile had the same age-specific crude incidence rates as the least deprived quintile.<sup>2</sup>

#### Lung cancer stages

Lung cancer is 'staged' according to the size and progression of the tumour. **Figure 1** shows the distribution of lung cancer by stage according to the 2017 NLCA. The four stages are:

- 1. Stage I: small tumours confined to the lung.
- 2. Stage II: larger tumours and those with spread to local lymph nodes in the same lung.
- 3. Stage III: the largest tumours, those invading important structures in the chest, or having spread to more distant lymph nodes.
- 4. Stage IV: tumours that have spread beyond the lung and thoracic lymph glands.

<sup>1</sup> Cancer Research UK, www.cancerresearchuk.org/about-cancer/lung-cancer

<sup>2</sup> Cancer Research UK, https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer/incidence#heading-Five



Figure 1: Distribution of lung cancer by stage of disease, NLCA 2017

Lung cancer is the first cancer workstream to follow the GIRFT process for determining ways in which to improve patient outcomes through the analysis of quantifiable data-driven evidence and qualitative data trust visits (deep dives). It was chosen as a priority due to its patients' low survival rate, both in comparison to other cancers, but also when compared internationally (see **Figures 2 and 3**). It is also evident from the NLCA that there is significant national variation in both practice and outcomes.



Figure 2: Five-year survival by cancer type, ONS, 2013



Figure 3: Five-year survival by country, OECD, 2010-2014

Currently it is anticipated that only around 16% of patients diagnosed with lung cancer in the UK will survive for more than five years, although this is significantly better than the figure of around 10% measured a decade ago. The low long-term survival is in part a reflection of the demographics of the patient population, with many being elderly and having multiple smoking-related comorbidities. Data from the NLCA shows that only just over half (53%) of patients have a 'good' performance status (0-1) at the time of diagnosis. There is also evidence to suggest that access to treatment and survival are worse amongst lower socioeconomic groups<sup>3</sup>. However, a key driver of poor survival is the fact that nearly half of patients have advanced metastatic disease (stage IV) at presentation (**Figure 1**). When diagnosed at its earliest stage, almost 60% of people with lung cancer will survive their disease for five years or more, compared with only 3% when the disease is diagnosed at the latest stage (**Figure 4**).



## Figure 4: Lung cancer five-year net survival by stage, with incidence by stage (adults diagnosed 2013-2017), Cancer Research UK

Evidence points to there being a number of other factors contributing to our poor outcomes in lung cancer – for example, under-investment in research and development with lung cancer receiving only 8% of all UK site-specific research funding, and challenges accessing the equipment or services needed to fully diagnose lung cancer. Furthermore, it is recognised that there is significant variation in both the quality and provision of lung cancer services across England which has been the focus of previous national reports<sup>4</sup>. This variation is described in more detail below and will be referenced throughout the report.

### Lung cancer service provision today

Many patients present with non-specific symptoms, or symptoms that are the same as common respiratory infections and so it can be difficult for primary care teams to differentiate them. The National Institute for Health and Care Excellence (NICE) has produced guidelines on recognition and referral of patients presenting to primary care with suspected lung cancer<sup>5</sup>. A substantial proportion of patients have an emergency presentation of their cancer and these are usually at an advanced stage and independently have a significantly worse prognosis, although this proportion has been falling in recent years (**Figure 5**).

<sup>4</sup> UK Lung Cancer Coalition (2020) Access Matters, https://www.uklcc.org.uk/wp-content/uploads/2020/01/UKLCC-Access-Matters-FINAL-1.pdf National Lung Cancer Audit (2018) NLCA Annual Report, https://nlca.azurewebsites.net/AnnualReport

<sup>5</sup> NICE (updated 2021) Suspected cancer: recognition and referral, https://www.nice.org.uk/Guidance/NG12





Some cancers are picked up incidentally when a chest x-ray (CXR) or CT scan is carried out for another reason. More recently, some lung cancers are found as part of targeted lung health check projects or locally resourced CT-screening pilots in various sites across England.

### Commissioning and configuration of lung cancer services

The majority of lung cancer services are commissioned and configured as follows.

Once a cancer is suspected, patients are referred to a lung cancer service at their local hospital (secondary care), where further investigations are carried out. If a CT scan has not already been done this is the first step, but other imaging investigations such as PET-CT and CT/MRI of the brain are usually needed to accurately stage the disease. A biopsy is always preferred but may not be possible or appropriate in a significant proportion of patients. The most common ways to undertake a biopsy are endoscopically (bronchoscopy) or percutaneously using image-guidance. The introduction of EBUS has been critical since it allows non-invasive diagnosis and pathological staging of the mediastinum in a single procedure. Finally, investigations to assess fitness, such as lung function tests and echocardiography, complement the subjective assessment of performance status and guide decisions regarding the ability of patients to benefit from specific treatment modalities.

Once these diagnostic procedures have been completed, patients are discussed at a multidisciplinary team (MDT) meeting, usually held weekly at the local hospital. These meetings are attended by respiratory physicians, radiologists, thoracic surgeons, pathologists, oncologists, palliative care specialists, specialist nurses, and sometimes other healthcare professionals such as physiotherapists, or dieticians. Administrative support for these meetings by MDT co-ordinators is crucial, and they assist in collection and submission of clinical data. All lung cancer services submit monthly data on their activity via the Cancer Outcome and Services Dataset (COSD) which underpins the cancer registration process and is used by the NLCA to benchmark performance.

Once a patient has been informed of their diagnosis, they are referred to and seen by the relevant treating specialist. Curative-intent resections can be delivered by thoracic surgeons in the 28 surgical units across England. Clinical oncologists can deliver curative-intent radiotherapy, sometimes in combination with chemotherapy – some of these treatments are given at the local hospital, but some require the patient to travel to a larger (tertiary care) centre. A specific type of radiotherapy, SABR, is highly effective for treating early stage non-small cell lung cancer, but although most hospitals have the workforce and equipment to deliver it, use was restricted to 26 centres that were specifically commissioned, with plans

to roll out more widely in progress. Clinical and medical oncologists also deliver treatments that have non-curative intent but can improve quality of life and improve life expectancy. There has been an enormous increase in the range of treatments available in the last few years largely driven by advances in pathological subtyping.

Palliative and supportive care services are important for all lung cancer patients, but especially those whose disease is advanced and incurable, where proactive intervention has been demonstrated to improve survival, and it is vital that palliative care professionals are an integral component of the lung cancer MDT. Lung cancer nurse specialists (LCNS) support patients throughout their journey, often facilitating the various investigations, hospital appointments, and treatments, as well as providing holistic assessment of needs. They are usually the primary point of contact for the patient and their carers throughout the whole pathway.

### Lung cancer activity in England

Data from the NLCA (2018 cohort) provides a detailed snapshot of the diagnostic and treatment activity, and provides evidence of apparently unwarranted variation across the country:

- Nearly 40,000 patients were diagnosed with lung cancer in 2018.
- 69% of patients have a pathological confirmation of their diagnosis of lung cancer.
- 74% of patients were assessed by a specialist nurse with 61% having the nurse present at the time of their diagnosis.
- Only 58% of patients had an anti-cancer treatment (surgery, radiotherapy, or systemic anti-cancer therapy).
- 27% of patients with pathologically confirmed NSCLC underwent surgery.
- 27% of patients underwent some form of radiotherapy.
- 81% of fit patients with early-stage NSCLC underwent curative-intent treatment.
- 69% of patients with SCLC received chemotherapy.
- 66% of fit patients with advanced stage NSCLC underwent systemic anti-cancer treatment.



### National Optimal Lung Cancer Pathway (NOLCP)

The poor survival rate and the need for a fast, efficient, and patient-centred pathway for patients diagnosed with lung cancer led to the development of a nationally commissioned timed pathway, the NOLCP<sup>7</sup> now updated in version 3, with a target to diagnosis of 28 days and to treatment of 49 days. Even before our deep-dive visits began, trusts had embarked on a process of implementation of various aspects of this pathway. An important consideration in the review process was understanding how quickly patients moved from initial suspicion of cancer through diagnostic testing and on to first treatment.



<sup>7</sup> NHS England (2020) National Optimal Lung Cancer Pathway version 3,

https://www.cancerresearchuk.org/sites/default/files/national\_optimal\_lung\_pathway\_aug\_2017.pdf

Implementing a more rapid pathway through diagnosis and treatment reduces the difficult period of anxiety and distress experienced by patients and carers as they wait to learn whether they have cancer and what can be done about it. Importantly, however, there is evidence that a faster pathway reduces the risk of the tumour growing or spreading, and the risk of performance status declining, resulting in more patients being fit for more effective treatment. It has been shown that the tumour doubling time for some lung cancers may be as short as 25 days.<sup>8</sup>

### Current commissioning for lung cancer

Most cancer services are commissioned locally which offers flexibility but has the potential to increase variation if evidence-based standards for services are not applied. Thus, national guidance should be followed, and local flexibility employed to implement the guidance within the local healthcare landscape. Local service planning should involve patient representatives and consideration should be given to co-commissioning of integral specialist services.

The Cancer National Programme of Care (NPOC) is a national body created to support the commissioning of specialised and highly specialised cancer services. This involves the development of national commissioning products, such as service specifications and clinical policy, as well as the provision of expert clinical and commissioning advice to support service improvement and innovation. There are three relevant Clinical Reference Groups (CRGs) that provide expert clinical advice and leadership relating to these services:

- 1. radiotherapy;
- 2. chemotherapy (and other anti-systemic cancer treatment); and
- 3. specialised cancer surgery (part of the adult thoracic surgery specialised commissioning specification).<sup>9</sup>

The Cancer NPOC is also supported by a National Specialty Advisor for PET-CT.

Cancer Alliances were formed by NHS England to plan for and lead on the local delivery of the NHS Long Term Plan. They provide operational and clinical leadership to their local cancer systems.

The local priorities and working arrangements differ somewhat across each Cancer Alliance. The Cancer Alliances have a central role in co-ordinating interactions between commissioners and providers. In most Cancer Alliances there will be a lung cancer site-specific group to develop network wide protocols, develop cross provider pathways and share clinical trial activity.

Recognising the central role that Cancer Alliances would play in the implementation of all local, regional and national recommendations of our GIRFT workstream, we sought to involve them in our work from the beginning. Cancer Alliance representatives were invited to all the GIRFT deep-dive visits and we have encouraged regional GIRFT implementation teams to work closely and collaboratively with the Cancer Alliance teams to maximise the scale and pace of change.

### Data sources used in the report

The following data sources were used by the GIRFT team in their review:

#### National Lung Cancer Audit (NLCA)<sup>10</sup>

The NLCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and has been delivered by the Royal College of Physicians (RCP) since 2015. The RCP works in partnership with several other organisations, but it is NCRAS that provides the data that underpins the audit. All trusts in England submit data to the audit. The NLCA dataset covers a wide range of process and outcome measures, and monitors data quality. For our deep-dive visits carried out in 2020 we used NLCA results based on patients who were diagnosed in 2017.

#### Trust questionnaire data jointly gathered between GIRFT and NLCA

The NLCA carries out an audit of the organisation and provision of local services every 2 years. GIRFT worked in collaboration with the NLCA team to adapt its 2019 questionnaire such that it included important additional questions that were relevant to the GIRFT deep dives. The questionnaire was administered during the summer of 2019 and returned by 128 trusts (92%).

<sup>&</sup>lt;sup>8</sup> Harris, K. et al. (2012) Small cell lung cancer doubling time and its effect on clinical presentation: a concise review. Clinical Medicine Insights. Oncology vol. 6: 199-203

<sup>&</sup>lt;sup>9</sup> NHS England (2017) Thoracic Surgery service specification, https://www.england.nhs.uk/wp-content/uploads/2017/07/thoracic-surgery-service-specification.pdf

<sup>&</sup>lt;sup>10</sup> National Lung Cancer Audit homepage, https://www.rcplondon.ac.uk/projects/national-lung-cancer-audit

#### Lung Cancer Clinical Outcomes Publication<sup>11</sup>

The Lung Cancer Clinical Outcomes Publication (LCCOP) is also commissioned by HQIP and delivered by the NLCA team in conjunction with the Society for Cardiothoracic Surgery (SCTS). Data from the NLCA on all patients who undergo a curative-intent surgical procedure for lung cancer is passed back to the clinical teams at each trust for validation before analysis of surgical activity, survival and length of stay. All surgical units in England participate in the process. For our GIRFT deep-dive visits carried out in 2020 we used results based on patients who were diagnosed in 2016.

#### **GIRFT** pre-visit questionnaire

Prior to each GIRFT deep-dive visit, each trust was asked to complete a pre-visit questionnaire providing up-to-date information to the GIRFT clinical leads on the organisation, structure and performance of their service. This data was invaluable in preparing for the visits, and some quantitative data has been used in writing this report.

#### Hospital Episode Statistics (HES)

All trusts in England submit details of their hospital inpatient and outpatient activity to NHS Digital. This dataset has been used to identify variation in lengths of stay and readmission rates.

#### National Cancer Patient Experience Survey<sup>12</sup>

The National Cancer Patient Experience Survey (NCPES) is carried out by the Picker Institute on behalf of NHS England. The use of this dataset has been limited by data suppression where there are low number of responses at a trust level, and it is appreciated that NCPES responders do not necessarily represent all patients with cancer.<sup>13</sup>

#### **Cancer Waiting Times**<sup>14</sup>

Data is published monthly by NHS England on the three cancer waiting time standards of 14 days from referral to seeing a specialist, 31 days from diagnosis to first treatment, and 62 days from referral to first treatment.

#### Trusts' MDT System Dataset

The existing Cancer Waiting Time targets do not provide the granularity needed to understand the successes and bottlenecks of specific components involved in local pathways. With the knowledge that often this more detailed data is contained within local MDT systems, we asked each organisation to provide dates of key points in the pathway (such as date of chest x-ray, CT scan, biopsy, treatment) for all patients diagnosed with lung cancer in the preceding 12 months. We were clear with local teams that we only expected this data to be provided if it could be automatically rather than manually extracted.

Data was returned by 123 trusts but was of a variable quality, reflecting the challenges faced by lung cancer teams and trusts in addressing barriers to rapid diagnosis. Although we wanted to analyse this data according to the route of referral i.e. GP referral, emergency admission, upgrade to a cancer pathway by a consultant, the data provided on this was difficult to interpret. Within deep dives we presented this data to local teams, benchmarked against all trusts to provide a crude guide to median times taken to reach key points in the pathway, to provoke discussion and reflection on local challenges.

#### National Institute of Health Research

Data was supplied by the National Institute of Health Research (NIHR) on the number of lung cancer research studies that each trust was involved with, and the number of patients recruited.

<sup>&</sup>lt;sup>11</sup> Society for Cardiothoracic Surgery (2017) Lung Cancer Clinical Outcomes Project, https://scts.org/\_userfiles/pages/files/2020\_lccop\_draft\_final\_web\_0.pdf

<sup>&</sup>lt;sup>12</sup> Picker (2020) National Cancer Patient Experience Survey, https://www.ncpes.co.uk/

<sup>&</sup>lt;sup>13</sup> Alessy et al (2019) How representative are colorectal, lung, breast and prostate cancer patients responding to the National Cancer Patient Experience Survey (CPES) of the cancer registry population in England? A population-based case control study, https://bmjopen.bmj.com/content/9/12/e034344.full

<sup>&</sup>lt;sup>14</sup> NHS England Cancer Waiting Times, https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/quarterly-prov-cwt/2019-20-quarterly-provider-based-cancer-waiting-times-statistics/ provider-based-cancer-waiting-times-for-q4-2019-20-provisional/

### Making a rapid and precise diagnosis

Some patients enter a lung cancer diagnostic pathway because of incidental findings on a test done for some unrelated reason or through a screening programme, but for the majority it is the development of symptoms that triggers them to seek medical advice. Unfortunately, symptoms and signs of lung cancer are often non-specific and can easily be dismissed by both patients and clinicians. This can result in a delay between a person first noticing symptoms and subsequently presenting to their GP or other provider for assessment. National campaigns and local enhanced awareness strategies have had a positive impact on the time taken to report symptoms. However, the scope of our review did not allow us to investigate or make recommendations on primary care.

Subsequently, and whatever the route of presentation, once the suspicion of lung cancer is raised and before treatment for lung cancer can begin, the diagnosis must be confirmed. The complexity of currently available treatment options is such that very precise assessment of disease extent, of the tumour subtype and molecular profile, and of the fitness and functional status of the patient must be made to ensure that the most appropriate treatment can then be delivered to provide the optimal outcome for each patient.

It is widely recognised that every delay, even of only a few days, can impact on the outcome for lung cancer patients, with the stage migration and growth of a tumour by only millimetres having an impact on their long-term survival, even in those eventually treated with curative-intent<sup>15</sup>. It is devastating for all concerned to see a patient enter the diagnostic process ready and willing to embark on treatment only to become incurable or even untreatable due to declining fitness or disease progression because the pathway through diagnosis to treatment has progressed at too slow a rate. Furthermore, this is a period of profound anxiety and stress for patients and carers which can be alleviated to a large extent by achieving a rapid and efficient diagnosis.

Until the recent introduction of the Faster Diagnosis Standard by NHS England there has been no national monitoring specifically of the time taken to diagnose (or exclude) lung cancer. However, data from the cancer waiting times dataset highlighted that between January and March 2020, 92% of all cancer patients saw a specialist within two weeks, 97% of lung cancer patients began treatment within 31 days of diagnosis but only 64% of lung cancer patients were treated within 62 days of referral.

The introduction of the NOLCP sets out challenging (within current resources) timescales for getting patients though their diagnostic pathway. Key principles include:

- much more rapid access to an initial CT scan;
- standardisation/optimisation of the diagnostic tests into bundles carried out in parallel rather than in series; and
- frequent triage of referrals and test results to progress patient care without undue delay.

Whilst progress has been made in implementing these recommendations, it is evident from the data available to GIRFT and from wider discussions with local lung cancer teams that there is significant variation in both access to secondary care investigations and the duration and complexity of the patient pathway. For example, using data received from trusts' MDT systems, there is a wide variation in the time between CT scan to an MDT treatment decision (interquartile range: 21-29 days). However, it is also clear that the reasons for this variation are not uniform across organisations. Minimising this variation and standardisation of processes to conform to best practice would result in significant improvements in the time to diagnosis and therefore improve outcomes, and in the longer term reduce the impact and cost of more advanced stage disease.

Consequently, it is these dual ambitions of improving patient experience and outcomes through diagnostic speed, efficiency and precision that guided our recommendations throughout this section.

### Flagging unexpected abnormal lung imaging

In many cases, the first suspicion of a lung cancer diagnosis comes from an unexpected finding on a CXR requested by a non-specialist healthcare professional in primary or secondary care. Similarly, a CT scan carried out for a variety of reasons (such as a CT pulmonary angiogram for suspected pulmonary embolus, a CT coronary angiogram to investigate chest pain or a surveillance scan following treatment for a cancer outside the lung) may also raise concern.

Although most organisations described a flagging mechanism to highlight unsuspected abnormal findings on a CXR suggestive of lung cancer, there was little evidence in practice of lung cancer services taking a proactive approach in fast-tracking these patients to CT or another appropriate investigation. The majority of services typically had a passive system of referral that relied upon a referral being made from primary care for further investigation.

We would recommend all services adopt the exemplar service that we saw evidence of during our visits to teams: following an abnormal CXR, immediate action is taken by secondary care to proactively arrange the CT scan and contact the patient without waiting for a direct referral. All responsibility for the pathway from the point of an abnormal CXR report therefore lies with the lung cancer team.

Importantly this relies upon the radiology, respiratory medicine, specialist nursing and allied administrative teams being appropriately resourced to communicate urgently with the patient and original referrer, initiate tracking and commence a diagnostic pathway. Our findings are reflected in a recent report by the Healthcare Safety Investigation Branch (HSIB) which itself makes a number of recommendations that support our own.<sup>16</sup>

#### **CASE STUDY**

At **Royal Liverpool University Hospital**, all patients who have a thoracic imaging test that raises concern for lung cancer have a code applied to the radiology report which triggers automatic entry onto an electronic spreadsheet. The respiratory medicine consultant team proactively check this list every day and take ownership of the next steps, contacting patients and organising the further tests as needed, without the need to wait for a 'referral' to their service.

#### Initial thoracic imaging

If we are to detect symptomatic lung cancer earlier, we need more patients to be referred to secondary care for diagnostic imaging. Primary care teams use NICE guideline 'NG12 - Suspected cancer: recognition and referral' to decide when they should suspect a diagnosis of lung cancer and refer the patient to secondary care for further assessment.<sup>17</sup> For most patients, a CXR is the first investigation but since there is a 10-15% false negative rate, a CT scan is usually still required, unless the CXR reveals a different diagnosis. In most areas of the country, primary care teams have the ability to directly request CT scans, although arrangements vary somewhat between Clinical Commissioning Groups (CCGs). However, most CT scanning for lung cancer is initiated by secondary care lung cancer teams.

Historically, patients referred to the lung cancer service would always have a face-to-face appointment with a consultant, and until around ten years ago it was relatively novel practice to try and organise a CT prior to that consultation. This pre-clinic CT scan is, appropriately, now almost universal, but we heard in some trusts that pressure on CT capacity meant some respiratory physicians would on occasion avoid requesting the scan in patients with a lower likelihood of cancer to try and mitigate this, thereby taking on the risk themselves. Of course, it is perfectly reasonable to omit a CT scan if it is not clinically indicated, but we felt this was an iniquitous position for those doctors to be put in based on resource constraints.

The NOLCP recommends a period of no more than three days from the time of an abnormal CXR being taken or GP/intra-hospital referral of a symptomatic patient, to the CT scan being performed and reported, but the deep dives highlighted that much variation exists in the speed and efficiency of this aspect of the pathway. There were some limitations in the dataset available to us regarding the timing between CXR and CT scan, partly due to relatively low numbers of patients included in this dataset, but also because it includes patients who have a normal and reassuring CXR whose persistent symptoms later triggered a referral. However, the data demonstrated striking variation across trusts with a median time of eight days and an interquartile range of three to 18 days (**Figure 7**), and this reflected the different practice we noted during our deep dives.

<sup>16</sup> Healthcare Safety Investigation Branch (2019) Investigation into failures in communication or follow-up of unexpected significant radiological findings,

https://www.hsib.org.uk/investigations-cases/communication-and-follow-unexpected-significant-radiological-findings/final-report/

<sup>17</sup> NICE (updated 2021) Suspected cancer: recognition and referral, https://www.nice.org.uk/guidance/ng12



#### Figure 7: Time from chest X-ray to CT scan, 2018-19, trust MDT systems

We visited trusts where there were long delays in chest X-rays being reported back to the GP, and problems in streamlining pathways due to outsourcing of reporting as a result of capacity constraints. In others, there was typically a ten-day wait for an urgent CT scan, and in some patients routinely attended an outpatient appointment before their CT scan was done. However, a number of trusts had developed rapid, patient-centred pathways with common themes, even when resources were stretched:

- CXR 'hot' reported while the patient was still in the radiology department, or at least on the same day, often by increased use of radiographer reporting to compensate for radiologist staffing shortages.
- 'Straight to CT' pathways that activate a CT scan directly within radiology departments following an abnormal CXR, without the need for a referral (using a Standard Operating Procedure for this delegated requester responsibility under Ionising Radiation Medical Exposure Regulations). In some trusts this was done in the same visit as the CXR.
- Scans being reported by radiologists with a sub-specialism in thoracic radiology.
- Mechanisms to circumvent the lack of a prior estimated glomerular filtration rate acting as a barrier to administration
  of IV contrast, such as the use of point-of-care testing.
- On table review of the scan by a thoracic radiologist to determine whether IV contrast for staging was required.
- Provision of high-quality information and support to patients, starting at the point of primary care referral, such that recall for a CT scan was not unexpected.
- Introduction of administrative roles or pathway navigators within radiology or respiratory departments to facilitate the processes with minimal clinical input.

#### **CASE STUDIES**

**Maidstone Hospital** has recently implemented a rapid access clinic following CT scan to allow for patients with suspected lung cancer to be seen well within the timelines recommended by NOLCP. The radiology department carries out 'straight to CT' for a proportion of patients with abnormal chest X-rays. They have implemented a risk assessment for contrast nephropathy and, where appropriate, will carry out point-of-care testing of renal function. The bundles of tests are booked at the time of clinic to facilitate a more streamlined pathway to diagnosis. A pathway navigator was appointed in March 2019 to support patients during the diagnostic process.

At **Oxford University Hospital**, the development of a nurse-led rapid diagnostic service for triage and non-face-to-face assessment early in the pathway has facilitated faster diagnostics, earlier contact and support for patients from the nursing team. Patients receive a triage call within 24 hours of referral, with the initial assessment with CT report available taking place within three days of referral. This has reduced time on the pathway and improved patient experience.

In our deep dive meetings, there was often a reluctance by clinicians to consider changing these pathways. Concerns were raised over the possible negative impact of 'straight to CT' on patient experience (with patients being upset at being called for a CT scan without discussing it with their GP first) and on other cancer site pathways, and whether there was any real benefit in "shaving a few days off". We would reject all of these perceived barriers and objections – through the hard work of innovative teams we have seen the art of the possible, reinforced by positive patient experience feedback. It should be emphasised that this is not additional work for a radiology department, although additional resources (such as booking staff, navigators or physical space) may be needed to allow flexibility of scheduling. A radiology-driven and suitably resourced pathway enabling a CT to be arranged and reported within a maximum of three days from the time of the abnormal CXR or referral being taken should be implemented immediately in all trusts, and with an ambition to move to same-day CT scanning in the next two years, as is already happening in a few organisations (see Recommendation 1, page 37).

Ideally, for those patients referred with symptoms but a 'normal CXR' then the same timescales should apply even if the mechanism of the pathway may be different. However, the likelihood of these patients having cancer is much lower and where resources remain constrained it may be preferable to focus these resources on achieving maximum speed in the higher risk group. Clearly, there is a need for CT scan (and indeed all diagnostic imaging modality) capacity, including the required staff, to be upgraded in many parts of the NHS and we point to our later recommendations about the responsibilities for providing clinical teams with the resources needed to carry out their roles effectively. The scale of the challenge has been highlighted by Professor Sir Mike Richards in his recent report on diagnostic services, which proposes a move towards community diagnostic hubs, although it remains to be seen whether there will be sufficient resourcing for this model.<sup>18</sup>

There is also a need for radiology departments to embrace new ways of working such as upskilling radiographers to report images, pooling of resources across networks, and through embedding agreed national standards for 'request to test' and 'test to report'. There is also enormous interest in the use of artificial intelligence systems to analyse, triage and even report some radiological images, which has the potential to make care quicker, safer and more efficient. This was beyond the scope of our workstream and these issues have been considered in much greater detail in the GIRFT national report for radiology.<sup>19</sup>

<sup>18</sup> Sir Mike Richards (2020) Report of the Independent Review of Diagnostic Services for NHS England,

https://www.england.nhs.uk/wp-content/uploads/2020/11/diagnostics-recovery-and-renewal-independent-review-of-diagnostic-services-for-nhs-england-2.pdf <sup>19</sup> GIRFT (2020) Radiology National Specialty Report, https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2020/11/GIRFT-radiology-report.pdf

#### **CASE STUDY**

At **Brighton and Sussex University Hospitals**, prior to 2015, if a GP-referred CXR showed an abnormality requiring further investigation, the GP had to make an urgent referral to a respiratory medicine physician. A planning group involving all relevant parties including the five referring CCGs was set up to implement a radiology-led pathway. The team created a dedicated CXR referral form that required a minimum dataset for entry into the pathway, and all patients were informed via a patient information leaflet that they may be recalled for a CT scan. CXR reporting was rationalised down from 31 to six reporters, fully trained in the pathway, and who are chest specialists. Subsequent assessments showed that patient experience had improved, GP feedback was positive and there was a significant shortening of the time taken from CXR referral to eventual diagnosis.

#### Triage and subsequent diagnostic work-up

There are a variety of downstream actions that might be anticipated after a CT scan depending on whether cancer has been ruled out, and although an outpatient appointment does not always occur, it is perhaps the most common next step. As an indication of the wide variation in practice, we observed an interquartile range of five to nine days (median seven days) between CT scan date and the first outpatient appointment (**Figure 8**). Similarly, there is a wide variation in the time taken from the CT scan through to the full diagnostic work-up to enable a treatment decision to be made (**Figure 9**), with an interquartile range of 21 to 29 days (median 26 days). Clearly on a 28-day pathway losing several days simply waiting to be seen in clinic is unacceptable and adds no value to patient care.



Figure 8: Median time from date of CT scan being performed to date patient seen in outpatient clinic, trust MDT systems, 2018-19



## Figure 9: Median time from date of CT scan being performed to date of MDT when a treatment decision was recommended, trust MDT systems, 2018-19

As can be seen in **Figure 9**, the overall length of the pathway varies significantly, with many trusts not able to deliver a diagnosis within 28 days. Given the complexity of the pathway to a complete diagnosis and staging of disease in lung cancer, as well as assessing the fitness of a patient for undergoing treatment, the diagnostic pathway requires careful co-ordination and planning. This is especially true where diagnostic tests are not available locally – for example, 22% of trusts do not have on-site EBUS and 70% do not have on-site PET-CT scanning. Some common themes and scenarios that we observed in our discussions with teams at our deep-dive visits are listed below, and centre around batching and capacity constraints:

- Rapid access lung cancer clinics running only once or twice a week limiting capacity, delaying the pathway, and leading to batching of all the subsequent diagnostic tests.
- Patients with CT scans that have excluded lung cancer still attending a cancer two week wait clinic just to be told their scan result, which could have been delivered remotely.
- Outpatient appointments scheduled around a routine weekly diagnostic MDT meeting where all CT scan results are reviewed and subsequent work-up planned, rather than daily triage and decision-making by an experienced respiratory physician.
- No clear separation of the lung cancer service from the general respiratory service with some consultants saying they would need to still see the non-cancer patients because of their symptoms.
- Diagnostic tests being carried out in series rather than in parallel, with requirement for MDT review of results to progress the pathway further.
- Generally inefficient administrative processes around scheduling, resulting in long waits.
- Tests ordered in the wrong order, e.g. EBUS before PET-CT, resulting in additional unnecessary biopsies.
- Poor communication with patients regarding next steps, leading to misunderstanding, dissatisfaction or missed appointments.

In contrast, some trusts have implemented mechanisms to process patients more rapidly and efficiently and we have highlighted several areas of best practice that can mitigate the above problems and which we recommend are implemented:

Administrative support in the form of a pathway navigator, whose role is to facilitate the booking and co-ordination of tests and appointments, to pre-book tests, chase up delays in the system and monitor progress for each patient within the 28-day pathway. We have seen evidence of local Cancer Alliance support to fund pathway navigator roles, but these need to be embedded and made sustainable for the longer term. Navigators have proved successful in breaking down more traditional boundaries between departments which can have a significant impact on efficiency within the lung cancer pathway. For example, some organisations have introduced shared electronic diaries to enable pre-booking following on from triage or have enabled the radiology department to book directly into a clinic slot where lung cancer is evident.

- Daily triage of patients based on their CT scan result into those where cancer is likely or possible, and those where the CT is normal or reveals another specific diagnosis. The triage will include a decision on whether to discharge the patient without further investigation, to refer to an alternative service, to carry out further diagnostic tests, or to assess the patent in a face-to-face setting, thereby freeing up space in the lung cancer clinic itself for those who actually require its expertise. This is usually followed by a telephone or written explanation to the patient, and it is important that patients are provided with adequate information at the time of referral such that they are not surprised when any of these possibilities occur.
- Spreading out the face-to-face or video clinic appointments across the working week so that slots are available for rapid access daily, rather than only weekly, achieved through modification of job plans rather than requiring additional resources. A small number of trusts have abandoned the traditional outpatient clinic model and moved to a system whereby the majority of the diagnostic work-up is done virtually, using telephone assessment/consultation rather than using face-to-face appointments (see below). Despite our initial concerns about the impact of such a model on patient experience, we were reassured in the deep dives that, when properly implemented and resourced, such a service can be efficient, timely and patient-centred.

The use of diagnostic bundles, originally developed at Manchester University Hospitals NHS Foundation Trust, was later refined and reissued as diagnostic standards of care by the national lung cancer Clinical Expert Group (CEG).<sup>20</sup> These bundles document the work-up required for different CT scan presentations of lung cancer, from small nodules to advanced metastatic disease. In some trusts, requests for additional tests such as lung function, cardiac imaging, or blood tests are arranged in advance to coincide with other planned visits to the hospital to speed up the diagnostic pathway and improve the overall patient experience. Key diagnostic investigations should be completed within 21 calendar days of the start of the pathway (see Recommendation 2, page 37).

#### **CASE STUDIES**

The **Liverpool Heart and Chest Hospital** operates a virtual diagnostic pathway. CT scans are triaged daily with the lead clinician having access to GP records to assess fitness and review relevant blood results/spirometry. A plan is made for appropriate diagnostic tests and a proforma passed to the LCNS who will contact the patient to explain the CT results and management plan and assess performance status. The patient is then seen face-to-face for the results and outcome of the MDM discussion. This process has become embedded in practice and has received positive patient feedback. If the LCNS identifies during the assessment process that the patient is PS3 or is more appropriate for a face-to-face consultation this can generally be organised on the same day due to daily cancer clinic slots.

In 2018, **Salford Royal Hospital** established a system which embeds daily virtual review of all patients on a lung cancer diagnostic pathway to ensure all results are actioned the same day they are available and tests are scheduled efficiently, minimising the total number of visits for a patient. They used the web-based software Sharepoint (Microsoft). A bespoke database was developed which allows clear tracking of individual patients' diagnostic bundles which is accessed and updated live within the trust intranet by all members of the lung cancer team. The implementation of this process was associated with a reduction of 14 days in the median time from referral to MDT discussion (from 30 days to 16 days).

### **PET-CT** imaging

Early and rapid access to PET-CT imaging is a priority for lung cancer because of its key importance in diagnosis, staging and identifying the most appropriate type of biopsy. While specialised commissioning mandates a time to delivery and reporting of PET-CT within seven working days for all cancers, not achieving this creates a significant problem for the delivery of a 28 day diagnostic lung pathway because of the number and timing of follow-on investigations required. For the majority of trusts in England, PET-CT services are off-site and many are provided under contract with a private provider. There does also appear to be a requirement for PET-CT requests to have been supported by a prior MDT discussion in some regions, which we feel to be entirely unnecessary.

Based on responses to our GIRFT questionnaires, as well as discussions in the deep-dive visits, there is significant variation in the PET-CT scan turnaround, with the median time to test being seven days (interquartile range (IQR) 7-10 days) but in some areas as long as three weeks, with additional time then for the report and images to be made available to the clinical team. We have regularly heard reports of limited access to PET-CT imaging which has impacted on the ability to deliver a 28 day diagnostic pathway. In some cases, there was evidence of fruitful discussions between the local PET provider and the clinical team, where scanning slots had been reserved for the lung cancer team such that patients could be directly offered an appointment by the clinical team. This was largely a result of individual relationships and negotiations rather than part of effective contracting. We also heard of situations where no progress had been made despite frequent attempts at both clinical team and trust level. There is an important role here for Cancer Alliances to support their local trusts in improving such access through monitoring turnaround times and leading negotiations.

However, such local negotiation should not be needed if PET-CT services are commissioned according to clinical need and demand on the service. We recommend that all PET-CT services deliver a seven calendar day turnaround from request (ideally electronic) to report and availability of images, which is the standard set in the existing contract, and that they should be performance-managed against this standard. Furthermore, we strongly support the recommissioning of this service to deliver a five calendar day standard from (ideally electronic) request to report, rather than seven calendar days, and that this should be available 52 weeks of the year (see Recommendation 3, page 37/38). This would ensure that reporting images are available from one weekly MDM to the next, and that the timeframe for reporting won't span two weekends.

Furthermore, trusts should work with their PET providers to streamline the ability to share images though PACS systems, such that the report and images are made available in the same timeframe. Setting such a challenging target for lung cancer is supported by the critical nature of the PET-CT in determining downstream work-up, and the impact of delays to treatment in this aggressive cancer. The commissioning contract should also include commitment to PET when performed as part of a research protocol as this is proving a barrier to clinical trial involvement in some trusts.

There is also variation reported in the content of the PET-CT report and its applicability for lung cancer. Standardised templates have been produced and are used routinely in a number of sites such as the Royal Free Hospital and King's College Hospital, improving the team's ability to make best use of the report with regard to their patients' care. The templates allow the application of validated tools, such as Herder score to a lesion, and enables a prediction of likelihood of cancer, especially where a PET-CT reporter is not present in the MDT, as is reported by 84% of the trusts we visited.

### Obtaining pathological confirmation of lung cancer

There are several methods used to obtain a tissue diagnosis. Best practice, as enshrined in NICE guidelines, encourages clinicians to carry out the biopsy which gives the maximum diagnostic and staging information at the least risk to the patient. Although it is inevitable that some patients may have to undergo more than one biopsy (for example a percutaneous lung biopsy after a negative EBUS), we were surprised at the variation in this measure across the services, as shown below in **Figure 10**, which shows some trusts carrying out multiple biopsies on up to 25% of patients. Although the data is not conclusive, there is likely to be a significant morbidity for patients as well as financial cost to the NHS in those services that have higher than expected repeat biopsy rates. Furthermore, very low rates of repeat biopsy may suggest an inappropriately imprecise approach to staging.

For those patients with early-stage disease there is a clear variation in approach to pre-treatment biopsy – some MDTs are very rigorous and aim to avoid any lung resection without a pre-operative pathological diagnosis, while others perform a frozen section diagnosis in theatre which dictates the subsequent operation. Similarly, there is variation in how often teams will pursue a biopsy before delivering SABR radiotherapy, especially since the COVID-19 pandemic when a high probability of cancer (Herder score >70%) has been considered sufficient to allow a treatment recommendation. Recognising regional variation in co-existing lung pathology (for example tuberculosis, which can mimic a lung malignancy), we did not feel that the available data allowed us to make any recommendations about these different approaches. However, the decisions should be made for clinical reasons rather than due to a lack of local expertise or capacity.



#### Figure 10: Proportion of patients with more than one biopsy recorded, 2018-19, trust MDT systems

Applying the diagnostic standards of care mentioned earlier is important to help individual clinicians choose the most appropriate biopsy. However, we did hear evidence that delays in obtaining PET-CT scans had impacted on the choice of biopsy, with clinicians choosing to carry out tissue sampling before the PET-CT to try and speed up their pathway, only to find out subsequently that alternative sampling would have been more appropriate. The choice of biopsy should ensure that sufficient tissue is obtained to perform all required histological and genomic tests. In practice, the three most common types of biopsy are percutaneous image-guided biopsy, EBUS and pleural tissue/fluid sampling.

#### Image-guided biopsy

Data obtained and discussions with the clinical teams have highlighted significant delays to image-guided biopsy, but perhaps most commonly for CT-guided lung biopsy. The median time to CT biopsy for those trusts visited was 7.5 days (IQR 7-11 days). However, in some centres we heard this could frequently be a three-week wait. Several factors seem to be responsible, including:

- Workforce shortages within radiology, both of appropriately skilled radiologists to carry out the procedure, and staff to assist and recover the patient, leading to delays scheduling the procedures. In many trusts, services are simply not covered during periods of annual leave, leading to several weeks' delay.
- Constrained access to CT scanners or suitable recovery space due to pressures on resources from other acute services (such as A&E and trauma), as well as the increasing use of CT for other reasons, such as cancer follow-up or cardiac assessment.

Identification and sampling of neck or supraclavicular fossa nodes is a simple and rapidly accessible test historically done by radiologists or pathologists, but in an increasing number of trusts this is now done more rapidly by respiratory physicians at the time of their first face-to-face assessment, which has the additional advantage of freeing up radiologists for more specialised work. Some teams have upskilled their respiratory physicians to carry out an even wider range of procedures.

The radiology GIRFT workstream has also highlighted these issues and recommended that all radiology services should have access to dedicated facilities to admit and discharge day case patents for interventional procedures.<sup>21</sup> Within individual Cancer Alliances, we visited trusts with an excellent and responsive image-guided biopsy service, many of whom had developed an ambulatory service, as well as those that were slower and with significant staffing gaps. There is an opportunity for groups of hospitals to work together to share expertise and resources to ensure that all patients benefit from the best possible service. This collaborative approach should be mandated where local capacity cannot provide biopsy within five days of request, 52 weeks of the year (see Recommendation 4, page 38). Indeed there is already a strategy, begun in 2019, to organise acute trusts into 24 imaging networks by 2022; this will then be consolidated to 18 by 2023.<sup>22</sup> The GIRFT national report for radiology has noted that 'network arrangements were at different levels of maturity' with ongoing significant practical challenges.

#### **CASE STUDIES**

At **Kettering General Hospital**, the respiratory physicians have upskilled in performing ultrasound-guided biopsies of peripheral lung, pleura, chest wall, neck lymph nodes and skin metastases. They have a respiratory ambulatory care unit providing the capacity to do these procedures rapidly, and as a result 90% of all biopsies are physician-delivered. They have a high overall pathological confirmation rate, and a shorter than average diagnostic pathway time.

In the Greater Manchester region, a regional lung biopsy service is provided by **Manchester University Hospital**. Radiologists working in this service can sample even very small lung nodules, and this expertise is available to all trusts in the region. The agreed MDT policy is to aim for a 'zero frozen section' approach maximising theatre efficiency.

The **Royal Free**, **London** has an exemplar CT biopsy service, with a high rate of diagnosis of early stage lung cancers, and pioneered the use of ambulatory valves to speed up recovery time following a complication post biopsy of a pneumothorax. Responding to increasing pressures in the radiology department for recovery space, due to increasing work within the interventional suite, the team proactively relocated their service to a different hospital site to maintain fast turnaround times and prevent delays as a result of constrained capacity.

### Endobronchial ultrasound (EBUS)

Endobronchial ultrasound transbronchial needle aspirate (EBUS-TBNA) has emerged over the past ten years as a critical investigation in both diagnosis and staging of lung cancer, offering the ability to safely assess the extent of nodal disease within the mediastinum without the need for surgical mediastinotomy or mediastinoscopy. As mentioned above we strongly advocate for the procedure to be done with the benefit of a reported PET-CT scan. According to the NLCA Organisational Audit (2019), most acute trusts now offer EBUS facilities on-site with only 22% referring to neighbouring trusts. We were impressed by the dedication of many teams to set up services of high quality and carry out regular audit of their diagnostic rates to ensure best possible practice.

However, there was very marked and apparently unwarranted variation in the use of EBUS, as demonstrated in **Figure 11**, with a median proportion of 14% of patients undergoing the procedure with an interquartile range of 7-27%. We were concerned that in many cases capacity constraints or the need to refer externally led to teams relying on radiological staging and not following published NICE guidance on obtaining pathological staging of the mediastinum where curative treatment may be an option. There was also some evidence that when EBUS took place, the quality of the procedure being carried out was sometimes suboptimal and focused on diagnosis where full systematic staging was needed. A full staging EBUS requires considerably more time and technical expertise as it necessitates sampling of multiple nodes, many of which will be small. These variations risk impacting on the outcome for the patient and may alter the ability to offer curative-intent treatment. Although the service specification suggests a minimum of 20 staging procedures per year for an individual practitioner to maintain competence, we feel this should be reviewed.



#### Figure 11: Proportion of patients with EBUS recorded, 2019, trust MDT system

Following the diagnostic standards of care as described above would allow for better scheduling of lists, determination of whether diagnostic or staging EBUS is required, and therefore the ability to plan appropriate capacity and workforce within the service. To ensure that EBUS services have adequate capacity, we recommend providing the test within five working days of the request rather than the seven days suggested in the national service specification (see Recommedation 5, page 38). Providing the expected diagnostic accuracy and efficiency is vitally important, and so regular audits should be undertaken for quality assurance in line with recently published national service specification<sup>23</sup>. Where necessary, services should work collaboratively with other EBUS providers in the locality to ensure access times are achieved across the entire Cancer Alliance. This will include cross-cover for annual leave and sickness, support for ongoing training and professional development and allowing patients to transfer into another service where access times cannot be met within their local service. There is an important role for commissioners and Cancer Alliances to ensure that EBUS services are not only providing the high quality outlined in this specification and to encourage collaborative working, but to decommission services where this does not occur. There are certainly some smaller EBUS services currently in existence where it is unlikely that operators will be able to achieve and maintain adequate competence, and in these cases the development of a regional service will be necessary.

### Pleural services

Diagnostic and therapeutic pleural services cross the boundaries of benign and malignant respiratory disease, and we have visited trusts where these services are a separate specialised service, carrying out a full range of procedures and highly responsive to the needs of the lung cancer team, and others where services are much less consistent. Many trusts reported a lack of dedicated space for procedures to be carried out, and in others pleural procedures were done ad-hoc, more on goodwill than as part of a specialised service, often due to lack of respiratory clinician time. Some trusts have overcome this second barrier by training nurses or advanced practitioners to carry out both ultrasound and pleural intervention. The benefits of this are that patients can often be seen more quickly and, in conjunction with consultants, the team can offer more flexibility throughout the week for appointments. Nurses trained in pleural ultrasound and procedures may also be able to provide inpatient review and possibly domiciliary visits to enhance patient care and improve time to diagnosis.

Although some lung cancer services have on-site medical thoracoscopy (58 out of 124), trusts may rely upon their tertiary thoracic surgical centre for video-assisted thoracoscopic pleural biopsy/aspiration/pleurodesis in the setting of suspected cancer, and although in some cases the turnaround time is rapid, in others delays of two or even three weeks can occur. This is especially problematic when the usual thoracic surgeon is on leave or not at work to accept the referral. It is vital that service level agreements (SLA) with tertiary centres are negotiated over 52 weeks per year and not 40-46 weeks as is currently commonly encountered. It is also imperative that this SLA contains agreement for cross cover where needed and not an exclusive arrangement with a single specialist (see Recommendation 6, page 39).

Detailed evaluation of pleural services was beyond the scope of our lung cancer deep dives, but we feel there is sufficient unwarranted variation in provision of services in this area that it should be covered by a separate national quality improvement audit.

### Pathology services for lung cancer

The recognition of targetable driver mutations within tumours and the introduction of the new treatments of immuno-oncology have dramatically increased the range of treatments available to patients, and they all rely on accurate and timely pathological assessment. The NOLCP sets a challenging target of three days to a pathological diagnosis, and ten days to full molecular profiling results. These results are usually required before a fully informed decision can be made regarding treatment.

We have seen evidence of wide variation in turnaround times from a cytological or histological sample being taken to a full result being available to the treating specialists. The NLCA spotlight audit on molecular testing published in 2020 (but evaluating patients diagnosed in 2017) found that the median turnaround time from tissue acquisition to EGFR mutation result was 18 days<sup>24</sup>. Although improvements have been made since then, the GIRFT/NLCA organisational audit of 2019 revealed that only 46% met the three-day target and 38% met the ten-day target. During our visits we heard from a number of centres who were not striving to achieve the three-day target as this target falls outside the Royal College of Pathologists (RCPath) Key Performance Indicators (KPIs) for reporting times. However, the RCPath 2018 Standards for reporting of lung cancers strongly recommend that departments work towards the NOLCP recommendations. We recognise that for a small percentage of tumours accurate diagnosis will be difficult and requires more complex testing and/or a second opinion. However, this should be regarded as an exception rather than the rule.

It was beyond the scope of our review to look in detail at the pathways from tissue acquisition to the full pathology report being available to the clinical team. We did hear examples of good practice, such as where samples were transported to the pathology laboratory team in a coloured bag to highlight the need for urgent processing, or flagging mechanisms such that when a SCLC diagnosis was made by a pathologist the clinical team was immediately notified so that assessment and treatment could be expedited. The majority of pathology departments now employ reflex molecular testing for all patients with NSCLC, and this should be implemented immediately where it does not currently occur. Moreover, all molecular and genomic test ordering and reporting should be electronically enabled with end to end links to enable integrated reporting and early visibility within the patient record.

The NLCA/GIRFT organisational audit data from 2019 suggested that the majority of trusts use larger regional laboratories for some or all of their molecular and biomarker testing. Over the last 18 months this has changed somewhat, and we have reviewed data from some trusts showing significant reductions in turnaround time by bringing the testing of a limited panel of genetic tests back to the local laboratory. This, however, is excluding some patients from potential therapies when the panel does not include a targetable mutation (e.g. BRAF).

However, with the NHS England (NHSE) reconfiguration to create a single NHS testing network via the formation of larger Genomic Laboratory Hubs (GLH), all tissue samples for genomic analysis will be required to be sent centrally. Whilst we strongly support the expanded genetic testing (as detailed in the national test directory) being routinely available to all lung cancer patients, uncertainty about the scope and shape of this regional service is currently limiting service development in local laboratories. It remains to be seen whether the new model of service delivery will impact positively or negatively on the turnaround times and we recommend that this is monitored closely across all lung cancer services.

To achieve the required clinically relevant timelines will require close co-operation between pathology departments in trusts performing diagnostic procedures, in terms of sample assessment and preparation, those involved with the logistics of specimen transportation and the GLH team in ensuring reports are available to the referring MDT. Indeed, we feel that the NOLCP turnaround time target of ten days from tissue acquisition should be part of the contracting arrangements with cross-organisational funding and accountability (see Recommendation 7, page 39). With the expanding role of circulating tumour DNA liquid biopsy analysis, NHS England needs to provide additional clarity to clinicians regarding commissioned pathways for both individual gene and wider panel testing at relevant points in the cancer pathway.

Throughout the GIRFT visits, there has been evidence of significant vacancies within pathology services. In order to provide a high quality and timely service and reduce delays, pathology departments and associated roles such as specimen delivery, must be appropriately staffed. This will be especially vital where specimen pathways are changed. In addition to this, secretarial and IT support must be available for the reporting and distribution of results to the referring teams. Where recruitment challenges cannot be overcome by a single organisation, trusts within a region or Cancer Alliance should consider working collaboratively to support rapid cancer diagnostics.

#### **CASE STUDY**

In order to meet the challenging NOLCP timelines for pathology reporting the team at **Leicester University Hospital** undertook streamlining of the laboratory service across two sites, addressing transport, clinical scientist and staffing issues. This involved triage at the point of tissue receipt, reflex testing and the training of both medical and scientific staff to report PDL1 and other molecular immunohistochemical markers, and cytogenetic FISH samples. Additionally, they introduced a small cell flagging system which resulted in reduced time to diagnosis and, as a consequence, a decrease in 30-day mortality.

The following table provides an estimate of the impact on the diagnostic pathway timings if our recommended changes are implemented.

Issues identified on deep dives	Potential solutions /best practice	Potential days saved in diagnostic pathway/impact of change in practice	
Rapid access clinics running only once or twice weekly causing delays to downstream tests.	Daily rapid access slots within clinics utilising increased digital and remote capability.	3-7	
Delays between CXR and CT scan requiring multiple patient attendances.	Same day CXR and CT in selected patients.	3-7	
Outpatient appointments scheduled around a routine weekly diagnostic MDT meeting where all CT scan results are reviewed and subsequent work-up planned.	Daily triage and decision-making by an experienced respiratory physician without waiting for MDT.	5-7	
Diagnostic tests carried out in series awaiting MDT review of each step before booking next investigation.	Bundles of care utilised allowing tests to be booked in parallel or even as one-stop clinics where lung function, PET and biopsy are all carried out.	10-14	
Patients with CT scans that have excluded cancer still attending rapid access clinics to be told scan results.	Remote consultations to inform patients with non-cancer of their diagnosis, using wider clinical team to release consultant capacity.	Release capacity for rapid access slots.	
Clinic capacity consumed by non-cancer general respiratory disease by those working in the lung cancer service.	Consultant-led clinical triage into the most appropriate clinic for patients' needs with appropriate administrative support to ensure patients are not lost to follow-up.	Patient seen by right clinician first time within appropriate timeframe.	
Systems and administrative staff working inefficiently around scheduling.	Pathway navigator facilitating booking and co-ordination of tests, chasing up delays and monitoring 28 day pathway. Clinician-controlled scheduling access to vital ring-fenced investigations for lung cancer.	5-10 days	
Investigations arranged in the wrong order leading to capacity constraints in services such as EBUS whereby unnecessary biopsies are arranged due to lack of clinical information.	Upfront PET with ring-fenced slots for rapid access within 5 calendar days to enable rest of pathway.	Up to 14 days	
PET arranged following review, with current commissioned pathway.	Carved-out PET slots accessible to clinicians to book direct from clinic with turnaround time of 5 days.	5-7 days	
Delays to CT biopsy due to lack of recovery space, constrained access to scanners or inadequate staffing.	Same day ultrasound guided node biopsy by respiratory physician in clinic or CT guided biopsy within 5 days of request.	7-10 days	
EBUS lists held once weekly with capacity for 3-4 procedures maximum.	2-3 flexible EBUS lists per week with capacity for staging and diagnostic EBUS.	7 days	
Pathology turnaround of 10-14 days with delays in getting full molecular results.	Full pathology turnaround of 10 days.	4 days	

Table 2:	Impact of	<sup>r</sup> recommended	l changes ir	n practice on	natient nath	way timings
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### Lung nodule pathway

The vast majority of nodules investigated and followed up do not result in a diagnosis of lung cancer and so this is somewhat outside the scope of our review. However, effective nodule management is crucial to diagnose those nodules that are malignant and to manage the non-malignant cases as efficiently as possible. Much of the decision-making can be readily protocolised due to the published validated national guidance on their management.

We recognised the additional burden that nodule management places on lung cancer teams and noted significant variation in the way lung nodule services were configured – for example, only 55% of trusts had a nodule MDM separate to the main lung cancer MDM, and only 22% did not have a formal pathway for nodule management.<sup>25</sup>

Where these services are not well structured, we saw evidence within the deep-dive visits of multiple challenges:

- Lack of robust governance increasing the risk of patients being lost to follow-up or having a missed diagnosis of lung cancer.
- Impact on clinic capacity due to multiple (unnecessary) attendances of patients for results of imaging tests.
- Lack of proper pathway co-ordination or administrative support to ensure timely CT booking and review.
- Workload not properly accounted for within job plans for consultants administering the pathway.
- Multiple clinicians all independently managing nodules without a central point of co-ordination, with lack of clarity regarding overall responsibility for the patient.
- Lack of appropriate skill mix within the pathway with costly consultant-delivered rather than consultant-led care.
- Lack of a separate nodule MDM with appropriate multidisciplinary attendance, or, where part of a main cancer MDM, discussions on reported risks of nodule being delayed as a result of discussions regarding cancer overrunning.
- Lack of IT infrastructure to enable and support virtual clinic follow-up of patients reducing need for attendance in outpatients.
- Lack of an appropriate negotiated tariff where commissioners recognise the significant burden of work nodules represent to respiratory medicine and imaging services.

Following clear evidence of variation nationally in nodule services, GIRFT would recommend formal commissioning of a nodule MDT with associated tariff and co-ordinator posts (see Recommendation 8, page 40). Many trusts are carrying out nodule work informally and the development of a virtual clinic to communicate scan findings to patients and primary care can help generate some income to support the additional administrative roles required.

Administrative support to the nodule service is essential, as is having appropriate tracking software or a database of all nodules. The pathway lends itself well to utilising better skill mix and modernising the workforce in line with guidance. There is potential for the nodule service, although consultant-led, to be predominantly delivered by other members of clinical staff, such as an advanced practitioner or nurse specialist. Likewise, the role for radiographer reporting of nodules and in future the wider implementation of artificial intelligence, will reduce pressures on radiologists to report the increasing volumes of nodules identified and requiring ongoing surveillance.

#### **CASE STUDY**

At **Nottingham University Hospitals**, a weekly meeting is held between a radiologist and respiratory physician, to discuss patients with newly detected indeterminate pulmonary nodules, in order to risk assess them and plan their further management. This is supported by volumetry measurements carried out by a reporting radiographer in advance of the meeting. The majority of patient management is conducted remotely without the need for face-to-face consultations, particularly during the surveillance phase. The service is supported by an administrative database to minimise the risk of patients being lost during follow-up.
## Recommendations

Recommendation	Actions	Owners	Timescale
1. Respiratory teams to immediately move to providing proactive management of unexpected abnormal chest radiology and work with radiology departments to implement pathways that deliver a three working day turnaround from abnormal chest	<b>a</b> Establish local mechanism for coding of abnormal radiology, sharing of information with lung cancer team, and transfer of clinical responsibility for further investigation.	Trusts, imaging networks	3 months from publication
	<b>b</b> Implement mechanisms within radiology enabling straight-to-CT for patients with abnormal CXRs.	Cancer Alliances, commissioners, trusts, imaging networks	6 months from publication
report.	<b>c</b> Provide adequate resources for changes to be made to existing pathways. This may require the introduction of co-ordinator roles to ensure effective and timely communication with patients by those with the appropriate skills to do so.	Cancer Alliances, trusts, imaging networks	1 year from publication
	<b>d</b> Begin a capacity planning exercise for implementing (within two years) a same-day turnaround for patients with an abnormal CXR.	NHSE, trusts, imaging networks	6 months from publication
2. Key diagnostic investigations should be completed within 21 calendar days of the start of the pathway by adopting best practice recommendations on service configuration and pathway planning.	a Daily triage of patients should be undertaken by a clinician with expertise in lung cancer diagnostics, in order that patients can have their pathway planned in advance through the use of diagnostic bundles, and where appropriate without the need for a prior face-to-face appointment.	Trusts	3 months from publication
	<b>b</b> Triage should include the facility for patients without cancer evident on a CT scan to be moved into a more appropriate service.	Trusts	3 months from publication
	c Capacity for assessing patients, requesting, and reviewing tests should be spread across the working week and where possible carried out daily to avoid batching and undue delay.	Trusts	6 months from publication
	<b>d</b> All lung cancer teams should have an administrative navigator post integrated into their specialist nursing team.	Trusts	1 year from publication
<b>3.</b> Renegotiate the national PET-CT contract to include a five calendar day turnaround from request to	<b>a</b> Commissioning of the national PET-CT contract should be modified to mandate the five calendar day target, 52 weeks of the year.	NHS England	2 years from publication
report and available imaging for initial investigations of new diagnoses of lung cancer.	<b>b</b> Trusts and PET-CT providers should work together to ensure that the test images are available to clinical teams on the same day as the written radiologist report.	Trusts, PET-CT providers, imaging network	1 year from publication
	<b>c</b> Local requirements for PET-CT scan requests to be supported by an MDT discussion should be abandoned when the indication sits within the diagnostic Standards of Care.	PET-CT providers, trusts, imaging network	3 months from publication
	<b>d</b> PET-CT turnaround times should be monitored, and action taken if contractual arrangements are not met.	NHSE Specialised Commissioning, imaging network	3 months from publication
	<b>e</b> Use of PET-CT reporting templates should be considered best practice and adopted widely.	PET-CT providers, imaging network	3 months from publication

Recommendation	Actions	Owners	Timescale
<b>3.</b> Renegotiate the national PET-CT contract to include a five calendar day turnaround from request to report and available imaging for	<b>f</b> Diagnostic and staging EBUS for lung cancer should be done with the benefit of a reported PET-CT scan (if indicated) to prevent unnecessary or inappropriate biopsies being undertaken.	Trusts	3 months from publication
initial investigations of new diagnoses of lung cancer.	<b>g</b> PET providers should reserve specified slots weekly for patients with lung cancer, with the facility for clinicians to book direct from clinic, to enable faster diagnosis.	NHS England, PET-CT providers, imaging network	6 months from publication
<b>4.</b> An image-guided biopsy service should be available for all patients 52 weeks of the year, with	<b>a</b> Ensure that day case capacity for patients requiring recovery, monitoring and treatment after a biopsy is adequate and does not act as a barrier.	Trusts	1 year from publication
appointments for the procedure being available (notwithstanding issues such as anti-coagulation or anti-platelet therapy) within five working days of the request.	<b>b</b> Respiratory teams to identify individuals to upskill in performing a range of ultrasound-guided biopsies to release time from radiologists, with investment in appropriate specification point-of-care equipment.	Trusts, Health Education England	1 year from publication
	<b>c</b> Where a local service lacks necessary capacity or skill, resources should be shared across the Cancer Alliance.	Cancer Alliances	1 year from publication
<b>5.</b> EBUS for lung cancer should be available within five calendar days	<b>a</b> All providers of EBUS to work towards full compliance with national service specifications.	Trusts	1 year from publication
of request and must comply with the national service specifications, with regular monitoring of performance by local commissioners.	<b>b</b> Clinical teams to improve their selection of patients for EBUS by following diagnostic standards of care and ensuring a reported PET scan is available where indicated.	Trusts	3 months from publication
	c EBUS providers to regularly carry out audit of both diagnostic and staging procedures (separately), with the results being shared within the Cancer Alliance as specified in our recommendation on data collection (page 78).	Trusts, Cancer Alliances	1 year from publication
	<b>d</b> EBUS providers to establish a demand and capacity model for staging and diagnostic EBUS and agree sharing of resources with neighbouring trusts if capacity to provide these tests within five calendar days of request is insufficient.	Trusts, Cancer Alliances	1 year from publication
	<b>e</b> The national EBUS service specification should be updated to recommend a turnaround of five calendar days from receipt of referral, and the minimum number of 20 EBUS per year to maintain competence should be reviewed.	Lung CEG	6 months from publication
	<b>f</b> Trusts to ensure that endoscopy facilities are made available to the lung cancer service, with appropriate prioritisation with regards to the NOLCP, in accordance with demand and capacity models.	Trusts	6 months from publication

Recommendation	Actions	Owners	Timescale
<b>6.</b> Ensure a diagnostic and therapeutic ambulatory pleural service is available for all lung cancer patients, accessible	a Clinical teams should review their pathways to ensure they have rapid access to all relevant diagnostic and therapeutic pleural procedures and that they are delivered in a patient-centred way.	Trusts	1 year from publication
within five working days, 52 weeks of the year.	<b>b</b> Where staffing constraints cause delays, consider up-skilling nursing staff to be competent in pleural ultrasound and procedures.	Commissioners, trusts	1 year from publication
	<b>c</b> A quality improvement programme, such as a British Thoracic Society audit, should be commissioned to review pleural services.	NHSE/I	2 years from publication
7. Pathological services should provide a maximum ten calendar day turnaround time for molecular profiling according to the national test directory of lung	a There should be immediate and detailed communication provided through Cancer Alliances in conjunction with the Genomic Medicine Services to clinical teams regarding the scope and shape of the Genomic Laboratory Hubs (GLH).	NHSE	3 months from publication
cancers to meet the requirements of the NOLCP.	<b>b</b> Commissioners must agree a policy for immunohistochemistry (IHC) and next generation sequencing testing at local laboratory and central hub levels and provide funding for all components of the pathology pathway.	NHSE	3 months from publication
	<b>c</b> All local pathology services should provide reflex molecular and biomarker testing for the genetic targets as detailed in the National Genomic test directory, carried out locally or regionally with a maximum turnaround time of 10 days from tissue acquisition.	Trusts, GLH	3 months from publication
	<b>d</b> Turnaround times should be audited and reported back to trusts through the regional Cancer Alliances twice a year, and remedial action taken where targets are not being achieved.	NHSE/I, Cancer Alliances	6 months from publication
	e Pathology departments and associated support services must address local vacancies, if necessary by working with organisations within the same Cancer Alliance.	Trusts, Cancer Alliances, commissioners	1 year from publication
	<b>f</b> All lung cancer services should have systems in place to highlight samples where lung cancer is suspected to allow for prioritisation in processing, as well as a flagging mechanism to rapidly highlight patients newly diagnosed with small cell lung cancer.	Trusts	3 months from publication
	<b>g</b> The impact of transferral of work from individual trusts to the Genomic Laboratory Hubs on the speed of the diagnostic and treatment pathway should be monitored and addressed if timeliness is adversely impacted.	NHSE/I, Genomics England, trusts	1 year from publication
	<b>h</b> RCPath to update KPIs for lung cancer reporting to ensure this is carried out in line with timescales of the commissioned standard.	RCPath	1 year from publication

Recommendation	Actions	Owners	Timescale
8. Commission a specific, robust and predominantly virtual nodule pathway which is separate from the lung cancer MDT/MDM.	a Implement simple referral pathways for patients found to have indeterminate lung nodules, as well as mechanisms for safety-netting where referral does not occur.	Commissioners, trusts	3 months from publication
	<b>b</b> Create a distinct MDM for nodule management that is separate from the lung MDM, but which has easy access to their expertise when required.	Trusts	6 months from publication
	<b>c</b> Agree a robust protocol for lung nodule management, with IT and administrative support, including the ability to perform accurate volumetry where applicable.	Trusts	6 months from publication
	<b>d</b> Ensure that the clinical activity within the nodule pathway is commissioned, funded and recognised in job plans.	Cancer Alliances, trusts	6 months from publication
	e Provide patients with high quality information to support their journey in the lung nodule pathway and offer virtual assessment and follow-up as standard.	Trusts	6 months from publication

## **Delivering effective treatment**

Ultimately the aim of any lung cancer team is to reach a decision and offer treatment that provides the best outcome for each individual patient. The treatment should then be delivered as rapidly and as safely as possible. The optimal treatment regimen for an individual patient will depend on a number of factors including the type and stage of their cancer, their comorbidities, family support, availability of community and social services and their willingness to travel, but above all their own wishes regarding anti-cancer interventions. Shared decision-making, after the risks and benefits of all available options have been clearly explained and understood, is key to the therapeutic relationship between patients, their families, and clinicians.

International comparative studies suggest that to improve overall survival from lung cancer in the UK, rates of curative-intent treatment need to increase, and this has been the focus of groups such as the CEG, NLCA, UK Lung Cancer Coalition (UKLCC), Royal College of Radiologists (RCR) and SCTS for a number of years.

There remains unacceptable and unexplained variation in rates of curative-intent treatment and survival across the country,<sup>26</sup> and we aimed to use the available data in our deep dives with teams to drill down and better understand the contributing factors and potential solutions. Furthermore, for those patients whose disease was not curable, we looked at variation in the approach to palliative, supportive and end of life care. For all these treatments, we have evaluated the organisation of services in terms of delivery models, timeliness and patient experience.

## **Curative-intent treatment**

Curative-intent (also termed radical) treatment aims to eradicate all active malignancy within the patient. This can be achieved either by tumour removal (surgery) or through the use of radiotherapy or other ablative techniques delivered to the visible tumour.

Unfortunately, although tumours may appear localised there is a high propensity for microscopic spread, therefore many patients will be offered combination therapies to improve the potential for cure. This may be delivered in a neoadjuvant (before surgery or radiotherapy), concurrent (in combination with radiotherapy) or adjuvant (after surgery or radiotherapy) manner. Since the potential for cure is greater in patients with early-stage disease, a drive for earlier diagnosis and treatment is critical, and underpins developments like the national public awareness 'three-week cough' campaign, and the pilot lung health checks. Moreover, the associated morbidity of treatment is lower with a single modality of treatment.

If overall survival is to improve, it is essential that all patients who might potentially benefit from curative intent treatment are offered this and receive it. However, there is evidence from our data of significant variation between trusts (ranging from 50% to 100%) in the number of patients accessing radical therapy, even when adjusted for age, sex, stage of disease and socioeconomic status. These differences cannot be purely accounted for by population differences or performance status.

**Figure 12** shows the wide range of use of curative-intent treatment in good PS patients with early-stage NSCLC across different trusts, which is clearly statistically significant in many cases. In many MDTs we heard that teams had internally reviewed their own rates of radical treatment and felt that there were local reasons why they were lower than the median for England, for example comorbidities and lung function. However, the value of an objective peer review should not be underestimated as, by the nature of how MDTs work, they are unlikely to dispute their own decision-making process. We were not able to conduct an in-depth review at each service at patient level to ascertain processes for robust decision-making but many local action plans (agreed with teams following a GIRFT visit) include strong recommendations to ensure that every patient has been properly considered for active anticancer treatment.



Figure 12: Proportion of NSCLC cases with stage I & II PSO-2 receiving radical treatment, NLCA, 2017

There is no agreed optimal radical treatment rate, and there is undoubtedly a balance to be struck between obtaining a potential cure from lung cancer and the toxicity associated with treatment. However, what are the differences that could account for one trust delivering 'cure' rates of over 90% where others struggle to achieve 60%?

There were data issues cited by teams in deep-dive visits, whereby performance status had been mis-recorded, meaning that those unfit for treatment were counted amongst this population, or that patients declined treatment. Importantly, we have made many recommendations within local action plans challenging teams to review their data accuracy before submission to the national audit and this is discussed later in more detail. We don't feel that such data inaccuracies can account for the extent of the variation seen, and it is very disappointing to hear that after more than 15 years of national audit, some teams still struggle to record simple clinical data accurately. Factors contributing to unwarranted variation largely fall under two categories:

### Variation in access:

- Access to local lung screening programmes identifying greater numbers of early-stage, potentially curable disease as highlighted earlier.
- On-site presence at MDT of surgeon or clinical oncologist throughout the year. This is discussed in more detail in the chapter on effective MDT working.
- Access to a high-risk MDT to identify opportunities to optimise a patient or arrange investigations required to define suitability for anaesthesia and peri/post-operative risk.
- The availability of an effective suite of supportive care, e.g. dietetics and physiotherapy, to optimise patients of borderline fitness and support them through treatment. This may include a formal prehabilitation service or enhanced supportive care.
- Variability in access to modern radiotherapy techniques which would enable treatment of more advanced stage disease.
- Delay in accessing treatment where a significant wait for one modality of treatment may cause a patient to elect an alternative.
- Travel time to a regional surgical or radiotherapy centre impacting on patient choice.

#### Variation in practice:

- Variation in comorbidity or perception of comorbidity influencing individual treatment outcomes, e.g. dementia or cardiovascular disease.
- Differences in attitude to the rapeutic intervention in patients with low grade carcinomas, particularly in the elderly and those with comorbidities.
- Perception of efficacy and toxicity of multimodality treatment by MDT members and patients.
- Ways in which information about risks and benefits of different treatment options are provided in shared decision-making.
- Variability between individual surgeons and centres in technical approach and identification of patients amenable for surgery. The GIRFT national report for cardiothoracic surgery in 2018 reported wide variation in the use of robotic and video-assisted thoracoscopic (VATS) techniques for lobectomy. VATS lobectomies result in faster recovery, reduced post-operative pain and complications, and facilitate adjuvant chemotherapy where needed, compared with open surgery.
- Equipoise between surgery and SABR within some MDTs results in a bias towards radiotherapy over surgery given the lower acute risk of mortality where patients may not have had the opportunity to meet with both a surgeon and clinical oncologist when making their decision.

These influences are likely to be further compounded by the perceived and actual risk of COVID-19 complications.

Whilst surgical resection would usually be considered the gold standard of therapy for eligible patients it is recognised that a patient's underlying comorbidities may make surgical risk unacceptably high and a better balance of risk and benefit can be obtained with non-surgical therapies. The NLCA has recently published its second report on the management of patients who have early-stage disease and good performance status and noted that of those who did not have surgery, 62% received radiotherapy, mostly with curative intent, and that this had risen significantly compared to 2015.<sup>27</sup> As a result, while in the past great focus was put on increasing resection rates, in the modern multimodality era and with more modern radiotherapy techniques, the distinction between types of curative-intent treatments is less clear and focusing on overall radical treatment rates is more applicable.

Improvement	NSCLC patients with Stage I-II disease and PS0-2 receiving radical treatment	Additional number of patients receiving radical intent treatment
Overall NLCA 2017 total	5,748 (80.8%)	_
All trusts reach NLCA median as minimum	81.8%	287 (5% increase)
All trusts reach target treatment rate	85.0%	416 (7% increase)
All trusts reach NLCA best quartile as minimum	87.2%	522 (9% increase)

#### Table 3: Impact of increasing radical treatment rates, NLCA, 2017

**Table 3** demonstrates that if all trusts achieved the NLCA target of 85% patients eligible for curative-intent treatment with early-stage disease, an additional 416 patients would be treated annually – a 7% increase. If all trusts achieved the best quartile performance, 522 more patients would receive radical treatment. This would result in an overall radical treatment rate in NSCLC across England of 88.1%, surpassing the NLCA target and resulting in a significant difference to outcomes in lung cancer (see Recommendations 9 and 13, pages 51 and 52).

#### **Thoracic surgery**

Thoracic surgical services for the treatment of lung cancer are configured as 28 tertiary centres across England delivering surgery for their own and networked trusts. Surgery is usually offered for patients with potentially curative (radical) intent. Rarely, a palliative procedure will be offered for symptom control. The GIRFT national report for cardiothoracic surgery identified the variation in surgical approach to curative-intent surgery. The cardiothoracic surgery workstream continues its review of the implementation of recommendations within that report. This review will therefore not focus on the technical aspects of the surgery or data separately reviewed within the cardiothoracic surgery workstream. We have focused our discussions on overall treatment rates and on access to and timings within the surgical pathway following a diagnosis of lung cancer.

Although it is impossible to define a national optimal surgical resection rate, the NLCA reports starkly the variation in surgical resection across England with a range of 5-34% (one centre reported a zero resection rate but this is a data reporting issue).

MDTs with a resection rate for patients with histologically confirmed NSCLC below the median of 25.8% as reported in the NLCA 2017 report should urgently improve their practice and implement local actions using the NLCA toolkit to increase their resection rate (see Recommendation 10, page 51). If all trusts were to improve to the median this would lead to an additional 415 (7%) patients each year receiving curative surgery. If all trusts were to improve to the upper quartile, then 855 (14%) additional patients would receive curative intent surgery.



Figure 13: Proportion of histologically confirmed NSCLC patients receiving surgery, NLCA, 2017

In many situations, the optimal treatment involves multiple modes of therapy including systemic therapy (either as neoadjuvant/concurrent or adjuvant), and/or radiotherapy and/or surgery (for example in stage III lung cancer, or where patient is of borderline fitness). Where this is the case, or where there are curative-intent options to decide between, best practice identified through deep dives are multidisciplinary clinics where treating clinicians (usually an oncologist and a surgeon) can meet with the patient together to discuss fully the options available and enable the patient to make a fully informed decision. Such clinics also had the benefit of improving mutual understanding between clinicians with regard to best patient care and are likely to impact over time on MDT practice and culture.

Patients with lung cancer frequently have other significant comorbidities such as COPD or cerebrovascular or ischaemic heart disease which impacts on their fitness for surgery. Best practice identified in deep dives is for a 'high risk MDT' comprising at least two thoracic surgeons, a cardiothoracic anaesthetist, a thoracic CNS and administrative support. These MDTs determine how best to optimise the patient, co-ordinate post-operative care and any special circumstances and ensure that all relevant tests are carried out prior to surgery. The high-risk MDT meeting can:

- Gather all the pre-operative data for a patient together (usually the referring MDT will not have seen, for example, the cardiopulmonary exercise testing and the anaesthetic assessment).
- Look for opportunities to optimise the patient before surgery (e.g. prehabilitation, smoking cessation, anaemia, nutrition).
- Decide the perioperative treatment plan (usually high dependency unit (HDU) versus ward bed booking, but sometimes management of perioperative issues such as plasmapheresis in myasthenia, renal failure etc).
- Ensure that the correct pre-operative diagnosis and treatment plan have been communicated to the patient, since this may change after the initial surgical consultation with new information, e.g. cardiology or other assessments.

There must be robust processes in place to ensure that communication of the outcomes from these meetings, both to the referring team and then onwards to the patient, is clear, precise and timely. Discussion at these meetings should not add substantial delays to the patient pathway. We have seen considerable variation with respect to these MDTs, with only some trusts having access to high-risk surgical MDTs. We feel that every surgical unit should have a high-risk MDT to ensure improved access to surgery for borderline fitness patients and to improve radical treatment offered.

### **CASE STUDY**

**Barts Hospital** surgical team have increased the surgical resection rate by their extensive use of navigational bronchoscopy to biopsy small lesions, performing sublobar resections (often utilising robotic surgery) which facilitates the treatment of medically borderline cases. They provide a second opinion service for neighbouring centres.

Currently, widely used assessments of fitness for both radical and palliative treatment are used by MDTs. These are World Health Organisation or Eastern Co-operative Oncology Group performance status. Most NICE recommendations are also based upon these scales, which are a crude and rather blunt tool when determining the ability of a patient to benefit from recommended treatment.

Innovative practice identified in visits is the implementation of a more complex assessment of frailty and comorbidity, often in conjunction with an oncogeriatrician, and these should be researched more widely as an urgent priority to inform more comprehensive and up-to-date decision-making by the MDT.

There is unwarranted variation in the speed in which patients move from the decision to operate to the operation itself. Although half of patients wait less than 14 days (and within the NOLCP standard of 16 days), 16% wait over four weeks (**Figure 14**). Even these relatively short delays can be associated with tumour growth and may mean an operation is less likely to provide a cure or even render the operation technically impossible. It was noteworthy that during the visits it became apparent that not all MDTs were re-staging patients who had delays in the pathway prior to surgery due to limited access to PET and/or repeat CT. The reasons for delays in providing treatment are multifactorial but ensuring that surgical support is provided 52 weeks of the year would be expected to lead to improvements.

Variation was also noted in the case prioritisation. The majority of centres operate a team based 'white board' approach, prioritising advanced stage cases over early-stage disease rather than a strict order of referral to a named clinician. However, this is not uniform practice which potentially disadvantages some trusts' patients. All trusts should ensure that they are compliant with NOLCP and that patients wait no longer than 16 days from decision to treat to surgery unless they require medical optimisation. If there is greater than a six-week delay from the last cross-sectional imaging, because of the risk of stage migration, repeat CT or PET-CT imaging should be obtained prior to treatment.

Local pathway redesign should be undertaken in order that treatment should commence by day 16 after a decision to treat has been made (see Recommendation 16, page 53).



#### Figure 14: Waiting time from treatment decision to surgery, trust MDT systems, 2019

#### Radiotherapy

Two main radiotherapy techniques are used to effect a cure in lung cancer: SABR and external beam radiotherapy.

**Figure 15** demonstrates the wide variation in rates of radical radiotherapy (including both SABR and external beam) from the NLCA 2017. Whilst we are aware there may be some data inaccuracies, ensuring that data submitted nationally accurately reflects the service should form a key part of the MDT's work.



Figure 15: Proportion of Stage I & II PSO-2 NSCLC patients receiving radical radiotherapy, NLCA, 2017

It might be expected that the centres with high surgical resection rates for early-stage disease would have correspondingly lower radiotherapy rates, and this is supported to some extent by our data which showed a moderate correlation between these modalities (**Figure 16**). However, there remain a significant number of trusts where rates of radiotherapy and surgery are lower than the median.



Figure 16: Correlation between patients at stage I & II and PS 0-2 receiving surgery compared to patients receiving radical radiotherapy, NLCA, 2017

If all trusts currently below the line of regression were brought up to the median then an additional 202 patients would receive radical radiotherapy.

## Stereotactic Ablative Radiotherapy (SABR)

SABR is a technique that uses highly conformal radiotherapy to deliver a potentially curative dose of radiation to the tumour while sparing surrounding normal tissues. A high dose per fraction (treatment) is utilised resulting in fewer treatment visits (between one and eight depending on tumour position and size). Local control rates are superior to conventional fractionation schedules of radiotherapy. SABR is currently commissioned for patients who have medically inoperable early-stage lung cancer without evidence of lymph node spread. At the time of writing there is no randomised evidence to demonstrate whether surgery and SABR have equivalent outcomes in terms of local control and overall survival.

At the time of writing, only 24 centres are commissioned to deliver SABR in lung cancer. We heard in our deep dives that patients in some trusts have declined SABR as a treatment option due to the travel requirements involved to attend one of the 24 commissioned centres (between 35 and 150 minutes in the 41 trusts who answered this question). In addition to travel time, paucity of public transport and cultural factors were cited as barriers. In some cases patients have been offered conventional external beam radiotherapy (with a lower chance of cure) and others have declined treatment altogether. All of the commissioned centres we visited described a service conforming to SABR consortium guidelines (see Recommendation 11, page 52).

NHS England Specialised Commissioning has committed to increase the number of centres able to offer SABR for primary lung cancer and oligometastatic disease and a programme of mentoring is proposed. As authors of this report, we strongly support this initiative and feel that SABR must be offered as standard in every cancer centre that delivers lung cancer care.

However, wider commissioning must be accompanied by the additional resource to train staff, deliver all aspects of planning and treatment delivery, review cases alongside radiology in a formal SABR MDT, and support the service with administrative staff. It will also require an expansion of the clinical and scientific workforce. With the introduction of lung cancer screening, demand for SABR is likely to increase significantly. Urgent work to ensure that capacity matches demand for those with lung cancer is required.

#### External beam radiotherapy

External beam treatment (20-36 fractions), given as either a single modality or in combination with systemic treatment, is the standard of care for patients of good performance status who are ineligible for surgery or SABR. For selected stage III patients radical chemoradiotherapy may be employed in the neo-adjuvant setting. External beam radiotherapy may also be considered in the adjuvant setting in the event of an incomplete resection.

It is usually delivered using Intensity Modulated Radiation Therapy (IMRT). This technique uses three-dimensional or more usually four-dimensional planning to allow oncologists to deliver potentially curative doses of radiation to the cancer and regions of potential spread while relatively sparing healthy tissue in the field. Radiotherapy when delivered using IMRT enables larger target volumes to be treated with curative intent while keeping the doses to critical organs below what are conventionally termed tolerance limits. For patients with stage III NSCLC disease the optimal approach would be to offer concurrent chemoradiation, potentially to be followed by consolidation immunotherapy for eligible patients.

It is recognised that this requires excellent supportive care to be delivered throughout treatment to mitigate the acute toxicities of this therapy. A proportion of patients will not be candidates for this combined approach due to their comorbidities or cancer distribution. In such cases sequential chemoradiotherapy, accelerated hyper-fractionated radiotherapy (CHART) or conventionally fractionated radiotherapy may be considered. It is noted that few radiotherapy centres continue to offer CHART despite strong evidence for its efficacy, largely due to the complexity of treatment scheduling.

The RCR published consensus guidelines on radiotherapy treatments in 2020 following consultation with all 62 treating lung cancer units in the UK. These were examined through the GIRFT pre-visit questionnaire and discussion with the oncologists at individual trusts during our visits. We found that in a number of areas there is a significant gap between the best practice recommended in these guidelines, and the clinical practice actually being delivered (see Recommendation 12, page 52). This variation is described below.

In delivering external beam radiotherapy it is critical to use the most modern techniques available in order to maximise effectiveness of treatment and at the same time minimise the toxicity to the patient.

As discussed previously, IMRT should be the technique of choice for external beam radiotherapy. Where this is not available it may exclude some patients from radical therapy, reduce effectiveness or increase toxicity. All trusts should rapidly implement the use of IMRT or partner with a neighbouring trust and refer all patients there for external beam radiotherapy. In order to accurately deliver IMRT, the linear accelerator is required to be of an adequate specification. This would be standard in trusts who have maintained their rolling replacement programme in line with national guidance.

We have noticed on our visits that measures for motion control are extremely variable around the country. 4D CT is the most common technique in place, but should be considered the minimum necessary, with only a minority of trusts having access to a second form of motion control (such as active breathing control, abdominal compression or gating). Not to have access to optimal motion control techniques risks a geographic miss of the cancer and reduction in local control and survival for the patient in the future, and it should be a priority for all trusts to review this aspect of their service and implement appropriate improvements.

Image-Guided Radiotherapy (IGRT) allows the clinician, usually a therapeutic radiographer, to image the tumour immediately before or even during the time radiation is delivered to compensate for the movement of the lungs during the procedure. Both the updated 'On Target 2' guidance<sup>28</sup> and RCR consensus guidelines now recommend that daily cone beam imaging is implemented. This reduces the risk of a geographic miss if the anatomy has changed, for example because a lobe of the lung has re-inflated. Of the 55 trusts we visited who answered the question, 54% were using daily IGRT; 36% use IGRT for the first three fractions and then weekly. There was also variation regarding whether this was online or offline review. All trusts need to ensure that their image-guidance protocols meet the newly revised specification.

The visits have identified that a small number of academic centres now have access to Magnetic Resonance Linear Accelerators which give exceptional motion control during delivery of radiation therapy. The Christie and the Royal Marsden hospitals are leading the development of these services in lung cancer and will be central to sharing the learning and rollout in the future if this becomes standard treatment.

The RCR guidance strongly recommends peer review of both outlining and the resulting treatment plan. There is evidence from outlining studies that without this some of the cancer may be excluded from the high dose region in a percentage of patients (a geographic miss). During our visits we found that there was variability in how this was being conducted. Many clinical oncologists did not have dedicated time identified for this in their job plans and a number were performing it for selected patients only.

During our deep dives we visited centres with vacancies which had not been filled for a number of years, leading to workloads for individual consultants in excess of RCR guidelines. For centres which only have one clinical oncologist specialising in thoracic oncology it is imperative that formalised arrangements are made for cross cover and peer review. Operations boards within radiotherapy operational delivery networks (ODNs) should consider a team-based approach to thoracic radiotherapy planning not necessarily exclusive to individual trusts. Thus, the focus could move towards delivering radiation therapy closer to the patient's home while ensuring oversight from a larger clinical team. In order for this to be effective significant investment in IT systems to communicate between planning systems and clinical teams is required.

As we observed with surgery, we have seen that some patients experience long waits to access their radiotherapy treatment with similar potential consequences. Particularly pertinent to radiotherapy is the potential for a geographic miss due to tumour growth beyond the defined target volume and distortion of the anatomy e.g. lobar collapse, which necessitates re-planning of the treatment (both time consuming and adding further delay in therapy). It was apparent within visits that many radiotherapy centres were not working to the new NOLCP timings and need to undertake significant pathway redesign to expedite all elements of planning and quality assurance. Best practice saw team-working across radiotherapy delivery with staff working flexibly to accommodate patients rapidly, undertake regular peer review of planning and using the most up-to-date radiotherapy delivery techniques. Centres should implement these areas of best practice so that radiotherapy is delivered within 16 days of decision to treat regardless of the speed of the preceding diagnostic pathway (see Recommendation 16, page 53). This was demonstrated in Leeds, where the team have revised their patient and planning pathway to reduce the time to commencing treatment from 28 to 16 days.

### **Ablation therapy**

Interventional radiologists offer minimally invasive thermal ablation techniques including microwave ablation and radiofrequency ablation to eradicate tumours. Initially developed for the treatment of oligometastatic disease their role in the treatment of primary lung cancer is now established, with retrospective data-based reviews suggesting it is non-inferior to SABR. There is a paucity of randomised evidence between different modalities for the treatment of stage I disease. Thermal ablation therefore may provide an option for patients who are medically unfit for surgery and for whom SABR is contraindicated due to anatomical location, movement or density of their tumour or an underlying comorbidity e.g. interstitial lung disease.

Despite NICE guidance there is still limited uptake of this form of treatment across MDTs, with significant geographic variation and lengthy waiting times. As evidence for its use emerges further, it should be considered alongside other curative-intent forms of treatment as a commissioned treatment option with a set of guidelines. We have heard evidence that there have been interruptions in ablation services due to COVID-19 as a result of reduced access to anaesthetic lists. It is crucial where services refer patients for this form of treatment that they are subject to the same rigorous timepoints as for surgery or radiotherapy. They must have a robust referral pathway and undertake local audit to ensure the procedure is safe and effective. Cancer Alliances should ensure that across their region, there is a service available for patients with lung cancer to access.

#### Radical multimodality therapy

Combination chemoradiotherapy delivered either sequentially or preferably concurrently is the standard of care for inoperable patients with stage III disease (followed by adjuvant immunotherapy for eligible patients). However, notwithstanding the heterogeneity of this group of patients, evidence from our deep dives, supported by research, has demonstrated a relatively low use of combined modality therapies, which varies considerably across the country.<sup>29,30</sup>

In addition to factors identified as common barriers to radical treatments we identified a number of factors that may be particularly relevant to these findings:

- Use of CHART radiotherapy.
- Concerns over additional toxicity, with inadequate availability of consultant time and supportive care for managing complications.
- Regional differences are perpetuated by trainees who have had limited exposure to chemoradiation taking up consultant posts in the same region.

During our visits, it was clear that some trusts felt that their data under-represented the number of patients receiving this treatment modality. Regardless of whether this is the case, we feel that regional audit of the usage of combination treatments should be carried out, and where variation exists it should be addressed through education and training, local mentoring programmes, and investment in staffing and other resources.

Although systemic therapy as a single modality would not be considered a potentially curative treatment, it has an important role to play in the post-surgical setting for patients with adverse prognostic features. Although all centres offer adjuvant chemotherapy after surgery (albeit sometimes centralised in a cancer centre rather than a cancer unit), it was not possible to quantify the percentage of eligible patients receiving treatment as part of this review. It is recognised that as surgical rates increase to include more borderline patients that patient fitness will preclude adjuvant therapy in a proportion of cases. However international comparator studies<sup>31</sup> suggest that UK treatment rates fall below those of other European countries. Whilst there is justification for lower treatment rates due to the current COVID-19 pandemic, we suggest that centres should aim to treat in excess of 40% of potentially eligible patients once the excess infection risk is normalised. As it is an important component of radical treatment with potential to improve long term survival this should be reviewed as part of the NLCA (see Recommendation 14, page 53).

To improve the outcomes in lung cancer, in addition to screening to identify earlier stage disease, the next most important intervention would be to improve overall radical treatment rates in patients with stages I-IIIA disease. As the NLCA does not currently incorporate this as a reported measure, it is not possible to quantify the potential gains across stages I-IIIA so we have performed our analysis on stages I&II (see **Table 3**).

There is some data specific to rates of treatment in stage III disease available across England.<sup>32</sup> It is recognised that this stage of disease represents a very heterogeneous group where individualised decision-making is imperative. We were therefore not able to focus on this within our deep dives but would recommend that as this is an important and contentious area within lung cancer that it forms a key metric within the NLCA in future years (see Recommendation 15, page 53).

<sup>31</sup> Chouaid C. et al (2018) Adjuvant treatment patterns and outcomes in patients with stage IB-IIIA non-small cell lung cancer in France, Germany, and the United Kingdom based on the LuCaBIS burden of illness study, Lung Cancer Volume 124, pp310-316. https://doi.org/10.1016/j.lungcan.2018.07.042

## Recommendations

Recommendation	Actions	Owners	Timescale
9. All trusts should have an overall radical treatment rate of 85% or more in those patients with NSCLC stages I-II and of performance status 0-2. This	a Trusts with radical treatment rates lower than 85% should develop an action plan which is externally peer-reviewed by their Cancer Alliance. Results should be shared with commissioners to help address local pressures.	Trusts, Cancer Alliances, Specialised Commissioning	1 year from publication
(surgery, radiotherapy including SABR, multimodality treatment and thermoablative techniques)	<b>b</b> Trusts should ensure that data submitted to the national audit is clinically validated and accurately reflects the service.	Trusts	6 months from publication
and the moablative techniques).	<b>c</b> All patients with potentially curable disease should have access to a joint multidisciplinary clinic with clinical oncologist and surgeon within one consultation to enable patients to make an informed decision about their treatment. This could utilise remote video facilities now widely available across the NHS.	Trusts	1 year from publication
	<b>d</b> Cancer Alliances should co-ordinate the sharing of audit data from each local trust on patients with PSO-2 who do not receive radical treatment.	Cancer Alliances, radiotherapy ODNs	1 year from publication
	e Trusts should consider implementation of more comprehensive frailty and comorbidity assessments to ensure that every patient eligible is given the option for radical treatment.	Trusts	1 year from publication
	<b>f</b> Trusts should have access to thermo-ablative therapy for those medically unfit for surgery and for whom SABR is contraindicated due to anatomical location, movement or density of their tumour or an underlying comorbidity. Data on ablation therapy should be included in NLCA as radical intent treatment.	Cancer Alliances, Specialised Commissioning, NLCA	1 year from publication
	<b>g</b> Improve the information and support given to patients and carers to help with their decisions of whether to undergo treatment for their cancer.	Trusts, charitable organisations	1 year from publication
<b>10.</b> All trusts should have an overall surgical resection rate for	<b>a</b> All trusts should have access to a high-risk MDT.	Surgical centres	6 months from publication
NSCLC of over 20%.	<b>b</b> All trusts should have prehabilitation services with access to physiotherapy, dietetics, psychological support and smoking cessation to optimise patients prior to surgery.	Trusts, CCGs, ICS	1 year from publication
	<b>c</b> All trusts should ensure that patients referred to surgery wait no longer than 21 days from decision to treat to date of surgery.	Surgical centres	1 year from publication
	<b>d</b> Cancer Alliances should peer review NLCA Quality Improvement Toolkit implementation at regional level.	Cancer Alliances	6 months from publication
	<b>e</b> Surgical cover for non-surgical units to be provided 52 weeks of the year.	Surgical centres	1 year from publication
	<b>f</b> Surgical centres to ensure all referring trusts receive equitable access to theatre lists.	Surgical centres	6 months from publication

Recommendation	Actions	Owners	Timescale
<b>11.</b> All trusts that treat lung cancer with radiotherapy should be able to deliver SABR in line with the clinical commissioning	<b>a</b> This should be accompanied by the appropriate resource to train staff and provide mentoring while services develop SABR services from a neighbouring centre.	NHSE, Health Education England (HEE)	1 year from publication
policy.	<b>b</b> Job planning must include time for planning and treatment delivery.	Trusts	6 months from publication
	<b>c</b> All trusts should have the facility to discuss SABR cases with radiology in the form of a SABR MDT.	Trusts	6 months from publication
	<b>d</b> There should be adequate administrative and scientific clinical staff to deliver a consistent service 52 weeks per year.	Trusts, HEE	1 year from publication
<b>12.</b> All trusts should deliver radiotherapy in line with the RCR consensus statements. <sup>33</sup>	<b>a</b> All trusts should rapidly implement the use of IMRT or partner with a neighbouring trust and refer all patients there instead for radical external beam radiotherapy.	Trusts	6 months from publication
	<b>b</b> All trusts should implement daily IGRT for IMRT planned patients.	Trusts	6 months from publication
	<b>c</b> All trusts should employ motion control with 4D CT as a minimum standard and ideally with a second form of motion control such as active breathing control, abdominal compression or gating.	Trusts	6 months from publication
	<b>d</b> Time should be recognised in clinical oncology job planning for radiotherapy contouring and planning peer review.	Trusts	6 months from publication
	e Operations boards within radiotherapy networks should support peer review across trusts, especially where single-handed oncology services exist.	Cancer Alliances, radiotherapy ODNs	1 year from publication
	<b>f</b> Radical radiotherapy should be delivered within a maximum of 16 days from decision to treat to meet the NOLCP timeframes.	Trusts	6 months from publication
	<b>g</b> Continue research into reduced fractionation schedules to encourage patient uptake of active therapy.	National Cancer Research Institute (NCRI)	2 years from publication
	<ul> <li>h Centres with significantly low rates (below two standard deviations) of radiotherapy should be subject to formal external review overseen by the Cancer Alliance to allow them to improve.</li> </ul>	Trusts, radiotherapy ODNs, Cancer Alliances	1 year from publication
<b>13.</b> Where a patient has early stage disease but is declined for	<b>a</b> Trusts should confirm that they have an effective mechanism to get a second opinion in borderline cases.	Trusts	6 months from publication
radical treatment, or does not have access to the full range of radical treatment options, more effective mechanisms should exist for a second opinion.	<b>b</b> Trusts should ensure clear recording of reasons for treatment decisions made.	Trusts	6 months from publication
	<b>c</b> Establish regional audit of rates of treatment with external case review for outliers.	Cancer Alliances	6 months from publication

<sup>33</sup> The Royal College of Radiologists (2020) Radiotherapy for lung cancer: RCR consensus statements. https://www.rcr.ac.uk/system/files/publication/field\_publication\_files/radiotherapy-for-lung-cancer-rcr-consensus-statements.pdf

Recommendation	Actions	Owners	Timescale
<b>14.</b> Trusts should monitor rates of post-surgical adjuvant and neoadjuvant treatments and this data should be available for national benchmarking.	<b>a</b> Data on neoadjuvant or adjuvant treatment with all treatment modalities should be recorded within NLCA.	NLCA	1 year from publication
	<b>b</b> Cancer Alliances should review trusts' performance on adjuvant treatment rates and review where rates fall below 40%.	Trusts, Cancer Alliances	2 years from publication
<b>15.</b> Trusts should record and monitor multimodality treatment in stage IIIA disease	<b>a</b> All PS 0-2 patients with stage III disease should have comprehensive staging including brain imaging and EBUS mediastinal staging.	Trusts	3 months from publication
and offer radical intent treatment as standard in fit patients	<b>b</b> Data regarding multimodality treatment should be recorded within NLCA as standard.	NLCA	1 year from publication
patients.	c All patients with good performance status and stage IIIA disease not offered radical treatment should be offered a second opinion if considered borderline on anatomical or physiological criteria.	Trusts	6 months from publication
	<b>d</b> Local audit of practice should be shared at a regional level to guide further actions such as education and training, local mentoring programmes, and investment in staffing and other resources.	Radiotherapy ODNs	1 year from publication
<b>16.</b> Radical intent treatment should commence by day 49 of the overall NOLCP pathway.	<b>a</b> Where needed, pathway redesign within radiotherapy units must be undertaken to meet NOLCP timeframes, including adequate time for planning.	Trusts	1 year from publication
Furthermore, for surgery, thermoablation or radiotherapy, treatment should commence by day 16 after the decision to treat in line with NOLCP.	<b>b</b> Breaches of NOLCP 49 day pathway should be discussed at regular governance meetings within cancer services and escalated to board level if harm has been caused or 49 day target is consistently not achieved.	Trusts	6 months from publication

## Non curative intent treatment

The majority of lung cancer patients currently present at a stage when a cure will not be possible. This may be due to the bulk or stage of the cancer or patient-related factors such as frailty or comorbidity. In recent years, technological advances in radiotherapy, a huge expansion in the number of systemic treatment options, and advances in supportive and palliative care have improved the prognosis, both overall and in terms of the progression, survival and quality of life of patients who are not imminently dying from their lung cancer. Implementation of best practice frailty and comorbidity assessments can better guide delivery of anticancer therapy in a palliative setting and should be employed more widely. These include options such as palliative radiotherapy and other palliative systemic anti-cancer treatments.

### **Palliative radiotherapy**

For patients with relatively localised disease, external beam radiotherapy has a significant role either as a primary treatment or to consolidate the benefits of systemic therapy. During our visits we found a variation in approach to the delivery of high-dose palliative radiotherapy within centres. Although most centres have now moved towards CT planning, a significant minority were not able to offer conformal or IMRT treatments to this group of patients. Reasons cited included a lack of radiotherapy planning time for medical staff and medical physics capacity. An inability to offer these modern techniques places a greater burden of toxicity upon the patient and a lower therapeutic ratio and should be addressed as a priority.

For patients with low volumes of metastatic disease, stereotactic radiosurgery (SRS) for brain metastases from NSCLC is well established. This may be given for either synchronous or metachronous oligometastatic disease. No anxieties were raised about access or pathways, either within the questionnaire or during visits. It is also recognised that metachronous metastatic disease outside the brain may be suitable for SABR. It is important that the oncology community supports ongoing trials in this area and has established pathways of referral to maximise patient access to therapy. With increasing availability of SABR we would expect rates of SRS to also increase, alongside increasing use of SABR for metachronous disease.

There are also many patients suitable for palliative radiotherapy for whom extension in life is not the main goal of treatment. In these cases, radiotherapy may be used for symptom control – short courses of therapy are indicated for the relief of symptoms such as pain, cough, haemoptysis or breathlessness, resulting in improved quality of life and a reduction in the use of strong painkillers.

We did find significant variation between trusts in patients accessing any radiotherapy, see **Figure 17**. The main barrier cited was again the requirement for travel. This is a frequent reason given by patients declining treatment, particularly those who are older, more frail or less affluent, where the focus is on quality rather than length of life.



### Figure 17: Proportion of patients receiving radiotherapy (adjusted), NLCA, 2017

We identified best practice examples of satellite radiotherapy units allowing treatment to be delivered close to home (e.g. St Luke's, Surrey and Sussex Healthcare NHS Trust) or dedicated radiotherapy units allowing for assessment, scanning planning and treatment to be delivered in one day (e.g. The Christie at Salford Royal NHS Foundation Trust).

Whilst external beam radiotherapy using modern techniques will enable the palliation of most symptoms there remain rare occasions where access to intraluminal brachytherapy for thoracic malignancy would be desirable. During our visits we have found that this is now available in just nine centres of the 72 who returned the questionnaire, the majority of which have only one oncologist with experience in the technique. We would propose that a national network of practitioners should be formed to review case selection and educate the practitioners of the future.

#### Palliative systemic anti-cancer treatments

Systemic therapies are used to help control or ease the symptoms of lung cancer and extend lifespan. They include chemotherapy, targeted therapy, monoclonal antibody therapy and immunotherapy. Treatment may be administered intravenously, subcutaneously or orally. Cytotoxic chemotherapy must be delivered in a dedicated area administered by chemotherapy trained staff.

Systemic anti-cancer treatment regimens are externally reportable through the Systemic Anti-Cancer Therapy dataset (SACT). Review of timely SACT data was not available to the GIRFT team, but during the visits we found little variation between trusts in the systemic therapy regimens utilised since best practice is clear within NICE guidance. However, we would recommend that local teams audit their use of SACT against the NICE treatment pathways, particularly with regard to the use of targeted treatment when a sensitising mutation is present.

During our visits a frequent theme explored was the impact of molecular genetics, particularly in the treatment of lung cancer. It is recognised that a move towards personalised therapy is the future of lung cancer care, especially in a palliative setting, and the requirement for a whole genetic profile/signature will become more imperative. These will not be unique to lung cancer and are likely to require access to a genomic MDT as NICE approves more histology independent therapies.

The GIRFT questionnaire demonstrated that there appears to be variation in the use of G-CSF and/or prophylactic antibiotics during chemotherapy cycles. Both treatments reduce the risk of neutropenic sepsis, a significant cause of morbidity and mortality in lung cancer patients. Historically the costs associated with G-CSF have been significant and some commissioning areas have restricted its use to patients receiving radical treatment. However, due to products coming off patent the costs have reduced dramatically and must be seen in comparison to the cost of an inpatient admission and potential mortality. Similarly, in recent years there has been a shift in attitudes to prophylactic antibiotics which can lead to side-effects and antibiotic resistance. Furthermore, there are concerns that broad-spectrum antibiotics may reduce the effectiveness of immunotherapy.

Therefore, our view is that best practice is for G-CSF to be offered to patients undergoing cytotoxic chemotherapy who are at high risk of neutropenic sepsis, who are able to self-administer the injections, with prophylactic antibiotics reserved for patients in whom G-CSF is not appropriate or who have additional risk factors.

The Early Access to Medicine Scheme (EAMS) aims to provide patients with access to medicines that do not yet have a marketing authorisation but for which there is a clear unmet medical need and trial evidence to support the application for marketing authorisation. On our visits we found variable uptake, with the constraints being doctor time and pharmacy resource, particularly in district general hospitals.

Similarly, we also found significant variability in the compassionate use of drugs, again with higher uptake from academic centres. These require approval by local commissioners in addition to the individual patient and clinical team but provide access to potentially therapeutic agents for specific, individualised patient conditions.

All trusts should have access and enable the use of EAMS and compassionate use schemes.

### Variation in treatment rates

Although there was not much variation in the range of treatments offered in each trust, we did find significant variation in the proportion of patients who received these treatments for both small cell and non-small cell carcinoma, see **Figures 18** and **19**.



Figure 18: Proportion of SCLC patients receiving chemotherapy, NLCA, 2017

Figure 19: Proportion of NSCLC patients Stage IIIB & IV PSO-1 receiving chemotherapy, NLCA, 2017



Patient choice was frequently described as a reason for otherwise fit patients not receiving treatment. Although this must be the case for a number of patients, other factors such as more negative feeling about risks and benefits of treatment within the MDT and inadequate staffing resources are likely to contribute to the low percentage receiving treatment in some trusts. NLCA recommends that treatment rates of 70% in small cell cancer should be achieved. Furthermore, in fit PS 0-1 patients with advanced stage NSCLC (Stage IIIB/IV) treatment rates of 70% are possible, especially with the increased armamentarium available to oncologists. Trusts unable to achieve such rates of treatment should review their practice within the Cancer Alliance and put into place an immediate action plan to improve (see Recommendation 17, page 64). Additionally, treatment should be delivered rapidly such that 80% of patients commence treatment within 14 days of pathological confirmation.

Improvement	All SCLC patients receiving chemotherapy	Additional number of patients receiving chemotherapy
Overall NLCA 2017 total	2,629 (70.5%)	-
All trusts reach NLCA median as minimum	70.8%	136 (5% increase)
All trusts reach NLCA best quartile as minimum	76.4%	267 (10% increase)

## Table 4: Impact of increasing chemotherapy treatment rates for SCLC patients, NLCA, 2017

**Table 4** shows that if all trusts were to achieve, as a minimum, the median rate of 70.8% SACT in small cell cancer, this would see an additional 136 patients every year offered life-extending treatment, an increase of 5%. Were every trust to achieve that of the best quartile units, then 267 more patients each year would receive chemotherapy, an increase of 10%. It is hard to contest the impact this would have for patients with such an aggressive disease and is, as can be seen in many units, entirely achievable.

Improvement	All Stage IIIB & IV PS0-2 patients receiving chemotherapy	Additional number of patients receiving chemotherapy
Overall NLCA 2017 total	4,428 (65.6%)	-
All trusts reach NLCA median as minimum	66.9%	330 (7% increase)
All trusts reach NLCA best quartile as minimum	73.6%	610 (14% increase)

## Table 5: Impact of increasing chemotherapy treatment rates for stage IIIB & IV PSO-2 patients, NLCA, 2017

Even more striking, for fit patients with advanced NSCLC, improving delivery of systemic anti-cancer delivery to that of the best performing quartile would result in an additional 610 patients receiving treatment (**Table 5**), and given the range of better tolerated treatments available, affording additional quality time to do what matters to the patient.

There was significant variation identified in the questionnaire and visits in how chemotherapy services were organised. These factors have implications for waiting times to commence therapy following a decision to treat. These factors are not unique to lung cancer patients and may be best addressed by a specific chemotherapy workstream. However, the implications of a delay in access to treatment are amplified in the lung cancer population as performance status can deteriorate very rapidly with many patients dying within six weeks of presentation. There is variability in access to chemotherapy dependent on the pharmaceutical agent involved. Intravenous treatments have longer waiting times than oral agents. Some units described patients waiting up to 21 days from decision to treat with cytotoxic chemotherapy or immunotherapy. The recommendation within NLCA is that 80% patients receive chemotherapy within 14 days of their pathological diagnosis. A number of trusts fall well short of this target and should urgently review their pathways of care.

Capacity in chemotherapy suites is constrained and there are delays in people starting treatment, although most trusts were operating within the NOLCP standard. Reasons for delays include a lack of a trained chemotherapy workforce, lack of specialist cancer pharmacists but also physical chair space. This has been exacerbated by COVID-19 with increasing requirements for social distancing. Some trusts are only able to offer chemotherapy on two or three days per week, with longer regimens and regimens deemed to be more complex being delivered in a remote cancer centre.

In order to maximise the physical space on an individual chemotherapy unit, trusts have looked at innovative ways to deliver chemotherapy off-site. These include delivery of an oral chemotherapy service at home or to local pharmacies, the use of community outreach centres in community hospitals or GP surgeries and a chemotherapy bus.

Some hospitals are using non-medical prescribers to monitor patients and facilitate local delivery of therapies. During our visits we saw many examples of nurse and pharmacy-led clinics, particularly for the delivery of immunotherapy and tyrosine kinase inhibitors.

Prior to the commencement of chemotherapy, it is good practice to offer the patient and a relative or friend a 'new patient' talk. The purpose is to familiarise the patient with the chemotherapy unit, assess vascular access, ensure the patient is confident in accessing advice should they develop complications from their disease and to provide further information regarding the proposed treatment. Best practice identified Agenda for Change Band 4 assistant practitioners delivering new patient talks, releasing registered nursing staff to deliver chemotherapy, and excellent use of social media and online technology improving the quality and reach of available educational resources.

We also found many examples where hospitals were implementing initiatives that reduce the need for frequent travel to hospital, and these have been accelerated in response to the COVID-19 pandemic:

- Innovative processes for improving access to chemotherapy, including postal routes for chemotherapy and use of community hospitals, which help address the need to provide services closer to home.
- Utilisation of telephone or video consultations to assess efficacy and toxicity.
- Immunotherapy treatment schedules being modified, e.g. reducing from three-weekly to six-weekly.
- Increased use of patient self-administration for drugs such as denosumab, reducing the need for frequent travel to the hospital.

## Supportive interventions from diagnosis to end of life

Supportive care in cancer is used to describe the prevention and treatment of the adverse effects of cancer and its treatment and the optimisation of pre-existing comorbidities. When introduced early it can maintain and even improve performance status to enable a greater number of patients to benefit from the available disease-modifying therapeutic options. We are aware that the evidence base for all aspects of supportive care is developing quickly and we did not benchmark services against each other within our visits. Rather we used this opportunity to raise awareness in trusts where supportive care was limited and recognise good practice in those trusts with established services.

#### **CASE STUDY**

The **Royal Cornwall Hospital's** MySunrise app has been rolled out across the Peninsula Cancer Alliance. It incorporates advice given within new patient talks and additional patient-centred information including emergency contact information for the clinical teams. Regular updates during the COVID-19 pandemic have provided patients with the most up-to-date information available regarding policies in place at their treatment centre e.g. visitor policies, and the impact of national guidance on their care.

#### Prehabilitation

Prehabilitation supports people physically and psychologically to prepare for cancer treatment. This should be instigated during the diagnostic phase of the pathway for maximum benefit. It promotes healthy behaviours and prescribes exercise, nutrition and psychological interventions based on individual need. There is growing evidence that this leads to improved outcomes for surgically treatable patients in terms of reduced length of stay, reduced risk of post-operative complications and improved exercise capacity and pulmonary function.<sup>34</sup>

Access to prehabilitation should be available for all patients undergoing radical lung cancer treatment but we have found that this varies significantly. During our visits, we found some areas of excellent practice and specific prehabilitation programmes for lung cancer patients. We also encountered difficulties in accessing certain elements of the prehabilitation pathway, with lengthy waits to access nutritional advice, a lack of smoking cessation services and reduced access to pulmonary rehabilitation programmes. This service needs to be delivered by an expert multidisciplinary prehabilitation team rather than relying on generic advice delivered by existing members of the MDT.

#### CASE STUDY

The **Heart of England** Rehabilitation for Operated Lung Cancer Patients (ROC) programme identifies potential surgical candidates with the aim of optimising their physical status and supporting their recovery post-surgery with a combination of pulmonary rehabilitation, smoking cessation, patient self-management and education and nutritional intervention.

**Greater Manchester** Prehab4Cancer represents a comprehensive programme for patients to access prior to, during, and after treatment comprising exercise, nutritional support, smoking cessation and emotional wellbeing.<sup>35</sup> Developed in the community the team have adapted during the pandemic to offer a remote service model. The programme has delivered improvements in PROMS and a reduction in treatment complications and resultant costs.

#### Specialist palliative care

Enhanced supportive care (ESC) is a term introduced to describe early palliative care to patients with life limiting disease. ESC utilises the skills of specialist palliative care physicians and their extended team to embrace a holistic approach to symptom management and side effect management.

We found that the term was not used in a consistent manner, despite the NHS England guidance and the Commissioning Quality and Innovation (CQUIN) scheme which ran from April 2016 to March 2019.<sup>36</sup> We also found variation in what is commissioned from trusts under this heading and understood by teams themselves.

Within lung cancer there is strong evidence that early palliative care improves survival.<sup>37</sup> We saw evidence of best practice whereby a small number of trusts, including Nottingham, Preston and Exeter, had developed an ESC service which oversaw significant improvements for inpatients and outpatients with lung cancer, including a reduction in admissions, improved symptom control and improved utilisation of resources including imaging, 2<sup>nd</sup>/3<sup>rd</sup> line treatments and a reduction in 30 day mortality.

<sup>34</sup> Bloom, E. (2017) Prehabilitation evidence and insight review, Macmillan Cancer Support. https://www.macmillan.org.uk/\_images/prehabilitation-evidence-and-insight-review\_tcm9-335025.pdf Greater Manchester Cancer (2017) Achieving world-class cancer outcomes: Taking charge in Greater Manchester 2017-2021. https://www.gmhsc.org.uk/wp-content/uploads/2018/05/GM-Cancer-Plan-Summary.pdf

<sup>36</sup> NHS England, Enhanced Supportive Care. https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf

<sup>37</sup> Temel J. et al (2010) Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, New England Journal of Medicine 363:733-742.

 $<sup>^{35}\ {\</sup>it Greater}\ {\it Manchester}\ {\it Cancer}\ website,\ https://gmcancer.org.uk/our-areas-of-work/prehab4cancer-2$ 

#### **CASE STUDIES**

The multidisciplinary ESC team at **Lancashire Hospital** are proactive in advanced caring, with regular use of holistic needs assessments and integrated palliative care outcome scale (IPOS) tools and good links with community teams. The implementation of this service has demonstrated a reduction in 30 day mortality and readmission.

The **Nottingham Hospital** team built on their existing specialist palliative care team to implement an ESC service, with uptake of over 90% of lung cancer patients referred into the service. They have demonstrated a reduction in 30 day mortality and an improvement in symptoms scores and quality of life.

There will always remain a percentage of patients for whom active oncological intervention will be unable to alter the course of the disease, either because their cancer is behaving in such an aggressive manner or whose performance status is poor. It is important that this is recognised early to prevent a burden of unnecessary investigation and/or treatment and that the focus is on helping them and their loved ones live well for the time that remains. This is particularly the case where a person is diagnosed with lung cancer as a result of an acute admission to hospital, where frequently there is advanced disease and significant symptom burden.

Of services who answered the pre-visit questionnaire, 32% only had access to five-day specialist palliative care services with no input across the weekend. This is unacceptable variation and results in poor patient experience over weekends, delayed transfer to hospice or home with appropriate support, and uncontrolled symptoms. Too frequently, we found evidence of a lack of seven-day services for palliative care support or significant work pressures within the clinical nurse specialist workforce impacting negatively on the ability to support people and their families manage their illness and come to terms with their prognosis. We also saw evidence of exemplar palliative care services. One trust had a strong service with daily in-reach to all admissions with end of life or palliative care needs and close communication and collaboration with the LCNS (see Recommendation18, page 64).

We also observed variation in access to community palliative care, with many trusts reporting deaths in hospital due to difficulties in discharging patients to their preferred place of care. During our visits we saw many different models of specialist palliative care provision. In the majority of cases specialist palliative care nurses were employed by the acute trust. However, this was not routinely the case for the consultant level support. A number of smaller trusts described in-reach from community and hospice-based consultant staff.

We did find examples of good practice with strong links between lung cancer and palliative care teams. For instance, at Wye Valley the respiratory physicians hold regular meetings with the community palliative care teams to discuss individual patients.

However, the expansion in non-cancer palliative services has not met with the equivalent and necessary expansion in the workforce to manage the additional workload. Many consultants also described their time being re-focused on inpatient care with a reduction in both outpatient clinic availability and MDT attendance. This needs urgent action to avoid disadvantaging patients with cancer, many of whom have short life expectancy and a significant symptom burden.

Advance care planning should be integral to each conversation in clinic by all members of the MDT. Team members should feel competent and confident in initiating and documenting these conversations and any additional training needs should be met. Opportunities for discussion around advance care planning must also be recognised during inpatient stays.

#### **CASE STUDY**

The palliative care team at the **Hillingdon Hospital** are an integral part of the lung cancer MDT with the palliative medicine consultant attending the MDM weekly and taking responsibility for recording meeting outcomes. The trust also holds a joint clinic with the palliative medicine consultant and LCNS for patients requiring specialist input, in order to address symptoms earlier on in the pathway and to provide support for patients receiving best supportive care.

#### Living with and beyond cancer

More people than ever are living with and beyond cancer. Receiving care that is tailored to individual needs can have a significant impact on patient experience and quality of life. NHS England has committed to this by supporting Cancer Alliances to ensure that patients receive personalised care and support interventions, stratified follow-up and measurement of quality of life.<sup>38</sup>

Holistic needs assessments (HNAs) should be offered at all significant points in the patient pathway and can be face-to-face or telephone based according to individual need. The Macmillan eHNA is an effective tool and offers the opportunity for patients to complete the assessment in their own home.<sup>39</sup> This tool can also assist in signposting patients to local active recovery programmes and health and wellbeing events to improve quality of life and assist them to cope with the physical, psychological and social concerns surrounding the impact of a lung cancer diagnosis.

Throughout our visits we found a wide variation in how trusts adopted services for living with and beyond cancer for their lung cancer patients. Although use of HNAs was widely recognised as good practice to identify unmet needs there was variability in how this had been implemented within teams. Where they had been implemented the results were often not visible to the whole clinical team, with the LCNS teams generally reviewing these. This limits the opportunity for intervention where there is need. We found some centres who were only offering an HNA when the nurses felt there was a problem. This introduces inherent bias and risks missing genuine need. Other centres offered an HNA such as iPOS at each oncological and enhanced supportive care encounter and reported that these could be used to focus consultations and identify significant unmet needs in patients which could then be addressed.

We found during our visits that local patient support groups were only available in a small proportion of centres. Often, we heard that barriers to these included the poor prognosis of lung cancer, lack of physical space and financial resource to support event room booking. Whilst we recognise that support groups can be difficult to sustain, we did find that trusts who ran such groups reported that they functioned well and were effective in providing valuable support to patients and family members.<sup>40</sup> In addition, they also provided patient-focused feedback on quality improvement initiatives within the trust. Exemplar practice was evident at James Paget University Hospitals NHS Foundation Trust where the LCNS team ran a support group in local pubs, held a Christmas party and held regular quiz nights that were attended by more than 40 patients consistently.

Support groups were generally co-ordinated by the LCNS team, sometimes in partnership with charitable organisations. Trusts which do not currently facilitate access to a support group should review this given the recent improvements in survival, signposting to online support forums if there is no face-to-face support group.

### **CASE STUDIES**

An excellent support package is available at **Whittington Hospital** for patients diagnosed with lung cancer. This includes annual patient conferences, with workshops and speakers, a support group called The 'C' Factor and a patient led group called 'Chatterbox'. There are also regular workshops covering yoga, exercise, therapeutic drumming, art, writing and the Help Overcoming Problems Effectively (HOPE) course.

**The University Hospitals of Leicester NHS Trust** has a well-established support group for mesothelioma and lung cancer patients – this group meets in a social setting each month for lunch with a quarterly meeting where speakers are invited to talk about treatment, trials, symptom management, dietary advice and other areas of interest to the group. The group has received excellent feedback from patients and carers.

<sup>38</sup> Macmillan Cancer Support website, Personalised care for people living with cancer. https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/personalised-care NHS England website, Personalised care and improving quality of life outcomes. https://www.england.nhs.uk/cancer/living/

<sup>39</sup> Macmillan Cancer Support website, Holistic needs assessments. https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/holistic-needs-assessment#electronic\_holistic\_needs\_assessment\_ehna

<sup>40</sup> Roy Castle Lung Cancer Foundation website, Lung cancer support groups. https://roycastle.org/help-and-support/support-groups/

#### **Patient information**

Patient information should include both verbal and written and be delivered in a form accessible to the patient. Specialist cancer charities e.g. Macmillan, Cancer Research UK and the Roy Castle Lung Cancer Foundation have developed excellent patient information websites to which patients can be signposted. Some organisations can support patients with a specific driver mutation by giving access to high quality information and support groups to further improve a patient's understanding and experience.

#### Follow-up

The NHS Long Term Plan for cancer promotes shared decision-making, personalised care and support planning and supported self-management where possible. The follow-up should be tailored to the individual's risk of recurrence, second malignancy and suitability for further treatment. Use of end of treatment summaries supports this and enables patients and their GPs to have an increased awareness of early warning signs to facilitate rapid referral back into the lung cancer service. However, relatively few trusts had successfully implemented or made robust plans to implement these. Inadequate consultant and nursing time were frequently cited as the underlying factor for lack of implementation. Furthermore, we saw evidence of clinic constraints within surgery and oncology as a result of the need to follow up patients no longer receiving active treatment, which had a subsequent impact on constraints to access for those newly-diagnosed.

In many trusts clinical follow-up is medically led although the specialty of doctor varies significantly. During our visits we saw good examples of LCNS nurse-led clinics for post-surgical and radiotherapy patients and immunotherapy non-medical prescriber clinics for patients who have completed systemic therapies. We recognised protocolised follow-up pathways as representing best practice following radical therapies as they can potentially reduce the number of scans and frequency of attendances required. We recognised that a risk-stratified approach to follow-up represented best practice, with the frequency of follow-up tailored to the risk of recurrent disease and risk of long-term complications.

Ensuring that capacity within oncology or surgical clinics was released by utilising other clinical members of the team such as advanced practitioners or LCNSs or, in some cases, radiographers and pharmacists where suitably trained, enabled workforce constraints to be managed and led to development of the skills within the wider MDT, for example at Wye Valley hospital. These follow-up schedules should be shared with patients and GPs in their end of treatment summary.

We recognise, however, that there is little published evidence. Published risk stratification models require further refinement to define an optimal imaging follow-up schedule, and these guidelines are likely to be derived by consensus within Cancer Alliances. We recognise from our visits that there is significant variation across England and that there are tensions between clinical teams requiring imaging and CT capacity in some trusts. However, given the opportunities for salvage therapy for localised relapse we recommend a minimum of five CT scans over five years for stage I disease and a minimum of six-monthly scans for the first 36 months for stage II-III disease and annual thereafter to five years (see Recommendation 19, page 65). The data could then be prospectively collected regarding pick up rates and guidance modified as risk stratification data becomes more robust.

#### **Smoking cessation services**

There is considerable evidence regarding the benefits of smoking cessation for lung cancer patients in terms of quality of life, improved tolerance to treatment and reduced toxicity, reduced post-operative complications, survival benefits and reduced risk of disease recurrence.<sup>41</sup>

Only one third of trusts provide treatment and support for tobacco addiction themselves, with some of this provision being delivered by community services, although uptake from patients is variable.

We heard frustrations from the clinical teams that their previous services and referral pathways had been dismantled both in the hospital and in the community due to financial constraints, resulting in a lack of equitable access to support. This is further confounded by a disappointing lack of training within the lung cancer team to deliver smoking cessation advice and prescription. This should be urgently addressed within every trust as a priority.

#### **CASE STUDIES**

The **University Hospitals of Derby and Burton**, in collaboration with the RCP, increased the provision of smoking cessation support to patients in the urgent lung cancer clinic. All current smokers are offered referral to community stop smoking services and prescriptions for tobacco addiction such as nicotine replacement therapy (NRT) or Varenicline are generated in the clinic. A quit box has been produced to demonstrate the various NRT products available and patients are offered the opportunity to record their carbon monoxide levels in the clinic. The lung cancer nurse specialist (LCNS) team have recently had approval of a patient group directive to enable them to distribute NRT outside of the urgent lung cancer clinic. Progress is followed up at each subsequent patient contact.

The Manchester Cure Project was launched at **Wythenshawe Hospital** in 2018 as a comprehensive opt-out tobacco addiction treatment service for all smokers admitted to hospital. It has embedded electronic systems to systematically screen all patients for their smoking status and all healthcare professionals are trained to provide brief advice to smokers. Prescribing clinicians are trained in the pharmacological management of tobacco addiction and provided with the skills to discuss and offer pharmacotherapy at the point of admission supported by a protocolised treatment pathway. A team of specialist practitioners offer specialist behaviour change support and ongoing pharmacology support on an opt-out basis both during the inpatient stay and after discharge. In the first six months of service this treatment pathway resulted in 22% of all smokers admitted to hospital being successfully abstinent from tobacco at 12 weeks following discharge.

#### **Clinical trials**

Clinical trials are used to test the effectiveness of different treatment options and innovations in selected patient groups, often resulting in the introduction of new treatment techniques. There is evidence that centres actively engaged in clinical trial activity have improved survival rates among all their patient groups. Clinical trials often offer a possibility of a treatment option at a point where no other standard treatment option exists. An active trials portfolio can benefit trusts financially as well as assisting with staff recruitment and retention through contributing to a more attractive job role.

Unsurprisingly, we found wide variability in access to clinical trials as shown in Figure 20:



#### Figure 20: Participation in clinical trials, National Institute of Health Research, 2018-19

We found that outside the large tertiary centres the majority of open clinical trials were industry-funded. These studies are often registration trials with significant complexity of follow-up and data collection. There are very few district general hospitals actively recruiting with significant research portfolios, and consultant job plans rarely include time for clinical trials. It is important that the time commitment is recognised due to the increased complexity and reporting requirements of research activity. In addition to medical consultant time, the expertise required from medical physics and diagnostic imaging and pathology departments should also be planned for by trusts. Where clinical trial recruitment is a focus for prioritisation, raised awareness in a region for access to clinical trials should be made available (see Recommendation 20, page 65).

## Recommendations

Recommendation	Actions	Owners	Timescale
<b>17.</b> All trusts should improve their treatment rates with SACT to achieve greater than 70% treatment for fit patients with advanced NSCLC, and greater than 70% chemotherapy rates in SCLC.	<ul> <li>Patients should receive systemic and supportive therapy as close to home as possible, utilising a range of initiatives such as local pharmacy collection from a community hub, community delivery in chemotherapy buses or satellite units and self-administration. Telephone/video consultations may be used to assess efficacy and toxicity.</li> </ul>	Cancer Alliances, Trusts	1 year from publication
	<b>b</b> Schedules of visits for review and treatments should be arranged to reduce the amount of travelling.	Trusts	6 months from publication
	<b>c</b> All trusts should support clinicians accessing NHS England EAMS schemes with dedicated resource to support rapid treatment.	Trusts	6 months from publication
	<b>d</b> Research should be carried out into the additional benefit of clinical frailty and/or other measures of comorbidity in determining selection for treatment.	Research organisations, clinical researchers	2 years from publication
	e The decision to offer chemotherapy to poor performance status patients or those whose disease was refractory to the previous line of chemotherapy should be peer-reviewed by a colleague.	Trusts, NHSE	1 year from publication
	<b>f</b> Services should ensure that they are able to move patients rapidly through to commence treatment within a maximum of 14 days from decision to treat (seven days for SCLC patients).	Trusts	3 months from publication
<b>18.</b> Ensure that all patients with lung cancer have access to enhanced supportive care and/or specialist palliative care. Inpatient specialist palliative care provision should be available seven days per week. <sup>42, 43</sup>	<b>a</b> All patients with incurable lung cancer should be offered early specialist palliative care, delivered by a multidisciplinary team within the outpatient environment. <sup>44</sup>	Trusts	6 months from publication
	<ul> <li>All smokers should have access to smoking cessation services and every MDT should have an agreed approach to supporting access to relevant services with the ability to prescribe nicotine replacement therapy.</li> </ul>	Trusts	6 months from publication
	c Every trust should develop prehabilitation for all patients being treated with curative-intent.	Trusts	1 year from publication
	<b>d</b> Every patient should have a holistic needs assessment carried out at regular intervals, using a validated tool such as the Macmillan eHNA with the results visible to the whole clinical team.	Trusts	6 months from publication

<sup>42</sup> NICE (2004) Improving supportive and palliative care for adults with cancer CSG4. https://www.nice.org.uk/guidance/csg4

<sup>43</sup> NICE (2019) End of life care for adults: service delivery NG142. https://www.nice.org.uk/guidance/ng142

<sup>44</sup> NHS England, Enhanced Supportive Care. https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf

Recommendation	Actions	Owners	Timescale
<b>18.</b> Ensure that all patients with lung cancer have access to enhanced supportive care and/or specialist palliative care.	e Representation from specialist palliative care should be integral to the lung MDT and present at over 90% of treatment MDMs, in order to identify patients who may benefit from their assessment.	Trusts	6 months from publication
Inpatient specialist palliative care provision should be available 7 days per week <sup>41,42</sup>	<b>f</b> ESC should be formally commissioned for all patients who will not be cured of their cancer.	CCGs	1 year from publication
	<b>g</b> Specialist palliative inpatient care should be available seven days a week.	Trusts	6 months from publication
	<ul> <li>h Every patient should be offered verbal and written information as well as provided with an opportunity for peer support and attendance at support events with 3rd sector charities.</li> </ul>	Trusts	6 months from publication
	i All patient-facing members of the lung cancer team should be trained in smoking cessation advice and prescription and smoking cessation advice and support should be offered at every patient contact.	Trusts	6 months from publication
<b>19.</b> Produce and implement protocols for follow-up pathways following radical	<b>a</b> MDTs should agree follow-up protocols to include imaging and clinical assessment for a minimum of five years.	Cancer Alliances, trusts	6 months from publication
therapies.	<b>b</b> National protocols to be agreed and implemented at regional level by Cancer Alliances.	Cancer Alliances	1 year from publication
	<b>c</b> An end of treatment record summary should be completed for all patients who have completed a course of treatment, and the content, including follow-up plan, agreed in a shared decision-making meeting with the patient and clinical team. This should be made available to primary care.	Trusts	6 months from publication
	<b>d</b> More research should be undertaken to define optimal risk stratified follow-up schedules.	NCRI	2 years from publication
<b>20.</b> Clinical trial recruitment should be considered a focus for prioritisation, with MDTs collaborating to offer a wider regional portfolio.	<b>a</b> Job plans should be reviewed to include time spent on clinical trial/research work.	Trusts	6 months from publication
	<b>b</b> This should be supported by a robust trials infrastructure, including adequate research staff, facilities and knowledge of available trials within a network.	Trusts	1 year from publication
	<b>c</b> Co-ordination should be across Cancer Alliances to maximise the portfolio available to patients within a geographical region, and to ensure referral pathways are clear and straightforward.	Cancer Alliances	1 year from publication
	<b>d</b> A greater focus should be put on opening radiotherapy, surgical and supportive care studies, to balance the available portfolio.	Funding bodies	1 year from publication
	<b>e</b> Increase awareness of available trials within the local MDT.	Trusts	6 months from publication

# Effective multidisciplinary working

Multidisciplinary team working (MDTs) in lung cancer has always taken place but was formalised as a result of the Calman-Hine reforms of the 1990s, with the introduction of regular multidisciplinary team meetings (MDMs) where an individual patient's management could be discussed, debated and progressed. Data from the NLCA has demonstrated a steady rise in the proportion of patients with newly diagnosed disease who were discussed in an MDM, reaching 91% in 2018.

The development of an MDT approach in the UK has delivered significant progress in enabling a more standardised approach to the diagnosis and treatment of cancer, along with providing a forum for education, peer support for clinicians and protected time for sharing opinions on complex cases. For the patient, the advantages have meant that they are more likely to receive treatment and that this treatment is more likely to be concordant with contemporary guidelines, with less variation in access to treatment. For trusts however, it represents an expensive resource in terms of clinician time which must be used in a time effective manner.

Culturally, decision-making by MDM has become a victim of its own success, and there has been mission creep leading to inefficiencies in practice, such as over-reliance on MDM decision-making rather than individual clinician-led action, multiple re-discussions risking inconsistent management plans and overly long meetings leading to decision-fatigue. All of these impact on delays to a patient's care and have led to less of a sense of responsibility for individual clinicians driving a pathway forward and being accountable for reaching treatment decisions swiftly. Effective leadership, commitment of core members, clear roles and responsibilities within the team, and supportive team dynamics are paramount for effective multidisciplinary decision-making. As the complexity of patients and their treatment options increases, review of the ways in which the team and meetings are organised both in terms of structure and function is important in ensuring the best outcome for the patient within the constrained resources of the NHS, as outlined in reports from Cancer Research UK and recent guidance from NHS England.<sup>45,46</sup>

The overall length of an MDM should be largely dictated by the number of patients undergoing diagnosis and management within the service. In a small proportion of trusts, MDMs are scheduled more than once a week which correlates with the size or extended specialism of their service. According to our data, the vast majority (90%) have a weekly MDM where treatment decisions are made. Any less frequent than this would seriously impact on the ability to deliver a faster diagnostic pathway and trusts should take immediate steps to review their practice and adjust job plans accordingly as a priority to facilitate a weekly MDM. We found the size of the service was not always proportionate to the length of the MDM, (see **Figure 21**) implying a need for effective streamlining.



Figure 21: Graph demonstrating lack of correlation between length of weekly treatment MDTs and size of lung cancer service, NLCA/GIRFT organisational audit, 2019

<sup>45</sup> Cancer Research UK, Meeting patients' needs – improving the effectiveness of MDT meetings in cancer services.

https://www.cancerresearchuk.org/sites/default/files/full\_report\_meeting\_patients\_needs\_improving\_the\_effectiveness\_of\_multidisciplinary\_team\_meetings\_.pdf

<sup>46</sup> NHS England and NHS Improvement (2019) Streamlining MDT meetings – guidance for cancer alliances. https://www.england.nhs.uk/wp-content/uploads/2020/01/multi-disciplinary-team-streamlining-guidance.pdf Multidisciplinary working involves complex interactions between numerous individuals, different hospitals and independent and public providers of specialist services and utilises many different electronic systems which rarely interface directly with each other. A detailed evaluation at each trust (including directly witnessing individual MDMs) was beyond the scope of our review. Instead, we have focused on the structural arrangements of the MDM in each unit, and as expected have encountered wide variation. We were aware that at the time of the GIRFT lung cancer programme taking place, a number of Cancer Alliances were carrying out local focused work into the quality and effectiveness of MDTs.

Throughout our visits we have recognised the following key elements of good practice:

- Length of the MDM (number of patients) is adequate to enable valuable and equitable discussion for each patient, but not too lengthy to risk decision-fatigue.
- MDT members have prepared in advance the information about patients for discussion and ensured all required information for decision-making is available.
- Imaging and pathology has been reported and reviewed by a thoracic expert.
- Treatment MDTs are held regularly and at a time in the week when all specialists required can be present, with cover for 52 weeks of the year.
- The timing of the MDM within the week dovetails with fixed diagnostic lists to allow for sufficient time for results to be available.
- A suitable environment with all necessary equipment required for effective communication between members, and real time capture and review of clinical information and MDM recommendations.
- Leadership of the MDM fosters a collaborative approach to patient care, with space for all members, to feel able to contribute to decision-making and advocacy.
- Information is presented by a clinician who has direct knowledge of the patient and their wishes.
- Patients who do not have a lung cancer diagnosis have been filtered out of the meeting and either managed or referred appropriately to an alternative service.

## Diagnostic versus treatment MDMs

In many trusts, there is now a separation between:

- A weekly 'treatment' MDM, where fully worked-up patients are discussed in a truly multidisciplinary environment to agree the most appropriate treatment options to offer the patient; and
- A 'diagnostic/triage' MDM with a smaller cohort of specialists, running one or more times a week, where discussions and decisions on the diagnostic strategy are made.

Sometimes the separation means little more than two separate agendas on one longer meeting, but when the meetings are temporally distinct, usually the diagnostic MDM is attended by just a respiratory physician, a radiologist and a navigator/LCNS, thereby becoming significantly less resource-intensive and reducing potential waits, but most importantly allowing the treatment MDM to focus on the cases where full multidisciplinary input is required. With effective planning and triage of patients with evidence of cancer on a staging CT scan, delaying further decisions to a weekly diagnostic MDM is unnecessary and results in batching and delay.

We concluded that best practice would comprise daily diagnostic planning meetings (or, as a minimum, no less frequent than three times a week) to examine all patients flagged or referred to the lung cancer service. This requires the participants to be sub-specialised in thoracic malignancy and hence proficient in relevant decision-making, thereby restricting the number of patients requiring wider consultation to a minimum.

## Streamlining MDMs

It is well recognised that there has been an enormous expansion in the numbers of patients referred for discussion in MDMs, and a frequent perception that decisions cannot be made unless it is in a meeting. As we have already noted, the use of triage and diagnostic standards of care can significantly improve the diagnostic work-up and avoid the need for many multidisciplinary discussions. Some teams have attempted to streamline and protect the MDM from being overwhelmed by screening the MDT agenda (usually done by a respiratory physician and specialist nurse) to divert patients to a more appropriate route. Streamlining should be considered to avoid the following scenarios:

- MDM discussion seen as a surrogate for referral to an individual clinician;
- MDM discussion acting as a second radiological opinion for the reporting radiologist;
- MDM being used as a forum to request a diagnostic test for existing patients with progression or relapse;
- MDM used to 'chase results' or collect information which is more appropriately done through other mechanisms;
- MDM being used to access a surgical or radiotherapy opinion for metastatic disease from other tumour sites;
- MDM review providing a convenient radiology opinion for patients without a firm cancer diagnosis.

### **CASE STUDY**

**Kettering Hospital** has introduced rigorous streamlining of the MDT led by the respiratory physicians and reduced the number of cases for discussion from an average of 35 per week to 15. This has enhanced the quality of discussion regarding these patients and reduced the time in the meeting by one third.

Although the data is not adequately robust, there was a strong sense that those teams employing a pre-MDM streamlining approach had fewer patients to discuss with a shorter meeting length. MDM streamlining is an effective approach to patient care and should be recognised appropriately in job planning.

Regardless of the exact structure, MDTs should ensure that they have mechanisms in place to reduce unnecessary burden on the treatment MDM through utilisation of triage by experienced respiratory physicians, use of diagnostic standards of care, and diagnostic MDMs. Where diagnostic and treatment MDMs are not temporally separate, it is highly recommended that the agenda is prepared in advance and structured in such a way that all core members of the treatment MDT do not need to be present for the diagnostic element of the meeting (see Recommendation 21, page 71).

## Maximising effectiveness

In order to make MDMs as effective as possible in providing the most appropriate option for a patient, the members of the clinical team attending the meeting must have adequate time for preparation of the patients for discussion. From questionnaires sent to all trusts in advance of visits, we have seen significant variation in formal recognition within job plans of appropriate clinical time for preparation for respiratory physicians, the radiologist, oncologist, nurse specialists and pathologists.

Core member presence at the MDT meeting allows for thorough discussion and multidisciplinary decision-making.<sup>47</sup> In order to provide patients with equitable access to all diagnostic and treatment modalities there should be representation and active participation from each discipline involved in the lung cancer pathway. Core membership must include administrative support and appropriate IT infrastructure to collate local data and outcomes, along with recording the outcome of discussions.

Many MDTs reported that while they had good radiology support, they lacked a trained PET-CT reporter in attendance (only 16% of 73 trusts returning the pre-visit questionnaire had a PET-CT reporter in the MDT) and while it would be desirable to have this expertise in all MDTs, this is probably impractical. It is however imperative that the clinical team can access the

reporting nuclear medicine specialist in a timely manner when interpretation of the report is nuanced. Of greater concern, not all thoracic radiologists felt able to advise on the feasibility of biopsy as this was not a procedure that they performed. It is therefore vital that radiology is prepared in advance of the MDT meeting by the radiologist so they can seek the advice of an interventionalist prior to the case being presented.

We also noted that in many cases the MDM lacked input from the specialist palliative care team, despite being named core members, due to the significant symptom burden of lung cancer, the evidence for early palliative care improving outcomes, and the proportion of patients who are eligible for palliative treatment only at the point of presentation.

Across a number of services, teams flagged to us real challenges in the continuity of services outside of the direct employ of the trust – for example, negotiated service level agreements with thoracic surgical centres or oncology services provided by an external trust contracted over 40-46 weeks per year, not 52 weeks. We have seen evidence that this significantly adversely impacts on patient care, with delays in clinic appointments or to treatment. Much of the time this was reported to us as feeling outside of the control of the lung MDT directly. The same challenge applies to extended roles within the wider MDT, such as access to allied health professionals (AHPs) and community services.

Where teams worked with one particular surgeon or oncologist, only rarely was cross cover robustly provided and, in some cases, even in a situation of unplanned absence of a specialist, the remaining team at the referring centre would not accommodate referrals accordingly. We recognise that this is usually due to significant workforce constraints within that centre and not a lack of desire to support another service, but it is important that trusts are aware of the negative patient impact of such negotiated contracts and build in clauses to ensure a smooth and consistent service every week of the year.

Where possible, it is good practice to have more than one treating specialist present at the MDT meeting. This is often difficult due to workforce and workload constraints, however peer review of decision-making at MDT is essential to ensure equality and access to optimal practice. There may be surgeons or oncologists offering different techniques or treatment regimens and who have different attitudes to risk and benefit. If, for example, the trust only has access to one surgeon who does not perform video-assisted thoracic surgery (VATS) procedures, the patients may be disadvantaged. It is important that all trusts have mechanisms in place to obtain a second specialist opinion where appropriate and that this can occur quickly and efficiently so as not to delay treatment unnecessarily. Trusts should audit their use of second opinions.

Strong and effective chairing of the MDM is vital to the effectiveness of the meeting, and this role may be taken by someone other than the clinical lead of the lung cancer service and may even rotate from week to week. Key outcomes include timekeeping, ensuring discussions are focused and consistent, resolving disputes, and ensuring all MDT members feel supported to provide input and advocacy.

In some trusts, we noted that AHPs such as dieticians or physiotherapists attended the MDM, and that their input influenced the treatment decisions for a proportion of patients. In practice, however, it may be more efficient for robust referral pathways/assessment clinics to be developed to ensure this resource is targeted appropriately.

## Super- or sub-specialist MDT meetings

In most cases, decisions on management of patients in an MDM are relatively straightforward, following national or local guidelines. However, some cases will present particular challenges and the best course of action may be uncertain or even a source of disagreement between members of the MDT. In order to review such complex cases and provide peer review in decision-making, sub-specialty MDTs have been introduced and are discussed in more detail in the preceding section on treatment. During our visits we have recognised that for some types of cancer (e.g. tracheal tumour, pre-invasive diseases) and treatments (e.g. brachytherapy, ablation therapy) local expertise may be minimal or non-existent, and there may be a role for regional or even national virtual MDMs to be developed in these areas. Cancer Alliances and national professional organisations should examine the role for implementation of regional sub-specialist MDTs to support treatments such as those above, and every trust should have equitable regional access to such expert opinion boards to avoid reintroducing variation into care.

## Communication

We have seen truly exemplary practice in many trusts, where support and information are provided from the moment a referral is received all the way through to the completion of treatment and end of life. Communication with patients and their families needs to be timely and of high quality as waiting can contribute to significant distress and anxiety. Additionally, patients require adequate time to absorb and process information, communicate with those important to them in order to develop their own support structure before making significant, often life-changing decisions. Likewise, primary care services should receive contemporaneous information as patients regularly seek advice from their GP or district nurse. Some innovative services have employed support workers or given additional responsibilities to administrative or nursing staff, often outside the perceived remit of their banded position. This enables the improvement of current services with minimal additional resources in addition to enrich the experience of the role due to high quality patient interactions.

Nursing roles in particular have extended to encompass management of the diagnostic pathway, telephone clinics for the initial 'abnormal CT' or 'normal CT and downgrade' result and breaking bad news clinics. Nurses working within these roles require additional training in order to plan and request investigations and document consultations. They work closely alongside the respiratory clinicians, administrative staff, and radiologists, and facilitate excellent outcomes both with regards to meeting targets and patient feedback.

We welcome the extension of nursing roles to embrace a workload previously held by physicians. However, we saw evidence that this often resulted in large amounts of administrative work, which would previously have been performed by a medical secretary, moving into the nursing role. This additional inappropriate work prevented specialist nurses using their clinical skills and experience for patient care and paradoxically in some cases worsened patient experience particularly with regard to inpatient care.

There are clear opportunities to improve the patient experience without significant additional resources by reviewing the skill mix and responsibilities of the nursing, AHP and administrative teams and ensuring an equivalent infrastructure to that received by medical professionals is available to them, i.e. appropriate private space in which to confidentially review and support patients, adequate IT support such as access to computers or laptops, and provision of secretarial support. Attention to these details by trusts is important to support the clinical teams with their work to care for patients (see Recommendation 22, page 71).

## **CASE STUDY**

Having historically received National Cancer Patient Experience Survey (NCPES) data suggesting patients struggled to obtain appropriate information, the team at **Plymouth Hospital** developed a patient held individualised care plan updated at each consultation, and changed working practices embedding an NOLCP navigator in the team. The nurse specialists demonstrated exemplary team working to ensure rapid and effective communication with patients and their families throughout the patient journey from referral to end of life.

## Recommendations

Recommendation	Actions	Owners	Timescale
21. Review operational arrangements for multidisciplinary working to ensure it is as timely, efficient, and effective as possible and meeting the needs of patients.	<b>a</b> Implement streamlining (with dedicated time in job plans) to reduce the number of low-value discussions in MDMs.	Trusts	6 months from publication
	<b>b</b> The treatment MDM should be at least weekly, with triage being carried out as part of the diagnostic planning process more frequently (ideally daily) to avoid batching.	Trusts	6 months from publication
	<b>c</b> Cases on treatment MDMs should be restricted to those with a firm lung cancer diagnosis, with alternative provision for discussion of non-malignant cases.	Trusts	6 months from publication
	<b>d</b> Ensure that core members of the MDT (or appropriate cover) attend the MDM 52 weeks of the year, particularly where services are commissioned from external trusts.	Trusts	1 year from publication
	e Ensure adequate physical space, IT infrastructure, and administrative support in the form of a pathway navigator and/or MDT co-ordinator to support the MDM and post-meeting communication and activities.	Trusts	1 year from publication
	<b>f</b> Ensure attendance at MDM by specialists in palliative/supportive care in all trusts.	Trusts	6 months from publication
	<b>g</b> Where resources allow, include more than one oncologist/ surgeon in the MDM; increase the use of second opinions where appropriate.	Trusts	1 year from publication
	<ul> <li><b>h</b> Quantify and recognise in job plans the time need for MDM preparation as well as post-MDM actions.</li> </ul>	Trusts	6 months from publication
<b>22.</b> Improve timeliness and effectiveness of communication from the MDT to lung cancer patients and primary care.	<b>a</b> Patients with lung cancer should be informed of the MDT recommendation within 24 hours either face-to-face or by virtual consultation.	Trusts	3 months from publication
	<b>b</b> The primary care physician should be updated immediately following the above interaction.	Trusts	3 months from publication
	<b>c</b> Clinical teams should review the range of written, electronic and verbal methods of support they provide patients, to ensure they are accessible and effective.	Trusts, primary care, Cancer Alliances	6 months from publication
	<b>d</b> All members of the MDT should be provided with adequate resources, particularly administrative support, IT and private clinic space, to enable them to effectively carry out their roles.	Trusts	1 year from publication
	e Proactive LCNS led support should be offered to the patient and their family from initial referral to discharge.	Trusts	3 months from publication

# Improving data and information

Within our trust visits, we noted that clinical teams have often felt disconnected from performance data and the clinical data shared with external bodies from their own services, and have not necessarily had access to the information they may need to drive changes within their service. We felt that encompassing the wealth, and in some cases dearth, of data within a section of this report and making recommendations for future improvements to join up clinical services with informatics would benefit ongoing quality improvement and outcomes further.

## National audit programme

Timely, accurate and relevant data flows are critical to the quality assurance and improvement of services. Details of cancer registrations have been available for many years but historically lacked the rich clinical information that allowed benchmarking of local services. The NLCA has profoundly changed the relationship that clinical teams have with data, and over the years clinical engagement with the audit has strengthened. It is now deeply established in all trusts in England and there are innumerable examples of the results from the audit workstreams being used to influence improvements locally, regionally and nationally. Furthermore, the audit is able to bring together all healthcare professionals working in lung cancer as a single community with shared vision and goals for improving patient care and outcomes, as well as increasing the visibility of the service within trust governance structures.

Recent years have seen the NLCA working very closely with NCRAS and integrating multiple datasets (such as the Systemic Anti-Cancer Dataset and the Radiotherapy Dataset). We have used NLCA data extensively in our deep dives, and assessment of future improvement will not be possible without a strong audit programme.

At the time of writing, the NLCA has received funding to extend its work to December 2021. We believe it is vital that the audit should secure a long-term funding settlement that allows the opportunity to continue its core functions while developing its ability to drive improvement. We also believe that there is an opportunity for a stronger patient voice in developing its priorities (see Recommendation 23, page 77).

Accuracy of the data is clearly important if the right conclusions are to be drawn, and clinical teams need confidence that reports and benchmarking appropriately reflect the quality and outcomes of their services. Whilst a large part of the data collection and submission from trusts is an administrative role, it is crucial that there is clinical oversight of the process. While all trusts submit data, we have seen important variation in the quality of the data across individual organisations. A good example of this is the proportion of patients where disease stage and performance status are available. Thirty eight trusts failed to meet the NLCA target to record stage in 95% of cases, and 120 trusts failed the same target for performance status (**Figure 22**).



## Figure 22: Proportion of cases with performance status or cancer stage completed, NLCA, 2017


Trusts with the best data completion tend to have processes embedded within their services that ensure as much data as possible is captured during the regular MDT meetings, and have at least one member of the clinical team with responsibility for updating and validating data submissions. However, although this activity is important it is frequently not recognised or job planned. Based on the data from the 2019 NLCA organisational audit, in around 35% of trusts the data was input by administrative staff and not subsequently validated by clinicians.

This led to a lack of full recognition of local obstacles or challenges and also risked misinformation regarding performance of that team being published nationally in NLCA reports or being made available to commissioners. Furthermore, although 67% of MDTs had a data quality lead, 57% had no dedicated time for this work and one third had no data quality lead at all. Only 19% of teams accessed 'Cancerstats' regularly via the NCRAS website. It has been apparent on our visits that some trusts have re-audited their service triggered by the receipt of their GIRFT datapack and immediately identified improvements in the quality and accuracy of their data which had been miscoded by administrative staff. The importance of understanding one's own performance cannot be underestimated in driving forward improvements in patient care (see Recommendation 26, page 78).

We noted in our reviews that the NLCA data was usually of a high quality, and often had undergone extensive validation, quality assurance and statistical adjustment in order to provide the most accurate and meaningful analysis and benchmarking of trusts. However, we also noted that there was a significant time lag between the clinical activity taking place (and Cancer Outcome and Services Dataset (COSD) submissions) and the publication of datasets and reports. Some degree of delay is inevitable since patient pathways from referral to treatment and measurement of outcome typically take around three months, but other reasons that are potentially modifiable include:

- Using fully registered cancer registration data from NCRAS rather than unprocessed COSD submissions adds a six month delay.
- Audit results typically take six months from analysis to publication due to the standardised reporting process required by HQIP.

Such a long delay limits the relevance and usefulness of the data in driving improvement. We would like to see the NLCA and NCRAS work together with trusts to ensure that the COSD data is of sufficient quality that it can be used for reporting (albeit with caveats) at a much earlier stage to drive quality improvement, with slower but more accurate data being used for ongoing quality assurance.

The NLCA has been able to bring together different datasets such as the Systemic Anti-Cancer Treatment Dataset, and the National Radiotherapy Dataset, to enable reporting on a wider range of measures. However, some important aspects of clinical care are not covered. For example, although the NLCA reports on first-line treatments, it does not report on the range of systemic treatment options utilised, does not report on second- or third-line treatments, nor on the overall quality of treatment, including adherence to best practice. In the era of personalised treatment and increasing identification of 'driver mutations' there is sadly still no national dataset that would allow correlation between these markers and the treatments received.

This type of audit of technical expertise should be extended to other specialty groups. The RCR strongly encourages peer review of radical radiotherapy treatments although we found that clinicians struggled to perform this formally within their job plans. Specialised commissioners have been piloting a platform 'pro-know' which enables remote review and audit of outlining and planning techniques. Real time feedback on radiotherapy planning has significant potential to improve patient outcomes. We would support the continued work by NHS England in this field.

The structure and data collection of the national audit lends itself well to secondary care but is less effective at benchmarking outcomes from tertiary centres. Mechanisms allowing for patient level outcome data to be published from tertiary oncology centres for lung cancer in much the same way as the Lung Cancer Clinical Outcomes Publication (LCCOP) does for thoracic surgery would be welcome and should be sought.

Specific data regarding the complications of treatment is not available in one centralised location. Whilst most trusts carry out regular mortality and morbidity (M&M) meetings within oncological and thoracic surgical services, this data is not incorporated into easily recognisable outcome data for the MDT to understand and utilise to patient benefit.

# **Pathway timings**

Lung cancer MDTs have long been aware of the timeliness of their pathway from referral to diagnosis and treatment through the NHS cancer waiting times dataset. In our deep-dive visits we saw that on the whole trusts were able to achieve high levels of compliance against the two week referral to first appointment target (95%), and the 31-day diagnosis to treatment target (97%) but struggled to achieve the 62 day referral to treatment target (66%), reflecting a diagnostic process that often requires multiple tests, and may involve several specialist teams and more than one trust. In preparing for the deep-dive visits we were interested to gain more granular information about the speed of the pathway at individual trust level and how this compared to the recommendations of the NOLCP (**Figure 23**). Analysing such data holds the key to understanding where the bottlenecks occur in a local patient pathway, allows benchmarking between organisations, and facilitates quality improvement and the recognition of best practice which can then be shared and replicated.



Our visits highlighted that very few trusts are auditing their performance against the 49 day NOLCP. It is our strong recommendation that services should use the NOLCP as the primary tool for the management and review of the speed with which patients pass along the lung cancer pathway (see Recommendation 24, page 78). Trusts need to embrace the reality that this is the commissioned pathway.

The COSD dataset contains much (but not all) of the information needed to map the patient pathway, but colleagues in NCRAS expressed concerns about using this data as it has not been fully processed and quality assured by their staff. We looked at a range of data sources, but none were sufficiently detailed nor contemporaneous for our purposes. Furthermore, although IT systems used in individual trusts do contain all the rich data needed to fully understand the pathway, it is usually contained in multiple disparate software solutions that do not communicate with each other.

We extended an invitation for trusts to send us data for the previous 12 months in a fully anonymised format, which we then used to map and benchmark components of the pathway. The data we obtained was very helpful in directing discussions with trusts about specific aspects of their pathway. However, the data has the potential to be much more powerful if available routinely and in near real-time in the future. Providing a local dashboard (benchmarked against other organisations) of current waiting times for key appointments, investigations and treatments allows the clinical team to manage patient expectations and allows clinical teams to work alongside managers to recognise and improve bottlenecks in the pathway.

#### **CASE STUDY**

The lung cancer team at the **Royal Wolverhampton** measured key time points within the lung cancer pathway to better understand local delays and obstacles. They asked members of their MDT to individually look at small changes that would speed up their pathway, on the basis that lots of small gains would prove significant. These targeted improvements resulted in a streamlined and more efficient pathway that was six days faster, and the changes have now become embedded into standard practice.

# Quality assurance data

#### **Diagnostic procedures**

Diagnosis and staging of lung cancer have been transformed by the introduction of EBUS. Efficient access to high quality EBUS services is paramount to facilitate the implementation of the NOLCP. During our reviews, we were able to draw on data from HES to indicate the numbers of EBUS procedures that were being undertaken, but in some cases, we heard that the data provided was inaccurate or out of date. In other trusts we heard that no distinction was drawn between staging and diagnostic EBUS procedures, and although many trusts reported that they collected information about the sensitivity, specificity and accuracy of their service, this was not routinely examined through the course of a deep dive. In early 2020 a service specification for EBUS was published by the Lung Cancer Expert Group.<sup>49</sup> This document includes a section on data collection requirements of an EBUS service, which we welcome and believe should be implemented in full (see Recommendation 25, page 78).

Regular audit of other forms of diagnostic service including complication rates relies on local service level audit. In some cases, national data is collected but this is not targeted at lung cancer per se (for example, the British Thoracic Society (BTS) national audit of pleural services). Diagnostic rates from radiological biopsy (CT and ultrasound) as well as pleural diagnostic services (including medical and surgical thoracoscopy) and their respective complications should form a routine part of an annual MDT review of the lung cancer service performance.

#### **Pathology services**

There are national quality assurance processes for England and Wales pathology services (external quality assessment), which are subject to NHS England reporting and are reviewed in a separate GIRFT workstream for pathology services. Availability of data with reference to lung cancer should be readily available to the lung cancer team and subject to annual review by the MDT.

Within the NLCA, rates of non-small cell lung cancer, not otherwise specified (NSCLC NOS) are used as a surrogate target of quality of report, given the importance of an immunocytochemistry cell type diagnosis to guide treatment. We found evidence of significant variation of processing techniques and timelines for reporting on both immunohistochemical and molecular information from cytology and histological samples that impacted on timeliness of access to treatment. Therefore, a mechanism for standardising and optimising laboratory processing and reporting standards would be of significant benefit within lung cancer.

#### **CASE STUDY**

**Manchester University Hospitals** introduced a prospective audit of EBUS activity and performance in 2016. A database was designed to capture all the relevant data, and this was later shared with other EBUS providers within the local Cancer Alliance.

All providers in the Cancer Alliance signed up to a set of quality standards and contributed data to the database. Subsequently, they noted an improvement in sampling of key mediastinal lymph node stations (4R, 4L and 7) and a reduction in the variability of staging sensitivity between centres.

## Patient experience information

In order to improve services for the benefit of lung cancer patients it is essential that they have the opportunity to be involved in shaping them. Due to the perceived stigma surrounding a diagnosis of lung cancer and high levels of psychological distress, patients may find it difficult to provide honest feedback about their experiences.

Data on patent experience was available for our deep dive reviews from the annual National Cancer Patient Experience Survey (NCPES).<sup>50</sup> This data is publicly available at trust level both for the cancer service as a whole and for each individual tumour site. However, the data is suppressed when the number of patients in a group is low to minimise the risk of disclosure of an individual patient's response. Furthermore, those patients with advanced disease and a poorer prognosis are often under-represented. The methodology of the data collection and the demographics of the patient population means that for lung cancer in particular, the data was suppressed for many of the trusts, and even where it was not, the numbers of responses limited the usefulness of the findings. Beyond formal survey tools, lung cancer teams have a responsibility to provide adequate opportunity for patients to express their opinions on issues pertinent to their care. At all stages of the pathway, patients should be encouraged to express their thoughts and opinions.

Some lung cancer teams were able to take important learning from their NCPES results, and had used it to make changes to the way their service was delivered. During our visits we found that a number of trusts had run their own patient experience surveys which have resulted in quality improvement projects. However, it was often the smaller services, with the least resource available to carry out local patient surveys that had no access to meaningful NCPES data. As a result, in many organisations no surveys took place at all. The need for this real time evaluation of services is particularly apparent with the service redesign that has been enforced by COVID-19.

Furthermore, measurement of outcomes in lung cancer has typically been mostly limited to survival. Measuring and integrating patient reported outcomes (PROMs) are increasingly recognised as central to the delivery of quality health care and have the potential to align patients, providers and commissioners towards a common goal of improving the value of care for lung cancer patients. Crucially, outcomes that matter to patients such as time to return to work, functional

performance, impact of side effects of treatment on daily functioning, and emotional wellbeing are commonly absent from hospital reporting metrics. Recently NHS England and NHS Improvement have begun a national programme to measure quality of life outcomes in breast, prostate and colorectal patients.<sup>51</sup> Although there is an internationally recognised framework for recording PROMS in lung cancer currently there is no national implementation of these and therefore no dataset was available for our deep dives.

We strongly recommend that trusts support their lung cancer teams to collect and review patient experience regularly, ensuring that the patient voice across the whole spectrum of age, disease stage, and treatment pathways is heard. Alongside this, we recommend that urgent work is carried out to develop meaningful PROMs with patient representation to better measure their experience of care and for this to be widely rolled out (see Recommendation 27, page 78). There are also other opportunities to harness patients' experiences though focus groups or local working groups, which should be taken at every opportunity.

# Recommendations

Recommendation	Actions	Owners	Timescale
23. Continue the National Lung Cancer Audit in the long-term in order to quality assure and improve services and bring the clinical community together with a shared purpose.	<b>a</b> National bodies should work together to ensure that the NLCA has a long-term funding model.	NHSE/I, HQIP	2 years from publication
	<b>b</b> All trusts should submit clinically validated high quality data to the NLCA.	Trusts	3 months from publication
	<b>c</b> National audit should work to reduce significantly the time taken to report benchmarked data back to trusts to a maximum of 12 months and to look at hybrid models of data collection, analysis and reporting that allow both rapid feedback of data as well as longer-term quality assurance.	NLCA, NCRAS	1 year from publication
	<b>d</b> The NLCA provider should ensure that patient and carer voices are central to the data collection analysis and reporting.	NLCA	1 year from publication
	<b>e</b> The NLCA provider contract should focus on analysis, reporting and improvement, with as much data collection as possible being done routinely.	NLCA	1 year from publication
	<b>f</b> The NLCA should consider and move to incorporate how complex treatments, delivered by tertiary centres, can be better recorded and benchmarked.	NLCA	1 year from publication
	<b>g</b> Data on neoadjuvant or adjuvant treatment with all treatment modalities should be recorded within NLCA.	NLCA	1 year from publication
	<b>h</b> Data regarding multimodality treatment should be recorded within NLCA as standard.	NLCA	1 year from publication
	i Every lung cancer service should have a member of the clinical team with responsibility for data collection, with job planned time to carry out the role.	Trusts	6 months from publication
	<b>j</b> Provider trusts need to ensure that their COSD submissions are timely, accurate and clinically validated.	Trusts	6 months from publication

# **Recommendations (continued)**

Recommendation	Actions	Owners	Timescale
24. Monitor and performance manage trusts according to the key time points within the National Optimal Lung Cancer Pathway.	<ul> <li>a National bodies should agree on a minimum dataset for monitoring the speed of the lung cancer pathway that includes key metrics defined in NOLCP (72 hours to CT scan from CXR; 21 days to MDT discussion staging and diagnosis confirmed; 49 days to commence treatment) that is more granular than the current cancer waiting times targets.</li> </ul>	NHSE	6 months from publication
	<b>b</b> This data should be collected routinely by administrative staff with clinical oversight and validation.	Trusts	1 year from publication
	<b>c</b> All lung cancer services should have access to real time data on individual steps in the pathway which will in future be based on the above minimum dataset (72 hours to CT scan from CXR; 21 days to MDT discussion staging and diagnosis confirmed; 49 days to commence treatment).	Trusts	1 year from publication
	<b>d</b> Trusts should share their data on a national performance dashboard to highlight outliers and allow sharing of best practice. This could be included in the Model Hospital website.	Trusts, NHS England, GIRFT	1 year from publication
<b>25.</b> Collect, analyse and publish an agreed EBUS dataset aligned to agreed performance metrics and standards.	<b>a</b> All EBUS services should collect a minimum dataset as outlined in the EBUS service specification.	Trusts	6 months from publication
	b National bodies should explore the opportunity to collect, analyse and publish these data in order to highlight outliers and encourage sharing of best practice.	NHS England, NLCA	1 year from publication
<b>26.</b> Improve the annual review of data within lung cancer services.	<ul> <li><b>a</b> All MDTs should conduct regular review of data within an operational meeting to include:</li> <li>Diagnostic accuracy rates (&gt;90%)</li> <li>Rates of NSCLC NOS (&lt;5%)</li> <li>Adequacy of sampling for molecular testing (&gt;85%)</li> <li>M&amp;M data from all specialties associated with treatment and diagnostics.</li> </ul>	Trusts	1 year from publication
	<b>b</b> Trusts should share results with other trusts in their Cancer Alliance to identify areas for improvement.	Trusts	1 year from publication
<b>27.</b> Develop more relevant and generalisable methods of collecting data on patient-reported experience and outcomes.	<b>a</b> National bodies should agree a common dataset and standard for measuring and reporting lung cancer patient experience and outcomes.	NHS England, NCRAS, NLCA, Lung Cancer CEG	1 year from publication
	<b>b</b> Trusts should carry out local patient experience surveys where return rates for NPCES are low.	Trusts	1 year from publication

# Resources, organisation and accountability

Building upon the recommendations we have made in the previous chapters, we wanted to reflect upon some additional organisational issues relating to how lung cancer is delivered locally and regionally, how resources are allocated, and where responsibility for the service lies.

We were fortunate to meet individuals at all levels, including local clinical teams, service managers, chief operating officers and chief executives, as well as representatives of a variety of regional and national bodies. In reality the interaction between all individuals, teams and organisations is complex and improving lung cancer care requires everyone to work in partnership to deliver the optimal service to all patients.

In this section, we wanted to try and understand why, after 20 or more years of audit, investment, and service improvement, we have made so little progress in improving survival compared to other cancers and other countries, and in reducing variation such that a GIRFT workstream for lung cancer was needed.

We have looked at local, regional and national challenges as well as proposing some solutions, some of which we saw evidence of, and many which we believe would lead to improving outcomes and quality of care for those people living with lung cancer.

# Local and regional challenges

## Multidisciplinary team leadership

Members of the MDT are the clinical experts guiding the diagnosis and treatment of individual patients. As professionals, we expect them to deliver high quality care and to keep up to date with best practice. However, teams need strong and effective leadership. It was good to see that all teams had a nominated clinical lead, and we were impressed by the way they conducted themselves in our deep-dive visits giving open and honest answers to our questions that were often quite challenging. These clinical leads have a variety of roles and responsibilities, including managing trainees and colleagues, representing the lung cancer service at the Cancer Board and Cancer Alliance or network groups, and leading service improvement and pathway redesign. This must be informed by regular business meetings where both pathways and outcomes are reviewed and discussed. Morbidity and mortality data should be shared by tertiary centres with local MDTs. The leads are also crucial in making sure the MDT does not become complacent and inward-facing and is constantly embracing new developments and ways of working. They should be supported in restricting their remit to cancer; all non-malignant work should be reviewed in a different forum.

For these reasons, we consider it mandatory that the clinical lead of the lung cancer service has job-planned non-clinical time allocated for this, although from the data submitted to GIRFT this was the case in only 37% of trusts (see Recommendation 28, page 87).

## Workforce

It was an almost universal finding of our deep dives that MDTs reported having inadequate staff to carry out their work. National commissioning guidance has provided some benchmarks for the level of staffing required for an effective lung cancer service, and trusts had reported on these through the NLCA Organisational Audit. As a result, we approached each deep dive with an awareness of the different staffing pressures at each trust, but it was through the subsequent discussions with teams that we were able to hear and understand better the impact of these issues. Measuring adequacy of staffing is quite challenging, and the metrics suggested in the commissioning guidance is not always clear due to the diversity of individual roles (see Recommendation 29, page 87).

We would suggest that these are revisited and that lung cancer teams then complete an annual report on staffing that is standardised and reliable. This can be fed upward to local trust cancer boards and shared at Cancer Alliance level to help inform planning. Complementing this data with patient impact stories can be especially powerful.

# Table 6: Workforce challenges and potential opportunities

Workforce challenge	Potential opportunities
<b>Respiratory medicine</b> In smaller trusts in particular, the size of the department, pressures from general and acute medicine (including more recently the response to COVID-19) as well as other sub-specialty management within respiratory creates logistical challenges in the delivery of best practice such as referral triage, daily rapid access clinics and MDT streamlining.	Negotiation of standardisation of referral pathways from primary care across an entire region rather than piecemeal across commissioning groups, allowing a consistent approach for triage. Coupling this with collaborative working across Cancer Alliances allows alignment of pathways and processes. Exploring and realising opportunities from the move to virtual clinics, allowing working cross-site or cross-organisation.
Radiology Many trusts had only one radiologist with thoracic expertise and outsourcing of reporting has become routine practice. This means that cancer CT scans will often not have been reported by an optimally skilled radiologist, which risks the quality and accuracy of the report, leads to a recommendation for inappropriate unnecessary further imaging or necessitates second-reporting which is inefficient and further compounds pressures. A shortage of appropriately trained interventional radiologists (or their support staff) means that a biopsy service is frequently not provided 52 weeks of the year, leading commonly to delays of two to three weeks.	Wider implementation of radiographer reporting releasing consultant time for specialised activities. Use of standardised templates for reporting on lung cancer scans to consistently offer staging results and suggest sites for sampling/biopsy. Streamlining MDTs to reduce burden of reporting and preparation for radiologists. Implementation of radiology networks across trusts to allow sharing of workforce for specialised reporting and interventional services.
<ul> <li>Oncology</li> <li>Oncology staffing for medical and clinical oncologists is predicted by both the RCR and RCP to become significantly worse over the next five years.</li> <li>An expansion in the workforce has not kept pace with the number, complexity and type of therapies available to treat patients with advanced disease along with availability of multiple lines of therapy.</li> <li>In most centres, oncologists cover up to three tumour sites, and often work cross-site necessitating travel which impacts on available time for direct clinical care. The result is that NOLCP timeframes are largely aspirational for many trusts. Waits of several weeks to see an oncologist and commence treatment are not uncommon.</li> <li>As well as the psychological impact this has on patients (and their families), it often results in deterioration in functional status during the waiting period</li> </ul>	Regional and national workforce and succession planning needs to take into account predicted expansion of therapeutic options. A focus on specific regional gaps would inform recruitment into regional training programs. Lung cancer MDTs can provide high quality immunotherapy care alongside managing complex cases more effectively when they utilise extended nursing, pharmacy and therapeutic radiotherapy roles to their fullest potential alongside consultant oncologists. Oncologists already work across regions but negotiating contracts on 52 week basis would reduce gaps in service delivery and pressure on remaining colleagues.

Table 6: Workforce challenges and poter	ntial opportunities (continued)
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Workforce challenge	Potential opportunities	
<b>Pathology</b> The role of the pathologist is vital to the rapid and high quality diagnosis of lung cancer. Sadly, there were many instances of vacancies within the pathology diagnostic services at every level including consultant, biomedical scientist and administrative. We visited regions where neighbouring trusts had significant vacancies and yet silo-working remained a theme. Regional solutions had in some cases sprung up to address shortfalls but this was the exception and depended on good relationships rather than systems enabling cross-organisational working.	Implementation of pathology networks with 'NHS passports' allowing cross-organisational working. Use of novel career development roles for biomedical scientists with enhanced responsibilities and training to support consultant colleagues would address shortfalls to some degree.	
<ul> <li>Lung cancer nurse specialists</li> <li>Lung cancer nurse specialists, as part of their role, provide a range of critical tasks including support, information, and navigation through the pathway.</li> <li>Our data shows that only around 30% of trusts have staffing levels that meet those in the current commissioning guidance (one whole time equivalent (WTE) per 80 patients). We recognise these recommended levels are based on the traditional role of the LCNS and do not account for the extended roles that they have taken on.</li> <li>Whilst we saw brilliant examples where care was provided seamlessly across the patient journey, it was common to hear that those patients diagnosed during an acute admission were relatively poorly served, or that patients lacked input after their diagnosis had been made. The importance of the LCNS team having equivalent administrative support as the medical workforce cannot be underestimated.</li> </ul>	<ul> <li>Wide introduction of pathway navigators and support workers would alleviate significant burdens of administrative work and release time for direct clinical activity.</li> <li>Uptake and rollout of enhanced supportive care to support inpatients with lung cancer.</li> <li>Addressing critical staffing shortfalls and opportunities for career development for Band 5/6 nursing workforce to allow succession planning.</li> <li>Plans to invest £10million in clinical placement programmes to increase nursing capacity through clinical placements across England, supporting the goverment's ambition to recruit 50,000 nurses.*</li> </ul>	

 $\label{eq:constraint} * Health Education England website, Health Education England to invest up to £10m in clinical placements across England, March 2020, https://www.hee.nhs.uk/news-blogs-events/news/health-education-england-invest-%C2%A310m-clinical-placements-across-england across-england across-engl$ 

## Collaborative working between clinical and administrative teams

The lung cancer service within a trust was the focus of our deep-dive visits but this exists within a much larger cancer unit, which itself is part of a larger directorate, or as is usually the case spans a number of directorates or divisions, each with competing pressures and priorities. This can exacerbate the challenges in delivering an effective and responsive lung cancer service. Unless a trust has a strong cancer board with an overarching line of sight of the challenges that may span all those services involved, priorities for development within the MDT may not gain traction or attention.

This is further exacerbated by senior leadership teams being more focused on overall performance against centrally monitored targets, financial balance and the intermittent crises associated with winter pressures, emergency department targets and now COVID-19. In one-third of those trusts visited, the leads of the lung cancer MDT reported to us that they were not aware of and/or did not have access to a trust cancer board, and 5% of leads reported that there was no executive

director with responsibility for cancer services. As a result, highlighting issues to the trust board were reported as being challenging, enabling problems to develop over time that become more intractable. As an example, very few trusts that we visited had carried out a deeper analysis into the factors that may lead to a breach of cancer waiting times but purely focused on working harder and not smarter. Furthermore, many divisional management teams exhibited a sense of relief to be 'off the radar' as a major cause for concern rather than demonstrating an appetite for exemplar performance and quality of care.

We saw striking variation in executive-level attendance at our GIRFT deep-dive visits, with those trusts that had already implemented significant quality improvement in their lung cancer pathway generally demonstrating better executive engagement.

Lung cancer services are externally commissioned either locally or through specialised commissioning (see below), but trusts are usually the employer of the staff that deliver the service. As already described, our data showed significant shortfalls against the recommended levels of staffing, with extensive use of bank, agency and locum staff in all specialties within the MDT. It was clear to us that while the clinical team had tried hard to recruit into existing gaps or expand the workforce to reflect increasing workload, there were often financial barriers that proved difficult to overcome, or simply not the workforce available to fill these gaps.

An opportunity to review workforce modernisation should not be overlooked as this may be the key to unlocking some of the challenges which impact on service delivery and care. Services should ensure that they have development opportunities for staff, making use of innovative roles such as radiographer reporting, pharmacist prescribers, assistant practitioners and nurse-led clinics, especially where vacancies exist and recruitment has been challenging. Far too often, teams reported that simple solutions such as flexibility of job description or role, banding on Agenda for Change or invest to save opportunities blocked obvious solutions. Unless trusts invest in a people plan for the NHS these problems will continue to impede quality improvement. For example, we heard from one team of their proposed solution to a significant shortage of consultant histopathologists involving the introduction of enhanced biomedical scientist roles with the opportunity for career development, additional training and enhanced responsibility. The team were unable to progress this business case for such reasons and the impact on overall morale of the staff was palpable.

As well as pressures on staff, we heard repeatedly about a lack of physical space, whether it be outpatient clinics, chemotherapy units, endoscopy access or recovery space post lung biopsy. This constraint further impacts on the ability to work at maximum efficiency. We found good examples where trusts employed novel mitigations such as creating spaces in under-used areas within the hospital or moving work into the community, for example, using a ward discharge area for recovery post-procedure, or chemotherapy buses in the community to deliver care nearer home. In some cases, however, staff reported that they were unable to take local innovative action as they were constrained by overly bureaucratic processes or lack of vision within administrative or management functions.

We visited a number of recently merged trusts who faced ongoing challenges in how to effectively merge two previously separate multidisciplinary lung cancer teams. In some merged trusts they continue to hold separate MDMs, while in others they have combined the MDM but all other processes remain separate. Without a strong vision to unify services fully and the support and mandate to do this, there is a risk of disparate pathways and inequitable services for patients and we have seen evidence of this in practice. Where services have merged, teams should be supported to process map existing pathways across all sites, define challenges to deliver equity and be supported to redesign pathways to meet the needs of all patients.

# Local commissioning

Commissioning is the process by which health and care services are planned, purchased and monitored. The majority of NHS England's budget is allocated to CCGs, but the way that commissioning is delivered in practice continues to evolve. Since 2016, 'system-level' planning structures (Sustainability and Transformation Partnerships – STPs, and integrated care systems – ICSs) that bring together commissioners and providers from the NHS and local government to plan collectively across local areas, have been developed. It is worth noting that there is significant variation in the maturity and effectiveness of these systems of care delivery across England.

Theoretically these commissioning structures should provide a powerful mechanism to ensure that adequate funding is provided for local lung cancer services and in turn that these services deliver best practice and optimal outcomes, with the opportunity to decommission a poorly performing local service and purchase it from another provider. National commissioning guidance gives commissioners a framework for measuring and monitoring the services that they purchase.<sup>52</sup>

However, in practice we saw some evidence of how commissioning arrangements acted as a barrier to service improvement.

Pulmonary nodules are a common finding on CT scans carried out for a variety of reasons, and while most are benign, a small number are early-stage lung cancers. Over the last five or so years, some respiratory teams in hospital trusts have developed 'nodule clinics' to identify, monitor, and manage patients with lung nodules, following a standardised protocol with robust governance arrangements. Much of this work is done remotely, avoiding the need for attendance at a hospital outpatient clinic. However, we heard that commissioning these services formally had proved difficult in many cases. This left services unfunded and therefore unable to be effectively resourced, either with IT infrastructure, appropriate recognised time within job plans, or additional clinical or administrative staff to support it. In the specific case of lung nodules, we have already described the governance risks associated with the lack of a formal nodule service.

Whilst some trusts have managed to effectively innovate within the existing financial envelope available to them, we saw many examples where funding arrangements being negotiated as a 'block contract' led to the perverse situation of them acting to disincentivise novel pathways of care. This can result in organisational inertia to drive quality improvement and should be recognised for its disadvantages as well as potential benefits.

Enhanced supportive care (ESC) should be available to all patients regardless of geography, but we saw many examples where it had not been formally commissioned locally. This is an example of unwarranted variation and there is evidence that ESC impacts positively on treatment rates and outcomes. We noted on some visits that where trusts were not providing ESC, commissioners did not seem to be sighted fully on the implications of this for patients, and there were missed opportunities to commission this fully and hold the trusts to account to deliver ESC.

Whilst the arrangements for local commissioning of services was outside the scope of our workstream, and whether it is primarily a problem of less strong commissioning or lack of resources, it seems clear that on occasions it is not working for patients in improving services and reducing variation. In practice, decommissioning a poor service is extremely difficult and risks making local services even worse. However, in such cases, commissioners and Cancer Alliances (see below) have a responsibility to be aware of the problems and to work constructively to resolve them.

# Stakeholders

## Non-governmental organisations

Charities such as the Roy Castle Lung Cancer Foundation and Macmillan play a vital role in patient advocacy. Not only do they help shape policy through national bodies, they offer a platform for patients with lung cancer to take on advocacy roles, share their experiences, raise awareness and ensure the patient voice is heard. As well as championing local support groups, they also provide a portfolio of patient information to empower patients in decision-making. The COVID-19 pandemic has unfortunately led to a reduction in available funding, and it will be important that efforts to recover this are successful in the future.

## National bodies

Ultimately it is national bodies such as NHS England and Health Education England (HEE) who set national direction, priorities, and the funding envelopes for achieving them. It is important to recognise from this report that there is likely to be an implication for funding review where we have highlighted a case of need for additional resource, infrastructure or workforce. This is not within the remit of the GIRFT programme, but needs to be reviewed as part of the whole report. Decisions taken have impacts on trusts and their services that manifest over long periods of time. It is important that national initiatives being funded centrally by NHS England develop clear lines of communication with clinical teams at trust level to fully understand the implications in practice.

## NHS England specialised commissioning

We wish to highlight the importance of national bodies on the provision of PET-CT scanning. This is a critical radiological assessment that determines disease stage and is often needed before any biopsy is undertaken. PET-CT is delivered by a variety of NHS and private providers, commissioned through a national contract managed by the specialised commissioning arm of NHS England. We repeatedly heard that clinical teams experienced delays in getting PET-CT scans carried out, and in reports being available, which not only led to a longer patient pathway, but in some cases meant that the order of tests

had been reversed leading to unnecessary biopsies. Whilst some teams had worked with their local provider to streamline PET-CT scanning in a very patient-centred way, others had failed to reach agreements and were routinely waiting between two and four weeks.

There is a clear role for specialised commissioning to set challenging targets for providers that fit in with expectations of national pathways, to monitor performance and ensure that best practice is being shared and used widely. This is likely to require commissioning of additional capacity as advised by Professor Sir Mike Richards in his report for NHS England on diagnostic services.<sup>53</sup> Provision within the national contract for PET required as part of a research protocol should be clarified, as some PET centres managed under the national contract were not providing this.

The rollout of SABR across all cancer centres in England is a welcome development and will certainly increase the uptake of this form of radical treatment especially where the distance to travel has been a barrier. However, the rollout must be accompanied by the appropriate increase in workforce, time for training, peer review and SABR MDT formation. This would need to be reflected in a commissioned contract.

## **Health Education England**

A third area to specifically highlight is the role of HEE in planning and training the workforce of the future. Current issues with staffing in lung cancer teams reflect decisions taken five to ten years ago when expansion of the non-medical workforce was prioritised. Most specialties predict a significant worsening in consultant workforce shortage over the next ten years. During our visits we observed an inequality of trainee numbers between trusts and indeed regions – for example trusts within the Peninsula Cancer Alliance do not have a medical oncology training programme. There is a recognition that the majority of trainees will take up a consultant post in the region where they have trained.

The historical allocation of training numbers favoured established teaching hospitals which, given the expansion of specialist diagnostics and oncological treatments being delivered in smaller district general hospitals, risks their long-term sustainability if they cannot attract suitably qualified candidates. We recognise and commend the development of the NHS People Plan, but there must be an understanding that a world-class lung cancer service cannot be delivered with a staffing model that is 'just about adequate'. In contrast, it needs to provide spare capacity and flexibility so that services have appropriately skilled practitioners across the whole range of medical, nursing and allied healthcare practitioners, able to give the same levels of high-quality care to all patients in all areas of the country 52 weeks of the year.

## **Cancer Alliances**

During our visits we have seen examples of very close interactions between trusts and Cancer Alliances but also others where there is less evidence of joint working. There are likely to be many contributing factors for this variation.

Representatives from Cancer Alliances were invited to each deep-dive visit, and while in most cases attendance was enthusiastic, in many cases, the non-clinical attendees had little background knowledge of the challenges faced locally and the trust's progress towards delivering the NOLCP.

Cancer Alliances have been specifically tasked and funded to support trusts to improve and transform pathways and services, particularly around implementation of the NOLCP. Unfortunately, we found evidence of some frustrations amongst lung cancer teams whereby this process didn't work as well as anticipated. In some cases this was due to misalignment of local and Cancer Alliance priorities for improvement.

The short turnaround time for allocation of funding was challenging for local teams to meet, and due to certain conditions not being met within funding applications or the inability to fund posts beyond the pump-primed period, the ability to use transformation funding to its maximum potential was lost (see Recommendation 30, page 88).

We have visited smaller trusts with very small lung cancer services which present particular challenges. We recognised that within these trusts there are often very dedicated, but sometimes single-handed, practitioners in various fields across the MDT who work extremely hard to deliver a good service for patients. Often the data showed good outcomes for some of the measures examined. These teams are often fiercely independent and desperate to continue providing a local service for their community. However, it was hard to see how these services could improve with the speed and scale that was required based on our reviews and action plans. In such cases, formally partnering with an adjacent organisation to share key elements

of the diagnostic pathway and expertise that comes from a decision-making treatment MDT is likely to assure the principle of delivering high quality care as close to the patient as possible. Cancer Alliances are well placed to recognise the need for joint working, to gain clinical consensus across a region, and to broker subsequent discussions between different trusts.

The GIRFT team are aware of thoracic surgical recommendations which advise a significantly smaller number of MDTs, but we would advise caution in this regard. At present, surgery is only possible in around 20% of patients due to the stage distribution. Whilst this may change if risk-based screening is successfully implemented across the country, at the present time the majority of patients have either comorbidities precluding surgery or advanced stage disease. They are likely to be best served by a local MDT where discussion is led by clinicians who know the patient and are best placed to advocate for them, particularly given travel requirements being reported as the greatest barrier to uptake for treatment. Ensuring quoracy of the MDT is critical, as discussed in an earlier section.

Through discussions with representatives of the Cancer Alliances at deep dive meetings, we learned the current resource allocated to Cancer Alliances would need to be reviewed alongside any material shift in the expectations to deliver the recommendations outlined in this report.

## Genomic laboratory hubs

Genomic analysis is revolutionising the treatment of lung cancer, and we welcome and commend the NHS Genomic Medicine Service plan to provide a world class genomic testing resource through a national testing network delivered through seven genomic laboratory hubs (GLHs), each responsible for co-ordinating services for a particular part of the country. The 2020-21 National Genomic Test Directory for cancer, which is currently being updated, specifies the genomic tests commissioned by the NHS in England for cancer, the technology by which they are available, and the patients who will be eligible to access to a test.<sup>54</sup>

However, none of the centres we visited had a clear vision of the processes which would be required for the change in practice and this uncertainty was limiting innovation within the local pathology service. In practice a single sample may need assessment in three separate laboratories to achieve a histological diagnosis, IHC testing for PDL1 and genomic sequencing. All MDTs expressed concern about the turnaround timeframes they had worked so hard to improve over recent months and years. Significant concern was raised by trusts regarding staffing commitment and costs associated with specimen preparation. The GIRFT reviewers understand that for most genomic hubs, the turnaround time in delivering results is likely to be seven to ten days from the receipt of the sample. Given the initial preparation time required at trust level, and the time needed to transport the specimen, we anticipate that turnaround times will be significantly and negatively impacted by this change. Moreover, while hubs are introducing a tissue assessment triage, the tissue specimen size requirements are greater than that currently collected in the majority of centres, which risks repeat procedures of CT biopsy and EBUS, already identified as bottlenecks in a large proportion of MDTs, as well as actual patient harm due to the morbidity of the procedure and further delays in patients receiving active treatment.

The GLH implementation team recognise these issues and highlighted that local pathology laboratories will continue to have an important role in testing for some time to come, particularly for those key tests where a rapid result is needed to guide immediate first-line treatment. They also acknowledged the need for better communication between the laboratory hubs and the local/regional clinical teams that would allay the existing concerns about the clinical pathways and help to develop them in partnership.

It is critical that both these hubs and local laboratories are adequately resourced and staffed if they are to fulfil their potential, with challenging performance targets being set to ensure they deliver timely results in line with the NOLCP.

#### **Risk-based screening for lung cancer**

Since the publication of the US National Lung Screening trial in 2011, which demonstrated for the first time that low dose CT scan screening could reduce mortality from lung cancer in high-risk individuals, there has been much research carried out into refining the screening methodology.<sup>55</sup> The recent publication of the population-based Dutch–Belgian lung cancer screening trial (NELSON) has confirmed the mortality benefits in a European population using volume-based nodule analysis and a rigorous protocol for management of detected nodules and showed a reduction in death from lung cancer at ten years of 24% in males and 33% in females.<sup>56</sup>

<sup>54</sup> NHS England website, National Genomic Test Directory. https://www.england.nhs.uk/publication/national-genomic-test-directories

<sup>&</sup>lt;sup>55</sup> Aberle D. et al (2011) Reduced lung-cancer mortality with low-dose computed tomographic screening. New England Journal of Medicine 365:395-409. https://www.nejm.org/doi/full/10.1056/nejmoa1102873

<sup>&</sup>lt;sup>56</sup> de Koning H. et al (2020) Reduced Lung-Cancer Mortality with Volume CT Screening in a Randomized Trial. New England Journal of Medicine 382:503-513. https://www.nejm.org/doi/full/10.1056/nejmoa1911793

In England, there have been several regional research-based screening programmes that have sought to better understand the best risk-based selection criteria, to maximise take up from hard-to-reach populations, to integrate smoking cessation into the programme, and to determine the best ways to manage other findings such as emphysema. One of these, the Manchester Lung Health Check programme, detected lung cancer in 3% of participants at baseline – 80% of these had early-stage disease and of these, 65% had surgical resection.

These results have led to funding for 14 local NHS lung health checks, located in areas with a high incidence of late-stage disease and high mortality rates. Sadly, many of these programmes were paused during the first wave of the COVID-19 pandemic but we understand, at the time of writing, that many are now re-opening gradually.

Although there is still potential to refine the screening methodology, we feel that the case for a national programme is overwhelming (see Recommendation 31, page 88). It will be a key driver of the NHS ambition that by 2028, 75% of patients will be diagnosed with early-stage cancer. It is difficult to quantify the real-world improvements such a programme would deliver, but it has been suggested that around 12.5% of the total lung cancer deaths in England would be prevented (around 3,750 people each year). In the NELSON trial, 69% of lung cancer cases in the screening arm were detected in stage I, whereas in the control arm about 70% were detected in stage III/IV.

Pressures within local systems for CT scanner access place a barrier to wider screening, along with concerns that the infrastructure within lung cancer services is insufficient to cope with the additional workload that would result.

## Clinical Expert Group (CEG) for lung cancer

A geographically representative panel of recognised national experts and clinical leaders within the CEG under the umbrella of NHS England was integral to the development of the NOLCP. The NHS Cancer Programme has reformed its governance structures and is able to call on clinical advice from national experts or experienced clinicians on lung cancer when required. The CEG, which formed part of the old governance structure, is being retained by the Roy Castle Lung Cancer Foundation as a UK wide expert group with representation from clinicians, commissioners, patients and the major lung cancer charities. As highlighted in this report, there remain a number of key areas where a panel review of the available evidence and guidance provision is crucial to standardise the clinical approach and reduce geographical variation including, but not limited to, follow-up imaging protocols post-treatment, the development of PROMS for lung cancer and the ongoing response to COVID-19 (see Recommendation 32, page 88).

# Recommendations

Recommendation	Actions	Owners	Timescale
<b>28.</b> Ensure all lung cancer MDTs have a named clinical lead for the service, with job planned time for the role to allow for service development and management.	<b>a</b> Trusts to reflect role in job description and to allocate supporting professional activities (SPAs) to the clinical lead to enable leadership and development of lung cancer service.	Trusts	6 months from publication
29. Ensure all lung cancer MDTs have appropriately skilled practitioners across the whole range of medical, nursing and allied health professions and healthcare scientists, able to give the same levels of high-quality care to all patients in all areas of the country 52 weeks of the year.	<b>a</b> The current lung cancer reference group (CEG) should review the recommended staffing levels in its commissioning guidance to make them more clear and useful.	CEG	1 year from publication
	<b>b</b> NHS England, through its People Plan and with HEE and other bodies, should review the implications of workforce challenges within lung cancer services to deliver a comprehensive plan for a sustainable workforce.	NHSE, HEE	1 year from publication
	<b>c</b> Service level agreements between organisations to provide thoracic surgery and oncology should be immediately renegotiated and agreed on a 52 week per year basis allowing for cross cover for absences and leave.	Trusts	1 year from publication
	<b>d</b> Lung cancer MDTs should review staffing levels against commissioning guidance on an annual basis and share the findings with trust boards and Cancer Alliances.	Trusts	1 year from publication
	e Trusts should ensure the lung cancer nurse staffing levels meet the national guidance of one WTE per 80 patients.	Trusts	6 months from publication
	<b>f</b> Services should ensure that they have development opportunities for staff, making use of innovative roles such as radiographer reporting, pharmacy non-medical prescribers and nurse-led clinics, especially where vacancies exist and recruitment has been challenging.	Trusts, HEE	1 year from publication
	<b>g</b> Cancer Alliances should monitor staffing levels across the region and facilitate discussions about sharing of resources.	Cancer Alliances	1 year from publication
	<b>h</b> Where there have been recent service reconfigurations, Cancer Alliances should work to support trusts to deliver equity of access to patients across the entire site.	Trusts, Cancer Alliances	1 year from publication

# **Recommendations (continued)**

Recommendation	Actions	Owners	Timescale
<b>30.</b> Review the process for funding allocations to ensure that transformation funding is used as effectively as possible.	<b>a</b> Ensure adequate timescales for transformation funding bids, and that clinical teams are actively involved.	Cancer Alliances	3 months from publication
	<b>b</b> Trusts should involve the clinical team in decision-making regarding bids.	Trusts	3 months from publication
	<b>c</b> Trusts to commit to continued funding of pump primed posts where they prove effective.	Trusts	3 months from publication
	<b>d</b> Trusts to work together within their Cancer Alliance footprint to ensure funding is distributed according to clinical need.	Trusts	3 months from publication
<b>31.</b> Roll out national implementation of risk-based CT screening for lung cancer.	<b>a</b> Provide roadmap for rollout of screening to all areas of the country.	NHSE, Public Health England (PHE)	6 months from publication
	<b>b</b> Work should begin to review the capacity and demand requirements for this.	NHSE, PHE	6 months from publication
	<b>c</b> Work to begin to ensure adequate trained staff will be available to deliver the screening services sustainably into the future.	NHSE, HEE, Society of Radiographers, PHE	6 months from publication
<b>32.</b> Ensure that a clinical reference group continues to be available to provide strategic and clinical advice.	<b>a</b> Discuss with relevant stakeholders where the national group might sit to enable support to a number of specialties and organisations within lung cancer.	NHSE/I	6 months from publication

The emergence of the COVID-19 pandemic has had an unprecedented impact on all aspects of healthcare, but the lung cancer patient community has been particularly affected across the entire pathway. Through our deep dives we were able to examine the challenges, the ways in which teams had responded to them, and to reflect on some of the opportunities and local innovations driven by the crisis. We have also drawn on information available from the National Cancer Programme and Cancer Alliances and that gathered by the UKLCC in its COVID-19 Matters report.<sup>57</sup>

# **Delayed presentation**

COVID-19 is a predominantly respiratory illness with symptoms that can be similar to those of lung cancer. Evidence collated by the National Cancer Programme for each Cancer Alliance showed that rates of referrals under the cancer pathway fell significantly in April 2020 compared with that of the previous year (average 39%, range 26-58%). Teams reported that there were real challenges for patients and healthcare professionals distinguishing symptoms of cancer from those of COVID-19 and further challenges accessing healthcare through non-emergency routes. Rates of referral slowly recovered throughout the year but at the time of writing are not yet back to pre-COVID-19 levels. The rate of chest X-rays to investigate respiratory symptoms significantly declined, even where symptoms had been present for more than a few weeks, making COVID-19 highly unlikely as a cause. Furthermore, in the interests of not placing additional pressure on the NHS, or due to fear of coming into contact with patients infected with COVID-19, attendances at emergency departments and GP practices fell dramatically.

To further compound the impact on making an early diagnosis of lung cancer, the lung health check pilots that had recently become, or were about to become, operational at the beginning of the year were paused in accordance with local action plans, removing the opportunity to diagnose these asymptomatic cancers. These are re-opening gradually at the time of writing.

To better support primary care services, the lung cancer CEG developed guidance on 'Differentiating the Cs', which is designed to provide GPs with a simple triage mechanism to better differentiate potential lung cancer symptoms from those caused by COVID-19.<sup>58</sup>

# **Delayed diagnosis**

Regrettably and inevitably the pandemic has resulted in delays in the diagnostic pathway within secondary care, which as we have seen in earlier chapters has a significant impact on patient outcome and experience. There is concern that this could reverse some of the progress in lung cancer survival achieved over recent years. Some of the main issues we noted are:

- Capacity pressures created by the number of COVID-19 diagnoses.
- Infection-control measures impacting on efficiency of diagnostic services.
- Additional workforce pressures due to redeployment of staff to front-line COVID-19 response and staff sickness or self-isolation.
- The need for a COVID-19 testing pre-procedure which has added a layer of complexity and delay for diagnostics.

However, commendably, there have been strides forward across many trusts in response to these challenges. In response to the need for rapid diagnosis in patients with suspected COVID-19, many trusts implemented new models for rapid radiology access with same-day chest X-ray reporting as standard. This obviously represents significant progress towards facilitating more rapid transition to CT imaging, and it will be important for trusts to sustain such innovations into their normal practice once the pandemic is over (see Recommendation 33, page 93).

Teams have moved their MDM to an online format, removing the need for travel time, and enabling members of the team to attend remotely and for selected parts of the meeting.

The need for patients to travel to the hospital for appointments has been reduced, facilitated by the move to remote appointments using video or telephone consultations. Whilst in many situations patients are pleased to be able to discuss their condition from familiar surroundings with the support of family members in the room, it is important to note that there are some limitations to remote consultation and these must be considered and overcome by lung cancer teams:

- Watching how the patient enters the consulting room is a good way of initially assessing general fitness and performance status.
- Physical review of the patient enables subtle signs of cancer progression e.g. loss of muscle bulk, and formal examination of a patient will sometimes be required to pick up important signs of both comorbidity and malignancy.
- Options must be available to overcome unfamiliarity with IT amongst older or less technically minded patients, for whom video consultation can provide an additional stressor, or those with unreliable internet connection or without internet access.
- Teams should take advantage of developments in virtual consultation to allow three-way consultations to facilitate joint clinics with other members of the MDT.
- There are challenges in communicating with empathy when sharing difficult news and building the patient's trust, especially by telephone.
- The move away from hospital-based consultation has increased the burden on community teams to provide phlebotomy services, measurement of vital signs and urine dip testing.
- Innovative methods of delivering prescriptions or requesting additional tests must be developed and established.

When face-to-face consultations do occur, there should be clear information given to patients in advance about who, if anyone, they are permitted to bring with them. Clinicians must ensure that they can be understood clearly when wearing personal protective equipment, and that there is continued availability of translators where needed. When patients are not able to have somebody to accompany them to appointments additional provision should be made to support their own and their family's needs after the appointment. This may include the LCNS team proactively contacting them.

Guidance from the CEG, endorsed by the BTS, the British Thoracic Oncology Group (BTOG) and NICE, has been published with recommendations on modifications to the diagnostic (and treatment) pathway as a result of the pandemic.<sup>59</sup> The pandemic has highlighted the need for an efficient and co-ordinated pathway, and we noted that those trusts which had already implemented the majority of the diagnostic elements of the NOLCP appeared to be more resilient to the impact of the pandemic. Other teams found that they were forced into developing new models of triage, remote working and bundling of tests, but that this had been a positive experience for them and their patients, and they planned to continue working in this way. However, it was relatively easy to work in new ways when referral numbers were very low, but as they rise back to normal, it is important that these new pathways receive appropriate clinician time and IT/administrative support.

Teams that have moved successfully to remote consultations have built in flexibility and innovation to allow attendance from more than one member of the team or, importantly, to facilitate a family member, friend or relative to 'attend'.

#### **CASE STUDY**

In **Exeter** the team utilises NHS COVID-19 volunteers and members of administrative staff to familiarise patients and their families with the technology required for video consultations, offering practice in a 'test waiting room'. Additionally the lung support worker contacts the patient prior to virtual oncology appointments and guides them through the iPOS holistic needs assessment to ensure it is available to the clinical team prior to the consultation, also identifying patients who would benefit from joint assessment with the enhanced supportive care team

Prior to the COVID-19 pandemic, lung cancer nurse specialists often met patients pre-diagnosis and then again at subsequent appointments providing support and continuity. With an increase in remote consultations, teams must develop ways of working that ensure the patient is not disadvantaged by remote consultations, continuing to provide multidisciplinary input as needed.

Rapid national guidance for bronchoscopy and EBUS was developed and published by the BTS to support decisions around safe aerosol-generating procedures, and to make recommendations regarding appropriate pre-test screening. Although bronchoscopy and EBUS have been impacted, we noted that for the most part these services continued with minimal interruption for patients with suspected lung cancer, albeit with more restricted access for procedures done in benign disease, such as sarcoidosis. This contrasts sharply with upper and lower gastrointestinal (GI) endoscopic tests which were stopped almost entirely for both malignant and benign disease.

Several lung cancer teams commented that they were having to compete for space in the endoscopy unit now that GI teams were trying to catch up on their backlog. Furthermore, the infection-control guidance issued around carrying out bronchoscopic procedures during COVID-19 has increased the complexity and reduced overall capacity.<sup>60</sup> Turnaround time between procedures has suffered where negative pressure facilities are not available which has further compounded the pressure for space in endoscopy. This is likely to significantly impact on national outcomes for lung cancer patients unless steps are taken to ensure that adequate time is scheduled for lists to go ahead without compromising the quality of the diagnostic pathway. The development of community diagnostic hubs may improve capacity as long as it is adequately resourced.<sup>61</sup>

# Treatment

Current recommendations for the approach to treatment have been published by the CEG and NICE (NG 161 and 162).<sup>62</sup> During the first wave, pressure on hospital infrastructure and workforce led to recommendations for stratification of priority for treatment based on overall likely benefit. Subsequently, these NICE recommendations have been revised to incorporate interim treatments where these offer a safer alternative to normal standard of care and best practice treatment.

We are aware that during the first wave there was sometimes reduced access to surgical lists and to Intensive Care Unit beds, and as a result a number of patients chose to have SABR or chemotherapy/radiotherapy as an alternative treatment. The results of an ongoing national audit to monitor rates and outcomes of radical radiotherapy treatment and how they might have changed because of the pandemic are important. Furthermore, fears about the impact of a COVID-19 infection on patients undergoing treatment with cytotoxic chemotherapy led to additional approval for some targeted therapies and alterations of some treatment delivery schedules which has freed up some capacity in oncology clinics. These included:

- omitting adjuvant chemotherapy;
- reducing the number of cycles of chemotherapy;
- prolonging the dosing schedules of immunotherapy based on pharmacological data but outside license;
- approval of targeted oral agents and funding of immunotherapy for expanded indications to avoid the use of cytotoxic immunosuppressive regimens;
- radiotherapy treatment volumes being planned on radiological criteria rather than the gold standard staging EBUS;
- less rigid approach to pre-treatment pathological confirmation, by using Herder score and frozen section for intraoperative confirmation;
- using hypo-fractionated radiotherapy regimens where possible.

Whilst the oncology community welcomed the access to targeted agents many other mitigations represented a compromise against best practice. The impact of these changes may not be realised for a number of years.

https://www.roycastle.org/bronchoscopy-services-during-the-COVIDpandemic-v2-1/

<sup>&</sup>lt;sup>60</sup> Lung Cancer CEG (2020) Recommendations for day case bronchoscopy services during the COVID-19 pandemic.

<sup>&</sup>lt;sup>61</sup> Sir Mike Richards (2020) Diagnostics: Recovery and Renewal. https://www.england.nhs.uk/wp-content/uploads/2020/11/diagnostics-recovery-and-renewal-independent-review-of-diagnostic-services-for-nhs-england-2.pdf
<sup>62</sup> Lung cancer CEG (2020) Lung cancer and mesothelioma service guidance during the COVID-19 pandemic.

https://www.roycastle.org/COVID-19-lung-cancer-pathway-recovery-v2-1/

# Multidisciplinary workforce pressures

As mentioned elsewhere, there are significant workforce pressures that impact on the lung cancer pathway, and these have been exacerbated by the pandemic. Respiratory physicians have been heavily involved in the frontline response to hospital admissions, with some of their time being diverted to manage inpatients with COVID-19 pneumonia, to implement 'long-COVID' clinics, and to deal with the backlog of elective work that was postponed from the first wave. For all staff, there have been much higher rates of absence from work, either due to actual COVID-19 infection, or the need for self-isolation after a contact. Some of the clinical workforce was redeployed during the first wave to areas of greater need, such as intensive care or respiratory wards. This has remained the case in the subsequent peaks of high disease prevalence. Teams have worked incredibly flexibly to blend roles and responsibilities within the MDT to compensate for staffing changes as a result of the pandemic, and this will need to continue for some time. There are further opportunities to maximise the use of technology to collate clinical information. The need for enhanced written and other forms of communication cannot be overemphasised.

As mentioned above, rules around social distancing in the workplace led to a widespread and rapid adoption of virtual MDT meetings usually based around video-conferencing software such as Microsoft Teams. As well as the reduction in potential exposure of staff to COVID-19, virtual MDMs should improve overall attendance of core and non-core members, and result in less travelling time for some specialists freeing up their time for clinical work. We do recognise, however, that there are significant challenges in implementation:

- The IT infrastructure must be adequate to allow 'switch on and go', with video, audio and bandwidth of adequate quality and specification for radiological imaging and digital pathology and to prevent dropouts during important conversations.
- It can be more difficult to ensure that all members of the MDT feel able to input into the discussions, and the skill of chairing the meeting and ensuring inclusiveness becomes even more important.
- Streamlining of the MDM is even more important to enable focus and concentration and consideration should be made to splitting out longer meetings into shorter, more frequent ones perhaps with differing core membership. That said, it remains essential that all 'treating' members of the team are present for all treatment discussions to avoid selection bias.
- As new members join the MDT, consideration must be given to how those individuals are integrated fully without the benefit of face to face meetings.
- Many trusts offered health and wellbeing events and support groups prior to the COVID-19 pandemic, however these were predominantly face-to-face, requiring patients to travel to either the hospital or local meeting points to access them. The pandemic led teams to develop innovative ways of continuing these events.

## **CASE STUDY**

The **Wirral University Teaching Hospital** has developed an increasing package of virtual support, education and health and wellbeing events virtually that have been well attended and well evaluated. The benefits of continuing these will be the inclusion of patients who may not otherwise have been able to access them.

# Recommendations

Recommendation	Actions	Owners	Timescale
<b>33.</b> National bodies and local lung cancer services should continue to respond to the challenges presented by the COVID-19 pandemic.	<b>a</b> Pilot lung health checks must be reactivated at the earliest opportunity.	PHE	6 months from publication
	<b>b</b> Local and national campaigns should be launched to increase awareness of lung cancer symptoms among patients and primary healthcare teams during the pandemic and to increase confidence in the ability of secondary care teams to respond.	PHE	1 year from publication
	<b>c</b> Adoption of streamlined diagnostic pathways as outlined in the report should be accelerated.	Trusts	6 months from publication
	<b>d</b> The impact of altered treatment options or delivery schedules should be audited.	Chemotherapy CRG, academic groups	1 year from publication
	e Flexibility in provision of face-to-face versus remote consultation should be maintained.	Trusts	3 months from publication
	<b>f</b> Increased use of virtual MDMs should be supported by investment in IT infrastructure.	Trusts	6 months from publication

# **Potential impact**

The primary purpose of a GIRFT workstream is to identify unwarranted clinical variation and make recommendations to reduce the variation through quality improvement measures.

Quality improvement often leads to more effective use of resources, and we have identified a number of areas during our review where we believe that implementation of our recommendations will lead to cost efficiencies being delivered to the NHS as a whole.

The key areas that are likely to result in a financial opportunity are:

# **Earlier diagnosis**

By increasing the proportion of patients who are diagnosed early, the cost burden on the NHS of treatment for lung cancer patients is reduced. At present, up to 35% patients diagnosed with lung cancer present as an emergency with their disease. Improving earlier diagnosis and 'stage-shifting' presentation would impact positively on bed days occupied as a result of a delayed lung cancer diagnosis and reduce need for palliative and social care support in the community. Moreover, by diagnosing a greater proportion of patients at a stage where they can be treated with curative intent, significant cost savings in systemic therapy with palliative intent will be realised.

# Litigation

We have already described the governance challenges around a missed lung cancer diagnosis picked up incidentally on a CT scan or X-ray. A well-developed and resourced nodule pathway should lead to a reduction in patients lost to follow-up as a result of not being the formal responsibility of a medical team, and the resultant litigation costs that are subsequently borne by the NHS.

# Workforce

By reviewing the skill mix of teams, and investing in innovative new roles, the overall cost of providing the lung cancer service can be reduced, or at least stabilised in an era of expanding clinical workload. In many cases, we saw tasks carried out by overly skilled personnel, or a lack of flexibility of job descriptions within Agenda for Change banding. There are potential opportunities to capitalise on staff working across traditional organisational boundaries, particularly where neighbouring trusts may look to use substantively employed and suitably skilled staff in a joined up manner across a region or Cancer Alliance. The implementation of wider honorary contracts or 'NHS passports' would see potential benefits on the costs of employing a temporary workforce and allow scarce resources to be shared across a network.<sup>62</sup>

# **MDM** streamlining

An MDM is an expensive meeting. Reducing the number of patients discussed, and the number of times that each patient is discussed, will release clinical time which can be diverted to other aspects of patient care.

# Chemotherapy

We saw a wide range of variation in the published NHS reference costs for chemotherapy. We heard in deep dives that some trusts with lower costs were providing in-house chemotherapy, suggesting a more cost-effective service. However, reference costs for care were universally poorly understood by clinical teams across our visits. Working more closely with the financial departments responsible for costing care would allow potential opportunities for savings to be identified by those with responsibility for clinical care.

## **Enhanced supportive care**

A formally commissioned ESC service should reduce admissions to hospital, reduce length of stay and lead to a reduction in the costs of chemotherapy realising cost savings across the healthcare system.

# **Biopsy**

Ensuring the most appropriate type of biopsy is selected initially will reduce the costs of a second procedure, reducing valuable patient and clinical time, admissions and patient morbidity or mortality.

Getting It Right First Time (GIRFT) is a national programme designed to improve treatment and care by reviewing health services. It undertakes clinically led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal, they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after the pilot programme, it delivered an estimated £30m-£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model has been applied in more than 40 different areas of clinical practice. It consists of four key strands:

- A broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors;
- A series of discussions between clinical specialists and individual hospital trusts, which are based on the data –
  providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area
  of practice, in the context of the national picture. This then enables the trust to understand where it is performing well
  and what it could do better drawing on the input of senior clinicians;
- A national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for improvement across the relevant services;
- An implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

# **GIRFT** and other improvement initiatives

GIRFT is part of an aligned set of workstreams within NHS England and NHS Improvement. It is the delivery vehicle for one of several recommendations made by Lord Carter in his February 2016 review of operational efficiency in acute trusts across England.

The programme has the backing of the Royal Colleges and professional associations and has a significant and growing presence on the Model Hospital portal, with its data-rich approach providing the evidence for hospitals to benchmark against expected standards of service and efficiency. The programme also works with a number of wider NHS programmes and initiatives which are seeking to improve standards while delivering savings and efficiencies.

# Implementation

GIRFT has developed an implementation programme designed to help trusts and their local partners to address the issues raised in trust data packs and the national specialty reports to improve quality. The GIRFT team provides support at a local level through the NHS England regional teams, advising on how to reflect the national recommendations into local practice and supporting efforts to deliver any trust specific recommendations emerging from the GIRFT visits. GIRFT also helps to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice. Through all its efforts, local or national, the GIRFT programme strives to embody the 'shoulder to shoulder' ethos that has become GIRFT's hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

## Ablation therapy

Radiofrequency ablation (RFA) and microwave ablation (MWA) are treatments that use image guidance to place a needle through the skin into a tumour within the chest. The heat generated destroys the lung cancer cells.

## Adjuvant therapy

Treatment given in addition to the primary (initial) cancer treatment to lower the risk of cancer recurring.

## British Thoracic Oncology Group (BTOG)

The British Thoracic Oncology Group is a multidisciplinary group for healthcare professionals involved with thoracic malignancies throughout the UK.

## British Thoracic Society (BTS)

The BTS is a charity whose objective is to improve lung health by influencing national policy, championing excellence in diagnosis and treatment and working in partnership with key stakeholders.

## **Cancer Alliances**

Cancer Alliances bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography. Together with the National Cancer Vanguard, they will lead the local delivery of the Independent Cancer Taskforce's ambitions for improving services, care and outcomes for everyone with cancer.

## Cardiopulmonary exercise testing (CPET)

A non-invasive simultaneous measurement of the cardiovascular and respiratory system during exercise to assess a patient's exercise capacity.

## Chemotherapy

Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing. Chemotherapy may be given by mouth, injection, or infusion, or on the skin, depending on the type and stage of the cancer being treated.

## Clinical Commissioning Groups (CCGs)

Clinically led statutory NHS bodies responsible for the planning and commissioning of healthcare services for their local area.

## Commissioning

The process through which the health needs of the local population are identified and the services purchased and reviewed to meet those needs.

#### Comorbidity

The simultaneous presence of two or more chronic (long-term) diseases or conditions in a patient.

## СТ

A CT scan or computerised tomography scan makes use of computer-processed combinations of many X-ray measurements taken from different angles to produce cross-sectional images of specific areas of a scanned object, allowing the user to see inside the object without cutting.

#### Day case

When a patient is admitted electively for care that day, without the use of a hospital bed or overnight stay.

## Endoscopic Bronchoscopic Ultrasound (EBUS)

A procedure that allows the doctor to look into the lungs and take samples of the glands in the centre of the chest (mediastinum) using the aid of an ultrasound scan.

#### EGFR

A gene that makes a protein that is involved in cell growth and cell survival. Mutated (changed) forms of the EGFR gene and protein have been found in some types of cancer, including non-small cell lung cancer.

#### **Elective surgery**

Surgery that is scheduled (planned) rather than an emergency.

#### Endoscopy

An umbrella term for any procedure where the inside of your body is examined using an endoscope. Bronchoscopy is a type of endoscopy.

#### External beam radiotherapy

External radiotherapy uses a machine outside the body to direct radiation beams at cancer to destroy it.

## **Faster Diagnosis Standard**

The new Faster Diagnosis Standard was introduced by NHS England in April 2020 to ensure that all patients who are referred for the investigation of suspected cancer find out, within 28 days, if they do or do not have a cancer diagnosis.

#### Genomic analysis

The identification, measurement or comparison of genomic features such as DNA sequence, structural variation, gene expression, or regulatory and functional element annotation at a genomic scale.

## **Genomic Laboratory Hub**

Genomic testing in the NHS is being provided through a national testing network, consolidating and enhancing the existing laboratory provision. The national genomic testing service is delivered through a network of seven Genomic Laboratory Hubs (GLHs), each responsible for co-ordinating services for a particular part of the country.

## Hospital Episode Statistics (HES)

Data collected by NHS Digital for each episode of admitted patient care in England.

# Holistic Needs Assessment/Personalised Care and Support Plans

Personalised care and support planning (based on holistic needs assessments) ensures people's physical, practical, emotional and social needs are identified and addressed at the earliest opportunity.

## Health & Wellbeing Information & Support

Health and wellbeing information and support includes the provision of accessible information about emotional support, coping with side effects, financial advice, getting back to work and making healthy lifestyle choices. This support will be available before, during and after cancer treatment.

## Health Education England (HEE)

The public body responsible for the planning, recruiting, training and education of NHS staff. This is achieved through Local Education and Training Boards.

## Healthcare Quality Improvement Partnership (HQIP)

An independent organisation led by the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices.

#### www.hqip.org.uk

## Imaging

Medical imaging is the technique and process of creating visual representations of the interior of a body for clinical analysis and medical intervention, as well as visual representation of the function of some organs or tissues.

## Integrated care systems (ICSs)

NHS organisations, in partnership with local councils and others, taking collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.

## Intensity Modulated Radiation Therapy (IMRT)

A type of three-dimensional radiation therapy that uses computer-generated images to show the size and shape of the tumour. Thin beams of radiation of different intensities are aimed at the tumour from many angles. This type of radiation therapy reduces the damage to healthy tissue near the tumour.

## Interquartile range (IQR)

The interquartile range is a measure of variability, based on dividing a data set into quartiles. Quartiles divide a rank-ordered data set into four equal parts. The values that divide each part are called the first, second, and third quartiles; and they are denoted by Q1, Q2, and Q3, respectively.

The interquartile range is equal to Q3 minus Q1.

## Interventional radiology

A range of techniques that use radiological images to diagnose and treat diseases in a minimally invasive way.

## Length of stay

The number of days that a patient is in hospital as an inpatient. Can be pre-operative, post-operative, or the sum of both.

## Lung Cancer Clinical Expert Group (CEG)

An expert group of people, including clinicians, academics, commissioners, patient and public representatives and nurses

## Lung cancer specialist nurse (LCSN)

Clinical nurse specialists are advanced practice nurses who work as part of a multidisciplinary team.

They provide high quality, patient-centred, timely and cost-effective care. They also provide education and support for patients to manage their symptoms.

## Lung nodule

A lung nodule is a small growth on the lung and can be benign or malignant. The growth usually has to be smaller than three centimetres to qualify as a nodule.

## Lung screening programme

A targeted lung cancer screening programme selects participants from a local population at high risk of lung cancer and offers low dose CT scans to eligible subjects.

## MDT

Multidisciplinary team. A group of healthcare workers who are members of different disciplines (e.g. psychiatrists, social workers, etc.), each providing specific services to the patient. In this document, it typically refers to multidisciplinary teams for cancer care.

#### MDM

The multidisciplinary team meeting is central to the communication and co-ordination processes and it is the place where clinical, investigative, and technical treatment information is integrated and debated, and patient centred recommendations determined.

#### Mediastinum

Area found in the midline of the thoracic cavity, that is surrounded by the left and right pleural sacs. It is divided into the superior and inferior mediastinum, of which the latter is larger.

## **Model Hospital**

A free digital tool provided by NHS Improvement to enable trusts to compare their productivity and identify opportunities to improve. The tool is designed to support NHS provider trusts to deliver the best patient care in the most efficient way.

#### https://model.nhs.uk

#### Mortality and morbidity (M&M) meetings

Meetings where clinical staff can discuss issues in recent care, share insights and learn lessons from clinical outcomes. The aim is to improve patient care.

#### MRI

Magnetic resonance imaging (MRI) use strong magnetic fields, magnetic field gradients, and radio waves to generate images of the organs in the body.

# National Cancer Registration and Analysis Service (NCRAS)

NCRAS is run by Public Health England. It is responsible for cancer registration in England to support cancer epidemiology, public health, service monitoring and research.

# National Institute for Health and Care Excellence (NICE)

Provides evidence-based guidance, advice, quality standards, performance metrics and information services for health, public health and social care.

#### www.nice.org.uk

#### National Lung Cancer Audit

The National Lung Cancer Audit (NLCA) is commissioned by the Healthcare Quality Improvement Partnership and works with a number of specialists to collect hospital and healthcare information and report on how well people with lung cancer are being diagnosed and treated in hospitals across England and Wales.

#### Oncology

The branch of medicine concerned with the prevention, diagnosis, and treatment of cancer.

#### **Operational Radiotherapy Delivery Networks**

There are 11 operational delivery networks (ODNs) for radiology covering the geography of England. Each Network is tasked with providing radiotherapy system leadership and the delivery of NHS England's vision and ambitions for the modernisation of radiotherapy services.

#### PACS (Picture Archiving and Communication System)

Medical imaging technology which provides economical storage and convenient access to images from multiple modalities.

#### **Palliative care**

Care given to improve the quality of life of patients who have cancer. Palliative care addresses the person as a whole, not just their disease. The goal is to prevent or treat, as early as possible, the symptoms and side effects of the disease and its treatment, in addition to any related psychological, social, and spiritual problems.

#### Pathology

The branch of medicine that deals with the laboratory examination of samples of body tissue for diagnostic or forensic purposes.

#### Pathway

An agreed set of evidence-based practices and interventions for a specific patient group.

#### Percutaneous

Any medical procedure where access to inner organs or other tissue is done via needle-puncture of the skin, rather than by using an 'open' approach where inner organs or tissue are exposed.

## Performance status (PS)

A measure of how well a person is able to carry on ordinary daily activities while living with cancer, providing an estimate of what treatments a person may tolerate.

## Personalised stratified follow-up (PSFU)

PSFU means that when a person completes their primary treatment, they will be offered information on what to look out for which could suggest their cancer has recurred, rapid re-access to their cancer team, regular surveillance and personalised care and support planning.

## **PET-CT** scan

Positron emission tomography (PET) scans produce detailed three-dimensional images of the inside of the body. The images can clearly show the part of the body being investigated, including any abnormal areas, and can highlight how well certain functions of the body are working. PET scans are often combined with CT scans to produce even more detailed images. This is known as a PET-CT scan.

## **Pleural disease**

Pleural disease occurs in the pleural space, which is the thin fluid-filled area in between the two pulmonary pleurae in the human body. There are several disorders and complications that can occur within the pleural area, and the surrounding tissues in the lung

## Prehabilitation

Prehabilitation prepares people for cancer treatment by optimising their physical and mental health through needs-based prescribing of exercise, nutrition, and psychological interventions.

## **PROMs**

Patient Recorded Outcome Measures assess the quality of care delivered to NHS patients from the patient perspective. PROMs have been collected by all providers of NHS-funded care since April 2009.

#### https://www.england.nhs.uk/statistics/statistical-workareas /proms/

## **Radical treatment**

Radical treatment is anti-cancer therapy which is given with the intention to either eradicate the cancer or provide a long disease-free period, as opposed to palliative treatment where there is no expectation of cure.

## Radiographer

Healthcare professionals who specialise in the imaging of human anatomy for the diagnosis and treatment of pathology.

## Radiologist

A doctor who specialises in diagnosing and treating disease and injury, using medical imaging techniques.

#### **Reference costs**

The average unit cost to the NHS of providing defined services to NHS patients in England in a given financial year. They show how NHS providers spend money to provide healthcare to patients. NHS providers submit reference costs annually.

#### Rehabilitation

Rehabilitation is provided by trained professionals with the goal of keeping patients active and able to participate as far as possible in work, family and other life roles. Its aims include reducing side effects and symptoms, maintaining independence and improving quality of life.

## Reporting

In radiology, reporting refers to the completed imaging being analysed and a written report being delivered to explain what the imaging shows.

#### Resection

A surgical procedure to remove part of an organ or gland, as a sub-type of a resection which might involve removing the whole body part. It may also be used to remove a tumour and normal tissue around it.

#### **Respiratory medicine**

The branch of medicine (as opposed to surgery) concerned with disorders of the respiratory (breathing) system, the lungs and the diaphragm.

## Royal College of Pathologists (RCPath)

A professional membership organisation, concerned with all matters relating to the science and practice of pathology. The College oversees the training of pathologists and scientists working in 17 different specialties, which include cellular pathology, haematology, clinical biochemistry and medical microbiology.

## Royal College of Radiologists (RCR)

Leads, educates and supports doctors who are training and working in the specialties of clinical oncology and clinical radiology.

## Society for Cardiothoracic Surgery (SCTS)

The independent, self-funded, representative body for cardiothoracic surgery in Great Britain & Ireland.

## Society of Radiographers (SoR)

A professional body and trade union that represents more than 90% of the diagnostic and therapeutic radiographers in the UK.

## **Specialised services**

Services that are not offered in all hospitals and so are not commissioned by CCGs. Instead, they are commissioned centrally by NHS England.

www.england.nhs.uk/commissioning/spec-services

## Stereotactic Ablative Body Radiotherapy (SABR)

SABR is a highly focused radiation treatment that gives an intense dose of radiation concentrated on a tumour, while limiting the dose to the surrounding organs.

## Stereotactic radiosurgery (SRS)

Stereotactic radiosurgery (SRS) is a non-surgical radiation therapy used to treat functional abnormalities and small tumours of the brain.

## **Tertiary unit**

A hospital that provides specialised consultative health care (as opposed to a primary or secondary healthcare provider).

## Thoracoscopy

Thoracoscopy is the visual examination of the lung surfaces and pleural space through a viewing tube (a thoracoscope).

## **Treatment summary**

A document produced by secondary care cancer teams, usually following treatment for cancer. It is designed to be shared with the patient, their GP and any other professionals the patient may choose, with the aim of highlighting essential treatment information.

## Ultrasound

Medical ultrasound is a diagnostic imaging technique used to create an image of internal body structures such as tendons, muscles, joints, blood vessels, and internal organs.

## **UK Lung Cancer Coalition**

The UKLCC is a multi-interest group campaigning for improvements in survival from lung cancer.

## Video-assisted thoracic surgery (VATS)

Thoracic surgery performed using a video camera inserted into the patient's chest via small incisions.

## X-ray

A form of electromagnetic radiation that can pass through most objects, including the body. Medical X-rays are used to generate images of tissues and structures inside the body. We would like to acknowledge the key support we have had in developing this national report. Project managers Caroline Ager and Yvonne Frewin have kept us organised, arranging deep dives across the country, and then by video-conference when COVID-19 struck. Analyst and report editor Matt Colmer has shown great patience in bringing together this national report, with five clinical leads all providing their own insights and opinions.

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Victoria Anderson, Monica Hugh - Specialist Nursing Leads.

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The full report and executive summary are also available to download as PDFs from: www.GettingltRightFirstTime.co.uk