Gaining perspective: What can the UK learn from lung cancer care in Europe?

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Thanks

Bristol-Myers Squibb and the Roy Castle Lung Cancer Foundation would like to thank the following UK lung cancer experts, European clinical witnesses, and UK specialist reviewers for their participation in this project.

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Executive summary

Lung cancer is the most common cause of cancer deaths in the UK and worldwide.\textsuperscript{1,2}

In 2016, the UK Lung Cancer Coalition (UKLCC) published \textit{25 by 25: A ten-year strategy to improve lung cancer survival rates}. The report made recommendations to improve the UK’s lung cancer five-year survival rate to 25 per cent by 2025. A key recommendation noted the potential for gathering insights on lung cancer care from across Europe, to inform improvements in care in the UK.

This report draws upon evidence from a number of European countries and considers how best practice in national policy-making, clinical practice and patient experience may help improve outcomes in the UK.

The evidence was gathered by a group of expert UK lung cancer clinicians and a patient advocacy specialist, through interviews with leading clinicians from four European countries (Denmark, France, the Netherlands and Sweden).

Following the interviews, the group developed recommendations across:

• National strategy and prevention
• Patient pathway – guidelines
• Routes to referral and diagnosis
• Access to treatment
• Data collection and evaluation
• Patient involvement
• Lung cancer workforce

The recommendations are designed to be realistic and implementable, targeted towards relevant policy-makers and NHS bodies that can effect change.

To address the pervasive issue of late stage diagnosis and lower survival rates in the UK,\textsuperscript{3,4} we must learn from European partners in areas such as access to molecular testing, treatment and better centralisation of services. However, there also exists good practice in the UK from which other European nations may learn. As the evidence in this report shows, patients in the UK are regularly listened to and involved in decisions around their treatment and care, and clinical nurse specialists are used effectively to improve patients experience.

Although there is no ‘one size fits all’ approach for lung cancer patients, all the individuals involved in the development of this report share the goal of improved lung cancer outcomes across the UK. By gaining perspective on the treatment, care and experience of patients elsewhere, we can celebrate best practice at home and learn how to drive up standards for the future.

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We have developed the following recommendations for policy-makers, based upon the written and oral evidence gathered as part of this project. Their overall aim is to support the delivery of the UKLCC’s ambition to improve five-year lung cancer survival rates to 25 per cent by 2025.
National strategy and prevention

- The UK Departments of Health should continue to recognise the significant need for investment in efforts to tackle lung cancer. As each cancer strategy is renewed, lung cancer must remain a priority with additional expertise and resources dedicated to improving lung cancer diagnosis, care, and treatment across the pathway. The complexity of current lung cancer management that results from the identification of multiple subtypes should also be recognised.
- UK governments should urgently re-prioritise smoking prevention and cessation services and ensure that they are sufficiently funded, to address concerns raised by some local authorities in England.
- Lung cancer and smoking prevention and cessation should be prioritised in the NHS Long Term Plan in England. There should also be funding plans for Northern Ireland, Scotland, and Wales.
- We encourage continued support for public awareness campaigns on the symptoms of lung cancer, recognising the impact of the Be Clear on Cancer lung cancer campaigns 2011-2014 in England and the Detect Cancer Early campaign in Scotland.

Patient pathway – guidelines

- NHS England should allocate funding to collect, analyse and share data on the implementation of the National Optimal Lung Cancer Pathway and Clinical Advice to Cancer Alliances for the Commissioning of the whole Lung Cancer Pathway to identify barriers to their adoption and to allow lessons to be shared between NHS Trusts.
- We urge policy-makers in the devolved nations to consult on, develop and implement optimal lung cancer pathways for their respective countries.
- Policy-makers should refocus their efforts on identifying variations in care at both the patient and population level. We support the roll out of NHS England’s Getting It Right First Time (GIRFT) and RightCare programmes and encourage similar programmes across Northern Ireland, Scotland, and Wales. This will allow a renewed focus on areas such as waiting times to ensure that patients are able to get into the system quickly, regardless of where they live.

Routes to referral and diagnosis

- We recommend that all two-week wait referrals adhere to the National Optimal Lung Cancer Pathway’s recommendation for Computerised Tomography (CT) in people who are at high risk despite a normal chest X-ray.
- We encourage the implementation of Lung Health Check pilots across the devolved nations, which include targeted screening of high-risk people with low radiation dose CT. The latter should follow the UK Lung Cancer Screening Trial recommendation for a minimum dataset to facilitate a UK-centred body of evidence on the effectiveness and the role of low-dose CT.
- Pathology laboratories should audit their turnaround times for diagnosis of lung cancer type and molecular testing results, with a view to being compliant with the goals of the National Optimal Lung Cancer Pathway.
- Policy-makers should consider the development of a Quality Assurance process to ensure consistency in tissue sampling across the UK. This should be developed with the British Thoracic Society, Royal College of Pathologists and the Royal College of Radiologists. This QA process would gather data on the number of procedures and allow an audit of biopsy success rates.
Routes to referral and diagnosis (continued)

• The UK should establish a national programme of molecular testing of lung cancers to ensure that all patients have timely access to high-quality diagnostics, giving them the best opportunities to receive the optimum treatment. The programme should be responsive to the introduction of new biomarkers.

• All patients should have access to a full range of analysis and staging investigations, delivered in a timely fashion to ensure compliance with the National Optimal Lung Cancer Pathway.

Access to treatment

• Centralisation of lung cancer surgery is associated with improved peri-operative outcomes and can facilitate both cost efficiency and sustainable workforce planning. Steps should be taken to achieve the NHS England minimum unit size of 150 cancer resections per year.

• We encourage the creation of a pilot study to examine the impact of an oncogene addicted/mutation driver specialist Multi-Disciplinary Team (MDT) for rare mutations, so that patients might have access to specialised treatments or clinical trials.

• As systemic anti-cancer therapies for lung cancer change, the appraisal system must be nimble enough to allow swift access for patients to innovative medicines. We support efforts to produce treatment guidance within 90 days of European marketing authorisation across the UK.

• All treatment options should be available to patients based on their clinical need and not restricted by their ability to travel to a centre. While we recognise different devolution of health policy, with different processes and delivery across the UK to access medicines, we feel this should not be a justification for ‘postcode lotteries’.

• Appropriate travel support should be made available to patients who need it, as outlined in the Lung Cancer Clinical Expert Group’s 2017 service guidance, to ensure that there are not any additional barriers to them accessing treatment.

• Investment must be made to ensure that all patients for whom it is suitable can access up to date radiation oncology treatments and techniques including chemo-radiotherapy, Intensity Modulated Radiotherapy (IMRT), Image Guided Radiotherapy (IGRT) and Stereotactic Ablative Radiotherapy (SABR). These should be made available at every radiotherapy centre, with decisions being made by appropriately trained clinicians based on each patient’s needs.
Gaining perspective: Recommendations

Data collection and evaluation

• Patient reported outcome measures and quality of life indicators should continue to be recorded and integrated with other datasets by the National Cancer Registration and Analysis Service (NCRAS) in England and their equivalents in Northern Ireland, Scotland and Wales. We urge NCRAS and other UK bodies to support and encourage the adoption of the International Consortium for Health Outcomes Measurement (ICHOM) Standard Set for Lung Cancer.

• Data on the molecular pathology of lung cancers should be collected routinely and linked to other national lung cancer data to make it possible to monitor the success of such a programme. The experience of France has shown that large scale molecular profiling can deliver improved outcomes for patients.

• The National Lung Cancer Audit (NLCA) and Lung Cancer Clinical Outcomes Publication (LCCOP) should be re-commissioned beyond its current end-date of March 2020 and be fully adopted by Scotland and Northern Ireland, with data made available for full integration into the NLCA reports.

Patient involvement

• We encourage UK policy-makers to design patient-centric services, based on feedback that is actively sought from both patients and carers. They should be able to be as involved as they want to be in decision-making around their care and feel able to request optimal lung cancer care.

• Evidence suggests involving patients in their care generally leads to better outcomes. The UK should undertake research to understand why UK lung cancer outcomes remain poor, despite the greater general involvement of patients in their care pathway, than in some European countries.

Lung cancer workforce

• We recommend that NHS England and NHS Scotland implement their cancer workforce plans as soon as possible, to limit the impact of vacancies on the clinical oncology, pathology, radiology and surgery workforces and the challenges with training new staff that this could lead to. We also support the development of the Wales Cancer Network’s cancer workforce plan.

• We welcome the news of research into the role of lung cancer specialist nurses and encourage greater investment in the lung cancer specialist nurse and Allied Health Professional (AHP) workforces, given their essential role in improving patient experience and outcomes.

• We support efforts to achieve the NLCA’s target of 90 per cent or more patients being seen by a lung cancer specialist nurse.
Lung cancer is the most common cause of cancer deaths both worldwide and in the UK. In 2016 there were 35,620 lung cancer deaths in the UK – over a fifth of all cancer deaths.
Main types of lung cancer

87%
Non-small cell lung cancer (NSCLC)
- Roughly 87 per cent of all lung cancers
- Three types: adenocarcinoma, squamous cell cancer, large cell carcinoma
- There are also a number of histological sub-types of NSCLC based on molecular markers, including EGFR, ALK and ROS-1, plus markers of immunological status, namely PD-1 and PD-L1

12%
Small cell lung cancer (SCLC)
- Approximately 12 per cent of all lung cancers
- Very strongly linked to smoking

Between 1971-1972 and 2010-2011 the men’s ten-year lung cancer survival rate in England and Wales has shown no improvement while women’s ten-year survival has only increased from three per cent to seven per cent. There has been an improvement in one year, and predicted five-year survival in recent years (1995-2012), but as Table 1 demonstrates the UK has performed relatively poorly in comparison with other European countries. The chance of a UK lung cancer patient surviving beyond five years is currently around four per cent lower than in the rest of Europe. The EUROCare-5 study found that between 1990-2007 the UK’s and Ireland’s 5-year survival rate was the second worst in Europe.

The urgent need to improve the UK’s lung cancer outcomes is clear and was addressed by the UK Lung Cancer Coalition’s (UKLCC’s) 2016 report, 25 by 25: A ten-year strategy to improve lung cancer survival rates. This Gaining perspective on lung cancer report, funded by Bristol-Myers Squibb and developed with the Roy Castle Lung Cancer Foundation (RCLCF), is intended to support the Strategy’s 11th principle: 'UK-wide taskforce set-up involving those across the lung cancer community, and led by the UKLCC, to set out renewed nation-specific recommendations for improving five-year survival based on learnings from existing European working groups (such as the Cancer Benchmarking Partnership and the European Lung Foundation) and in line with European best practice and standards. UK governments to commit to taskforce recommendations for achievement by 2025.'

Table 1 – Comparative lung cancer indicators from UK and European countries (note: the time periods and sources for data differ because it was not always possible to use the same dataset)
While lung cancer as a whole is a common disease, many of the recently identified sub-types (based on molecular markers) are rare. Therefore, the management of lung cancer is now a very specialised clinical area, with resulting implications for service delivery.

This report is based on evidence heard by a group of UK lung cancer clinicians and a patient advocacy specialist, through interviews with leading clinicians from four European countries (Denmark, France, the Netherlands and Sweden). Full details of the methodology, including the limitations, are included at the end of the report.

Figure 1 shows that while Denmark’s rate of improvement, in its five-year survival rate, out-performed that of the UK between 2005 and 2014, the UK was ahead of the other countries. However, for the overall five-year net survival rate, the UK lagged behind all of them by at least 3.3 per cent.

Learning from the experiences of a range of European countries will help to identify changes to services in the UK that can make a difference to lung cancer patients. Improvements throughout the pathway, from suspicion and investigation onwards, will affect patients’ experiences and their likelihood of survival.

Age-standardised five-year net survival (NS, per cent): adults (15–99 years) diagnosed with lung cancer by period of diagnosis

Figure 1 - Data obtained from CONCORD-3\(^3\)
National strategy and prevention

The development of a National Cancer Plan (NCP) can highlight a political focus on tackling the disease. By providing clear guidance, a delivery framework and sometimes metrics for measuring achievement NCPs demonstrate the priority attached to improving outcomes. The World Health Organization (WHO) has called for the development of NCPs to tackle cancer as a non-communicable disease (NCD). Each of the countries in this report has implemented a range of cancer plans and strategies, set out in Table 2 below:

<table>
<thead>
<tr>
<th>Country</th>
<th>Key national cancer/prevention plan(s)</th>
<th>Priorities</th>
<th>Recommendations of relevance to lung cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>Cancer Plan IV 2017–2020</td>
<td>16 initiatives focusing on prevention, early detection, access to innovative treatments and equity of care</td>
<td>Two of the initiatives focus on tackling smoking in young people and helping cancer patients to give up smoking</td>
</tr>
<tr>
<td>France</td>
<td>Cancer Plan 2014–2019</td>
<td>• Promoting early diagnosis and guaranteeing access for all to quality medicine and innovation</td>
<td>Improving smoking prevention is identified in the plan’s recommendations</td>
</tr>
<tr>
<td>Netherlands</td>
<td>National Cancer Control Programme 2005–2010, National Prevention Programme 2014–2016</td>
<td>• Ensuring that as few people as possible develop cancer, • Ensuring that those who do are diagnosed early and receive adequate care and support, • Ensuring that patients and those close to them have as good a quality of life as possible</td>
<td>The National Cancer Control Programme identified the reduction of smoking as the best way to control cancer</td>
</tr>
</tbody>
</table>

Table 2 – Key national cancer/prevention plan(s) in Denmark, France, the Netherlands and the UK
**Sweden**

**Key national cancer/prevention plan(s)**

_A National Cancer Strategy for the Future 2009–2014^31_

**Priorities**

- Reducing the risk of developing cancer
- Improving the quality of cancer patient management
- Prolonging survival time and improving quality of life after a cancer diagnosis
- Reducing regional differences in survival time after a cancer diagnosis
- Reducing differences between population groups in morbidity and survival time

**Recommendations of relevance to lung cancer**

There are no specific lung cancer recommendations

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**United Kingdom**

**Key national cancer/prevention plan(s)**

Due to the devolution of responsibility for healthcare policy in the UK, each of the four nations can determine if it requires a cancer plan. The absence of a plan in Northern Ireland is notable.

- Scotland – _Beating Cancer: Ambition and action 2016^33_
- Wales – _Cancer Delivery Plan for Wales 2016–2020^34_

**Priorities**

The key priorities across the strategies focus on:

- Upgrading prevention and public health
- Driving earlier and faster diagnosis
- Prioritising patient experience

**Recommendations of relevance to lung cancer**

In comparison to European strategies, the English, Scottish and Welsh strategies reference lung cancer to a much larger extent. The existence of a strategy is therefore not sufficient by itself to improve outcomes.

It is essential that all countries continue to make cancer a policy priority, particularly, because of the scale of its impact, lung cancer specifically. There should be a greater focus on ensuring full implementation of existing plans, including sufficient funding throughout the pathway.

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_Table 2 (continued) – Key national cancer/prevention plan(s) in Denmark, France, the Netherlands and the UK_
Smoking cessation and tobacco control policies

More than eight in ten cases of lung cancer are caused by smoking, and so policies to prevent its uptake and to encourage cessation are increasingly popular among public health officials and policy-makers.\(^{35}\)

While the strong association between smoking and lung cancer is important, it should also be recognised that lung cancer in never-smokers is the eighth most common cancer in the UK. However, even in never-smokers, approximately one in five cases is linked to passive smoking.\(^{35}\)

To tackle smoking and tobacco, in 2013 the WHO introduced its MPOWER initiative, which corresponds to elements of its Framework Convention on Tobacco Control (FCTC). MPOWER aims to reduce the demand for tobacco products at a country-level. In 2017, the WHO published country profiles on each of the countries which have signed the FCTC and tracked their progress in delivering the MPOWER aims, with all of the countries in this report at advanced stages of delivering them.\(^{36,37,38,39,40}\) However, France is identified as not reporting data on policies for smoke-free environments or implementing mass media anti-tobacco campaigns.

While Denmark and the Netherlands have either not implemented smoking bans or have done so only in a limited number of places. The UK is particularly advanced in its efforts to implement tobacco and smoking control policies, which place it ahead of all the other countries in this report.\(^{36,37,38,40}\)

Professor Jacques Cadranel stated that not enough is being done to reduce smoking rates in France. He identified smoking cessation, particularly among young people as his number one priority for improving lung cancer outcomes in France.\(^{41}\) The results of a 2010 French government survey showed that 51 per cent of young people who began smoking before the age of 14 would be heavy smokers at the age of 20, while 14 per cent of young people who began at 18 would be by the same age.\(^{42}\)

It is positive to see the UK’s leading position on tobacco and anti-smoking policies, and it is important that this position is maintained. There is also an opportunity for the UK to share its experience with the other countries and, as a beacon of best practice, to assist them in the implementation of their own policies.

Recommendations

- The UK Departments of Health should continue to recognise the significant need for investment in efforts to tackle lung cancer. As each cancer strategy is renewed, lung cancer must remain a priority with additional expertise and resources dedicated to improving lung cancer diagnosis, care and treatment across the pathway. The complexity of current lung cancer management that results from the identification of multiple subtypes, should also be recognised.
- UK governments should urgently re-prioritise smoking prevention and cessation services and ensure that they are sufficiently funded, to address concerns raised by some local authorities in England.\(^{45}\)
- Lung cancer and smoking prevention and cessation should be prioritised in the NHS Long Term Plan in England. There should also be funding plans for Northern Ireland, Scotland and Wales.
Patient pathway – guidelines

Clinical guidelines represent an opportunity for clinicians and policy-makers to set out an optimal and consistent approach to tackling lung cancer. They can help patients to understand the care process and help clinicians to improve the quality of care, decrease variations in practice and limit preventable mistakes and adverse events.\(^\text{43}\)
Streamlining diagnosis in cancer was identified as a priority in NHS England’s plan to take the Cancer Strategy forward. The National Optimal Lung Cancer Pathway was produced by the Lung Cancer Clinical Expert Group in 2017, along with Clinical Advice to Cancer Alliances for the Commissioning of the whole Lung Cancer Pathway [service guidance]. The pathway should deliver a maximum timeline of 49 days from referral to treatment, faster than the NHS target of 62 days. Its key features include:

- Chest X-ray to Computerised Tomography (CT) and clinic in less than 24 hours
- Scope for either primary or secondary care to lead to triage
- Rapid turnaround times for testing/reporting
- Direct to biopsy option

There are two further national clinical guidelines, which should be used in planning and delivering care:

- The Scottish Intercollegiate Guidelines Network (SIGN) has published a lung cancer guideline: SIGN 13748 for use in Scotland.

**Denmark**

In Denmark, the national health organisation developed a ‘Lung Cancer Package’ in 2009 specifying how patients should progress through the system from referral to investigation, treatment and follow-up. The package is reviewed every two years and must be offered to all cancer patients as standard practice. The packages are linked to national guidelines and sit alongside the national system for cancer care. They include a recommended timeline for the total duration of the package of care and support. The timeline starts from the first CT, stipulating that a decision on how to treat must be made within 28 days and that treatment must commence within 42 days.

**Sweden**

In 2011, the Swedish National Board of Health and Welfare produced national guidelines for lung cancer, containing 68 recommendations covering diagnostics, surgery, radiation treatment, chemotherapy, palliative treatment and care. In 2015 a national programme to standardise cancer pathways was implemented nationally. Dr Karl Kölbeck indicated that the programme was primarily focused on reducing waiting times. However, he had not yet seen a noticeable change in waiting times in the Stockholm City region, following the introduction of the programme, partly because it had implemented its own standardised schedules five to seven years earlier for the majority of patients.

**The Netherlands**

Professor Pieter Postmus indicated that the Netherlands has a national guideline with time limits for the diagnosis and treatment of lung cancer, although “it is old and needs updating.” He also suggested that many countries, including the Netherlands and the UK, are missing guidelines and targets in areas such as detection of recurrence, progression and follow-up investigations.

**France**

Professor Cadranel indicated that in France and the Netherlands there are no lung cancer-specific pathways. As in other cancers, the patient is referred after an initial GP consultation, diagnosed and will then begin treatment as appropriate. The evidence from Denmark and Sweden suggests that the implementation of guidelines and centralised pathways can deliver improvements in outcomes for patients. A centralisation of services has not yet been widely implemented across the UK, despite being recommended in the National Optimal Lung Cancer Pathway service guidance for commissioners. It should be noted that the Danish and Swedish populations are smaller than those of France and the UK. Therefore, centralisation efforts in France and the UK would be focused on the development of a number of regional centres of excellence, rather than a single centre. Nonetheless, the example of Denmark suggests that mandating the application of the guidelines might be a route to improved outcomes when paired with centralisation, as implemented in Sweden.

**Recommendations**

- NHS England should allocate funding to collect, analyse and share data on the implementation of the National Optimal Lung Cancer Pathway and Clinical Advice to Cancer Alliances for the Commissioning of the whole Lung Cancer Pathway to identify barriers to their adoption and to allow lessons to be shared between NHS Trusts.
- We urge policy-makers in the devolved nations to consult on, develop and implement optimal lung cancer pathways for their respective countries.
- Policy-makers should refocus their efforts on identifying variations in care at both the patient and population level. We support the roll out of NHS England’s Getting It Right First Time (GIRFT) and RightCare programmes and encourage similar programmes across Northern Ireland, Scotland and Wales. This will allow a renewed focus on areas such as waiting times to ensure that patients are able to get into the system quickly, regardless of where they live.
Routes to referral and diagnosis

Across the countries considered in this report the routes to referral and diagnosis are broadly similar. No country was lacking access to a diagnostic process that any of the others had. However, differences were observed in areas such as the first-choice diagnostic tool (X-ray/CT) and the existence of national molecular testing pathways.

An apparent key difference identified during the interviews was the high number of people in the UK being diagnosed following emergency presentation. This was not something that the experts we heard from considered to be a problem in their countries, all of which achieved higher levels of diagnosis through earlier stages of referral and diagnosis. However, to validate this comparison further work is required to confirm that all the countries gather the same data.

The countries all had access to the key molecular tests. However, France was highlighted as particularly advanced in its implementation of a national molecular testing pathway.

Table 3 below outlines the key differences between the countries in the routes to referral and diagnosis.

### Early diagnosis

Early diagnosis of lung cancer can increase the number of treatment options available and improve the overall outcome for patients. However, 33 per cent of patients in England were diagnosed following emergency admission in 2015. The reasons for patients’ late diagnoses are poorly understood. There is evidence that patient delays and health service factors are both involved, including a lack of symptoms, vague symptoms or a fear of symptoms associated with early stage disease, as well as patients not recognising that they are ill.

To reverse this trend, work is ongoing to pilot rapid diagnostic and assessment centres (RDACs) and to determine the benefits of lung cancer screening protocols such as the use of low-dose CT (LDCT). Currently none of the countries in this report has a national lung cancer screening programme in place. However, Dr Kölbek indicated that Sweden awaits the final result of the multi-year Dutch-Belgian NELSON lung cancer screening study, to determine whether to implement a national screening programme along with the UK.

### Urgent referrals

The Danish lung cancer care package highlights urgent referral pathways or ‘symptoms of alarm’, which enable the GP to refer the patient directly for a CT in any hospital radiology department either the same or following day. A CT is the primary point of entry to the lung cancer package, and chest X-ray is no longer used in Denmark at the point of diagnosis. The onus is placed on the hospital to carry out the procedure or investigation within the specified timeframe. This information is captured and publicly available in the national registry, which holds hospitals to account.

<table>
<thead>
<tr>
<th>Country</th>
<th>Direct to secondary care</th>
<th>CT or X-ray as standard before referral</th>
<th>National molecular testing network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>No</td>
<td>CT</td>
<td>No</td>
</tr>
<tr>
<td>France</td>
<td>Self-referral possible</td>
<td>CT</td>
<td>Yes</td>
</tr>
<tr>
<td>Netherlands</td>
<td>No</td>
<td>X-ray</td>
<td>No</td>
</tr>
<tr>
<td>Sweden</td>
<td>No</td>
<td>CT</td>
<td>No</td>
</tr>
<tr>
<td>UK</td>
<td>No</td>
<td>X-ray</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 3 – The routes to referral and diagnosis in the UK and European countries
Following an abnormal CT, the radiologist will order a same-day referral and the patient must be seen in a hospital oncology department within 48 hours. In contrast, England has a waiting time standard of two weeks between urgent referral and a hospital appointment to test for lung cancer. Across all four nations in the UK there are also 31 and 62-day targets for treatment to start.60,61,62,63

Professor Postmus indicated that the referral pattern at NHS Liverpool Heart and Chest Hospital “is the best I’ve seen”.53 He highlighted that GPs can order additional CTs without consultation by respiratory medicine specialists, saying “implementing a radiology fast track might reduce the referral time”.53

Dr Kölbeck highlighted elements of Sweden’s 2015 National Programme to Standardise Cancer Pathways.52 The programme introduced fast track handling procedures and established waiting times for evaluation and treatment. However, he indicated that the programme is underfunded and yet to show clear improvements in outcomes.52

In the Netherlands, GPs remain the gatekeepers to secondary care. GPs can refer for either a chest X-ray or CT. The route to diagnosis is likely to be faster in instances where a CT is performed for several reasons, for example it is a more sensitive test than a chest X-ray, the additional step for a chest X-ray is omitted and CTs are undertaken in pre-allocated slots each day. In the 2017 report Time to diagnosis and treatment for cancer patients in the Netherlands, 50 per cent of lung cancer patients were referred from their primary care consultation to secondary care within two weeks.44 It could be concluded, that in the Netherlands, GP access to high quality medical diagnostics directly affects how quickly patients receive treatment.

In France, Professor Cadranel said some patients simply refer themselves directly to a specialist. In addition, CTs are widely available and are the most common imaging test for suspected lung cancer.41 Professor Cadranel indicated that the French Society of Radiology discourages GPs from using chest X-rays at the point of diagnosis, preferring the use of CT.41 Although not specifically in relation to lung cancer, in 2009, the Haute Autorité de Santé published guidance on the conditions for appropriate use of X-rays.65

**Access to molecular testing**

For some of the treatment options, patients require molecular diagnostic tests to identify whether they are likely to benefit. These tests need to take place at the right point in a patient’s treatment journey, to support timely treatment decisions.

In the UK, if patients with NSCLC are considered fit for systemic treatment, MDTs can request molecular testing for indicators in relation to potential targeted therapies and immunotherapies, including EGFR, ALK, ROS1 and PD-L1. NHS England’s Accelerate, Coordinate, Evaluate programmes’ Lung Cancer Pathway Cluster recommended that pathology departments adopt ‘reflex testing’ for patients with advanced disease, where molecular testing is run after a diagnosis of NSCLC has been made.66 However, some units still test on request if this does not cause significant delay, to avoid testing patients where targeted treatments are not being considered. In England, efforts are being made to centralise genetic testing to seven Genomic Laboratory Hubs.57 However, ALK, ROS1 and PD-L1 are currently screened for through immunohistochemistry. It is also important that a tissue biopsy is managed carefully to ensure both accurate diagnosis and preservation of tissue for molecular testing.68

As lung cancer diagnosis and treatment becomes more specialised, the UK’s pathology and molecular testing landscape grows more complex.69 It is important that the NHS prepares for advances in molecular testing and the pressures on pathology services by leveraging technological advances. It is important that investment is made in delivering the high-quality pathology services that patients will need.

Professor Erik Jakobsen indicated that, in Denmark, all diagnostic tests are automatically undertaken as part of the package of care, within 28 days. This enables treatment to begin within the mandated timescale. EGFR, ALK and PD-L1 tests take place as standard, although ROS testing is only completed at the specific request of the oncologist.70

In Sweden, there is a standard evaluation schedule which sets out the molecular tests that should be carried out. However, anecdotally, Dr Kölbeck thought that there may be some delays in accessing molecular diagnostic tests in some hospitals and that not all hospitals provided all the necessary tests.52

In the Netherlands, Professor Postmus reported that patients’ access to molecular testing was generally good and that there were few, if any, delays in receiving the results.53
Professor Cadranel highlighted that improved access to molecular testing has been one of the key quality improvements in cancer services in France. A network of centres delivering and collecting data on molecular testing has been developed, which means that all cancer patients have access to the tests they need. The French Cooperative Thoracic Intergroup’s (IFCT’s) Biomarkers France project is notable as one of the first national attempts to collate data on molecular profiling for lung cancer. The study, funded by the French National Cancer Institute (INCa), has resulted in a database of over 17,000 patients with molecular profiling for EGFR, ALK, HER2, KRAS, BRAF, and PIK3CA. The study’s key conclusion is that the profiling ‘improved the survival of approximately 50 per cent’ of the screened patients, due to the ability to inform a personalised treatment approach.

There are opportunities to pilot elements of these countries’ routes to referral and diagnosis in the UK. The RDAC pilots are a good example of this. Consideration could be given to adopting other concepts, such as automatic ordering of all required molecular diagnostic tests once an initial diagnosis of lung cancer has been made, or implementing a radiology fast track process, as suggested by Professor Postmus.

**Recommendations**

- **We recommend that all two-week wait referrals adhere to the National Optimal Lung Cancer Pathway’s recommendation for Computerised Tomography (CT) in people who are at high risk despite a normal chest X-ray.**

- **We encourage the implementation of Lung Health Check pilots across the devolved nations, which include targeted screening of high risk people with low radiation dose CT. The latter should follow The UK Lung Cancer Screening Trial recommendation for a minimum dataset to facilitate a UK-centred body of evidence on the effectiveness and the role of low-dose CT.**

- **Pathology laboratories should audit their turnaround times for diagnosis of lung cancer type and molecular testing results, with a view to being compliant with the goals of the National Optimal Lung Cancer Pathway.**

- **Policy-makers should consider the development of a QA process to ensure consistency in tissue sampling across the UK. This should be developed with the BTS, RCPath and the RCR. This QA process would gather data on the number of procedures and allow an audit of biopsy success rates.**

- **The UK should establish a national programme of molecular testing of lung cancers to ensure that all patients have timely access to high-quality diagnostics, giving them the best opportunities to receive the optimum treatment. The programme should be responsive to the introduction of new biomarkers.**

- **All patients should have access to a full range of analysis and staging investigations, delivered in a timely fashion to ensure compliance with the National Optimal Lung Cancer Pathway.**
Access to treatment

Treatment for lung cancer will depend on factors such as the stage at which a patient’s cancer is diagnosed, the specific type of cancer they have, the location of the tumour, and their fitness (and consent) for that treatment. The witnesses highlighted that options for treatment in all of the countries are discussed by MDTs and then shared with patients.
Reimbursement for travel to treatment

There is evidence that access to treatments varies across European countries. There are a range of reasons for this, including cost, infrastructure and national clinical and cost-effectiveness assessment processes. Professor Cadranel and Dr Kölbeck both highlighted that, if patients are required to travel for treatment, the healthcare systems in France and Sweden will reimburse patients for the cost of travel. In addition, Sweden will also reimburse patients for accommodation costs when attending diagnostic tests or treatment away from home. While the NHS has a similar Healthcare Travel Costs Scheme (HTCS), which reimburses patients for reasonable travel costs when attending appointments, they have to meet specific criteria to qualify.

Survival after lung cancer surgery in England is very high. The UK National Lung Cancer Audit in their 2016 report stated that 98 per cent of patients were alive at 30 days, which the audit suggested meant that there is scope to increase the resection rate in the UK further. Professor Jakobsen estimated that in Denmark the resection rate is 22 per cent, in comparison to 17.5 per cent in England and 17.1 per cent in Wales. He noted that a process of consolidation has reduced the number of Danish centres that provide lung cancer surgery from eight to four. This means that no centre performs fewer than 100 lung cancer resections a year. Research into the overall hospital centralisation scheme in Denmark found that hospital productivity increased substantially and waiting times for planned surgery decreased, although there were concerns about increased staff stress and the distance that some patients had to travel to hospital.

Similarly, in Sweden, Dr Kölbeck highlighted that the Stockholm City region had centralised cancer care into one unit performing approximately 200 resections annually, and that he thought this was important for improving patients’ outcomes. The impact of centralisation of surgical units in the UK is being considered as part of efforts to improve outcomes for patients with lung cancer, learning from the Danish and Swedish experience. As an example, NHS England’s Thoracic Surgery Specification Guide recommends that by 2018/19 all units should perform at least 150 resections a year, with some units consolidating to achieve this target.

In France, there has not been a programme of centralisation of surgery and Professor Cadranel explained that, in some parts of the country, centres could be undertaking relatively low numbers of surgical procedures. However, he also highlighted that a surgeon must carry out a minimum of 30 surgeries each year. In his evidence, Professor Postmus expressed a concern about the lack of centralisation in the Netherlands and the potential negative impact this may be having on patient outcomes.

The key impact of centralisation is to reduce variation in care and outcomes. The Lung Cancer Clinical Expert Group’s 2017 service guidance notes that ‘larger centres achieve higher treatment rates and better surgical survival’. This is because they have larger MDTs, more diagnostics on site and more specialists in lung cancer diagnostics and treatment. It is therefore essential that the Group’s 2017 NOLCP and associated service guidance are implemented across England and learnings adopted across the UK.
Radiotherapy

Access to the relevant equipment is critical for the successful delivery of radiotherapy. This appears to vary across European countries, particularly for more specialist and innovative forms of radiotherapy, such as Stereotactic Ablative Radiotherapy (SABR) and intracranial Stereotactic Radiosurgery/Radiotherapy (SRS/SRT).

In Denmark, the timeline for accessing radiotherapy treatment is set out in the care package, with any treatment needing to begin within two weeks of being agreed at an MDT meeting. Professor Jakobsen estimated that this timeline was met for around 75 to 80 per cent of patients, with ten oncology centres across the country, four of which are able to deliver SABR. In Sweden, the evidence from Dr Kölbeck was that the most advanced radiotherapy techniques, such as SABR, are available mainly in university hospitals but that patients are willing to travel because their travel is fully funded. In France, Professor Cadranel explained that there are a lot of radiotherapy centres because of the reimbursement mechanisms and so access is relatively easy for all patients, often in private centres. Similarly, in the Netherlands, Professor Postmus was of the view that all centres now had access to SABR.

In England, SABR should be commissioned routinely for the treatment of patients with early stage non-small cell lung cancer who are unfit for or decline surgery, in line with the national radiotherapy service specification.

Yet, it is acknowledged there is a need for radiotherapy services to be modernised and that advanced radiotherapy techniques are not available uniformly across the country. A vision to achieve this was set out in 2014 and re- emphasised in Achieving World Class Cancer Outcomes: Taking the strategy forward. In 2016, NHS England announced a national radiotherapy equipment investment programme. Part of this programme included the creation of a network of specialist centres across the country as part of efforts to increase access to more specialist and innovative forms of radiotherapy, such as SABR, SRS/SRT.

In 2016, the UK National Lung Cancer Audit found an increase in the use of radiotherapy as a curative treatment, so it is critical that there is appropriate investment to ensure that patients can access the services they need. This also applies to innovative treatments, such as image-guided thermal ablation for patients where surgery and radiotherapy are contraindicated. The technique is not currently widely available, but in response to the Taskforce for Lung Health’s call for evidence the RCR and British Society of Thoracic Imaging suggested that it should be made available.

Chemotherapy and systemic treatment

The types of drug treatment available for lung cancer are changing quickly. The medicines available can be broken down into three categories:

- Cytotoxic chemotherapy, which kills cancer cells but can also harm other cells in the body.
- Targeted therapies, which target specific genetic mutations within the tumour.
- Immunotherapies, which stimulate or support the patient’s immune system to fight their cancer.

Patient access to NHS treatment in the UK is not immediate following the granting of marketing authorisation by the European Medicines Agency (EMA). This is due to clinical and cost-effectiveness assessments, which are carried out by NICE and the Scottish Medicines Consortium (SMC) for treatments in England and Scotland respectively. Northern Ireland and Wales will often also align with NICE guidance. These assessments can result in a period of more than 90 days before patients can access new therapies.

In recent years both NICE and the SMC have adopted changes to their assessment processes. In April 2018 NICE launched updated appraisal processes, following a consultation, to allow it to more efficiently review new medicines. For cancer medicines the assessment process now begins before the licensing process has concluded with the aim of guidance being produced within 90 days of a license being granted. In addition, since 2011 NHS England has operated the Cancer Drugs Fund (CDF), it ‘provides interim funding which means faster access to cancer drugs’.
If a medicine is considered by NICE to have potential ‘to satisfy the criteria for routine commissioning, but there is significant remaining clinical uncertainty which needs more investigation’, interim funding is provided through the CDF while additional data are gathered. CDF funding is also used after NICE guidance which recommends a medicine is issued to reduce the period between the guidance being published and the medicine being available to patients.92 In Scotland, changes to the SMC’s assessment processes for medicines used at the end of life or for very rare conditions mean there are now greater opportunities for patient and professional voices to be heard through a Patient and Clinical Engagement (PACE) group.93 These changes have improved patient access to treatment, but opportunities remain to do more.

Dr Köbeck explained that delays in accessing medicines in Sweden can occur because of additional evaluations of medicines that take place at a national level following a license being granted by the EMA. Each self-governing county in Sweden makes decisions about healthcare spending, which can lead to further delays and regional differentiations.52 In Denmark, Professor Jakobsen explained that there are no additional barriers to accessing new medicines following licensing, the decision is made solely by the treating clinician.70 This may mean that treatments are available to patients more quickly and easily in Denmark than in the UK.

In the Netherlands, negotiations sometimes take place over the price of a new medicine before it is added to the health insurance scheme.94 The Ministry of Health, Welfare and Sport decides which drugs are part of the national insurance scheme, with ‘registered’ medicines needing to be assessed before they can be included in the Medicines Reimbursement System (GVS).95 Professor Postmus indicated that the Netherlands has five specialist units to treat rare tumours, such as ALK, BRAF, ROS1 and EGFR mutations.53 ‘The reimbursement by insurance companies is restricted to these centres for these subgroup as the centres have specialised MDTs to consider these tumours.’53

Urinary Leakage

Professor Cadran indicated that following EMA approval, the French authorities will assess treatments in categories such as price and clinical effectiveness.41 These processes can take ‘several months and even more than a year’.96 However, he also highlighted that access to treatment, prior to marketing authorisation, can be enabled through a process of Temporary Authorisation for Use (ATU).96,97

Access to new therapies clearly differs between the countries. Both France and the UK can have long evaluation processes, while Denmark has few issues with patients rapidly accessing new therapies. And, while Sweden also carries out evaluations, Dr Köbeck indicated that even if a new treatment is not financially approved, his department will make it available to patients.52 Unlike the UK, Denmark and Sweden are advanced in their efforts to centralise treatment, particularly in areas such as surgery. Professor Jakobsen and Dr Köbeck both felt this had resulted in improved patient outcomes, while Professor Postmus expressed concerns that the Netherlands has not centralised enough and that this may be affecting patient outcomes.52,53,70 The level of access to radiotherapy was also very high in the European countries, in part because the health systems fund patients’ travel to treatment. The key area of similarity across all countries was the central role of MDTs in determining patients’ treatment.
Recommendations

- Centralisation of lung cancer surgery is associated with improved peri-operative outcomes and can facilitate both cost efficiency and sustainable workforce planning. Steps should be taken to achieve the NHS England minimum unit size of 150 cancer resections per year.

- We encourage the creation of a pilot study to examine the impact of an oncogene addicted/mutation driver specialist Multi-Disciplinary Team (MDT) for rare mutations, so that patients might have access to specialised treatments or clinical trials.

- As systemic anti-cancer therapies for lung cancer change, the appraisal system must be nimble enough to allow swift access for patients to innovative medicines. We support efforts of regulators to produce treatment guidance within 90 days of European marketing authorisation across the UK.

- All treatment options should be available to patients based on their clinical need and not restricted by their inability to travel to a centre. While we recognise different health systems exist across the UK, with different processes to access medicines, we feel this should not be a justification for ‘postcode lotteries’.

- Appropriate travel support should be made available to patients who need it, as outlined in the Lung Cancer Clinical Expert Group’s 2017 service guidance, to ensure that there are not any additional barriers to them accessing treatment.

- Investment must be made to ensure that all patients for whom it is suitable can access up to date radiation oncology treatments and techniques including chemo-radiotherapy, IMRT, IGRT and SABR. These should be made available at every radiotherapy centre, with decisions being made by appropriately trained clinicians based on each patient’s needs.
Data collection and evaluation are essential for understanding health system performance against key lung cancer metrics such as Patient Reported Outcomes Measures (PROMs), referral to treatment times and routes to diagnosis.
The advances of molecular testing also presents opportunities to develop national datasets on the genomic markers that lung tumours display. From the evidence the expert group heard, it is evident that the UK’s cancer registries and clinical datasets are well advanced.

### Cancer registries and clinical datasets

Each of the UK’s devolved nations manages its own cancer registration service, the largest being the National Cancer Registration and Analysis Service (NCRAS) for England which is run by Public Health England (PHE). NCRAS now also incorporates data from Wales. Table 4 outlines the breadth of the data collected by NCRAS and the National Lung Cancer Audit (NLCA). Expert group member Dr Anna Rich described the NLCA as ‘one of the best examples in Europe of a national patient-centred dataset specific to lung cancer’.80

Scotland is not fully integrated into the NLCA as it is not currently able to provide patient-level data but it does have its own lung cancer Quality Performance Indicators (QPIs).80,98 Data from Northern Ireland is also not currently available in a form for incorporation in NLCA reports.

### UK cancer registries, clinical datasets and patient experience surveys

<table>
<thead>
<tr>
<th>Name and country</th>
<th>Type of data collected</th>
<th>Managed by</th>
</tr>
</thead>
</table>
| National Cancer Registration and Analysis Service | Epidemiological  
| | • Incidence  
| | • Prevalence  
| | • Survival  
| | • Mortality  
| | National cancer patient experience surveys  
| | Clinical  
| | • Event dates  
| | • Tumour morphology and stage  
| | • Performance status  
| | • Socio-economic status  
| | • Treatment type administered  
| | • Proportion of patients seen by CNS  
| | • Diagnostic Imaging Dataset (from NHS Digital)  
| | • Systemic Anti-Cancer Therapy (SACT)  
| | • Radiotherapy Data Set (RTDS)  
| | • Molecular markers (in England) | Public Health England |
| National Lung Cancer Audit | Clinical data collected by NCRAS are a key source of information for the NLCA. Examples of data include:  
| | • Disease stage  
| | • Systemic anticancer treatment rates  
| | • Chemotherapy rates in SCLC  
| | • Proportion of patients seen by lung CNS  
| | • Proportion of patients with pathological confirmation of lung cancer | Royal College of Physicians – in collaboration with NCRAS |

Table 4: UK cancer registries, clinical datasets and the type of data collected
Like the UK, the Netherlands has a comprehensive cancer registry, Integraal Kankercentrum Nederland (IKNL), for the collection of epidemiological cancer data, including for lung cancer. The data held by IKNL are available in the public domain (via www.cijfersoverkanker.nl) with tailored datasets also available for clinicians and policy-makers. These data have been used to inform the work of the Netherlands’ Comprehensive Cancer Networks. IKNL registers the data, reports it and uses it to inform improvements in and regulations for lung cancer care. Professor Postmus noted that while epidemiological data are available, the Netherlands does not have a broad audit similar to the Lung Cancer Audit Database (LUCADA)/NLCA, which captures clinical data. However, there are elements of the Dutch Lung Surgery Audit, run by the Dutch Society of Lung Surgeons (NvVL), which allows clinical lung cancer data to be analysed.

The Danish Lung Cancer Registry (DLCR) aims to improve survival and the overall clinical management of lung cancer patients. It collects and publishes epidemiological results and PROMS data (primarily as quality indicators) on a monthly and annual basis, for both national and regional levels. There is a management information system where all results from the national registry are reported and this feedback has a big impact in encouraging managers to ensure high standards of care and outcomes.

Sweden also has a National Quality Registry for Lung Cancer, which provides information on diagnostic procedures, staging methods, tumour characteristics, planned treatment, study participation and follow-up. The limitations of France’s data collection were highlighted by Professor Cadranel who indicated that ‘some initiatives have to be done by French surgeons and clinical-molecular registries, such as the Biomarkers France project.’

A further area for which data can be gathered is PROMs. They can be a key route to measure the involvement of patients in their care and the achievement of outcomes of most importance to them. Work has been ongoing for some years and was recently codified through the International Consortium of Health Outcomes Measurement’s (ICHOM’s) Standard Set for Lung Cancer. However, PROMs were not specifically highlighted during the interviews and they are not yet fully integrated into UK national data registries and clinical datasets. The Welsh Government has established a programme promoting value-based health care, one element of which is the introduction of a national programme for the collection of PROMs data in lung cancer patients.

Sweden requires all healthcare providers to report all newly detected cases of cancer to one of six regional registries, which are part of the Swedish Cancer Registry. However, comparison with data from the Cause of Death Register suggests an under-reporting of cases of lung cancer. There are opportunities for the UK to share its expertise in data management and analysis more widely, through projects run by organisations like the European Respiratory Society. However, there are also areas for development in the UK such as the experience that France has gained in the development of its national molecular testing project.
Patient involvement

There is clear evidence which indicates that healthcare systems with high levels of patient engagement in their care deliver better outcomes, resource allocation and decision-making.105,106

This operates at two levels, both for individual patients and with patient groups being fully involved in policy-making. It is important that each individual patient is empowered through information and support from professionals to make informed decisions about the care, treatment and outcomes that matter most to them. An active patient voice in policy-making, service change and service delivery is also important. Active patient advocacy groups can make a significant difference by ensuring that the patient point of view is heard when decisions are made about treatment access, service delivery and health policy.

The UK currently has a very strong emphasis on patient involvement in care and treatment decisions. Through the evidence heard, it appears that the UK is ahead of many other European countries in supporting patient advocacy, engagement and involvement in decision-making. All of the clinical experts who gave evidence to the group noted that doctors in their countries generally told their patients what would be best for them and patients did not question this, or ask to be more involved in the decision.

In addition, support from nurse specialists was not available for patients in other countries, although it is possible that there are other opportunities for patients to seek information, for example during the longer consultation times offered in France.

To involve patients properly in their care requires more than a single point in the journey. It is essential that they are engaged and supported from referral and diagnosis, to treatment and beyond. This is why efforts to increase patient involvement are highlighted throughout this report with recommendations focusing on areas such as assistance with travel to specialist treatment and greater integration of PROMs in national datasets.

Recommendations

• We encourage UK policy-makers to design patient-centric services, based on feedback that is actively sought from both patients and carers. They should be able to be as involved as they want to be in decision-making around their care and feel able to request optimal lung cancer care.

• Evidence suggests involving patients in their care, generally leads to better outcomes. The UK should undertake research to understand why UK lung cancer outcomes remain poor, despite the greater general involvement of patients in their care pathway, than in some European countries.
Lung cancer workforce

The ability to deliver high quality lung cancer care can be severely hindered by an understaffed lung cancer workforce. In the UK, understaffing in the cancer workforce has been well documented by NHS and professional bodies. Apart from in Sweden, it was not highlighted by the witnesses from the other countries involved.
When asked what single change he would make to improve outcomes in Sweden, Dr Kölbeck said that he would like to interest chest physicians and oncologists in lung cancer, to educate them and increase the numbers working in the specialty. He noted that “it is not a popular field. There are other more popular fields of medicines… There is quite a high fall out rate.”

In the UK, details of the oncology workforce are collected by a variety of organisations and not all figures are up to date:
- NHS Digital compiles monthly data on the number of doctors within the NHS, including clinical and medical oncologists, radiologists and nurses. However, these data do not contain information on the specialty of staff.
- The NLCA produces intermittent organisational audits, but these are limited by lack of access to precise workforce details. Since 2007, Macmillan Cancer Support has run periodic censuses of cancer, palliative and chemotherapy specialty nurses and support workers.
- The RCR collates data annually on the clinical oncology and clinical radiology workforces.
- Data on the medical oncology workforce were gathered as part of Cancer Research UK’s 2017 Full team ahead report.
- In 2015, the Society for Cardiothoracic Surgery published a report on the cardiothoracic workforce.

Clinical nurse specialists (CNSs) form a core part of the cancer workforce. While there are pressures on the nursing workforce, most patients are allocated a CNS to support them. The NLCA includes a specific indicator to measure the number of patients seen by a CNS. Disappointingly, in 2017, only 71 per cent of patients in England and Wales were seen by a lung CNS against a target of 90 per cent. And only 58 per cent had a lung CNS present for their diagnosis, against a target of 80 per cent.

In July 2018, the Health Service Journal reported on research by The University of Nottingham and London South Bank University on the role of lung cancer CNSs in patient care. The findings, presented at the NCRAS conference in June 2018, indicated that patients receiving radiotherapy treatment are 17 per cent less likely to die within a year when assessed and cared for by a lung cancer CNS.

The Royal College of Pathologists notes the increasing complexity of work, paired with a rising shortage of pathologists. The College’s 2018 report Meeting pathology demand: Histopathology workforce census found that only three per cent of NHS histopathology departments have enough staff to meet clinical demand. The issue of pathology workforce problems is highlighted in Cancer Research UK’s report Testing times to come? An evaluation of pathology capacity across the UK and the first stage of the Cancer Workforce Plan by Health Education England.

The censuses and datasets show there are both current and anticipated workforce shortfalls across the nursing, oncology, radiology and surgery workforces in the UK with high numbers of experienced staff reaching retirement age. The loss of experienced staff means that there is likely to be a lack of experienced people to train new specialists, and this is compounded by the fact that these professions are struggling to recruit. It is likely that advances such as increasing provision of direct access CT and the possible introduction of CT screening for lung cancer will impact upon the workforce shortfall. It is essential that immediate actions are taken to mitigate any threat to patient care.

The 2017 lung cancer service specification sets out the recommended attendees at MDT meetings and the amount of time that specialist members of the MDT should devote to lung cancer.

This is notable because to achieve the recommended numbers of specialists in MDTs, workforce increases are likely to be required, particularly in areas such as nursing, oncology and radiology.

Similar workforce data at a national level do not appear to be available for the European countries we have heard from as part of this project. We heard evidence that MDTs were the main decision-making body for patients’ treatments and that specialist nurses were available to support patients. However, we are not able to compare the level of staffing between countries to identify if this is an area of development for the UK.

Recommendations

- We recommend that NHS England and NHS Scotland implement their cancer workforce plans as soon as possible, to limit the impact of vacancies upon the clinical oncology, pathology, radiology and surgery workforces and the challenges with training new staff that this could lead to. We also support the development of Wales Cancer Network’s cancer workforce plan.

- We welcome the news of research into the role of lung cancer specialist nurses and encourage greater investment in the lung cancer specialist nurse and Allied Health Professional (AHP) workforces, considering their essential role in improving patient experience and outcomes.

- We support efforts to achieve the NLCA’s target of 90 per cent or more patients being seen by a lung cancer specialist nurse.
Methodology

An expert group was identified to select the comparator European countries, hear evidence and develop policy recommendations.

The group was chaired by Professor Michael Peake, Clinical Director, Centre for Cancer Outcomes, University College London Hospitals NHS Foundation Trust and Hon Professor of Respiratory Medicine, University of Leicester. The other members of the group were:

- **Professor David Baldwin**
  Consultant Respiratory Physician and Hon Professor of Respiratory Medicine, Nottingham University Hospitals NHS Trust; Chair of the Clinical Expert Group for Lung Cancer, NHS England

- **Lorraine Dallas**
  Director of Information and Support, Roy Castle Lung Cancer Foundation

- **Dr David Gilligan**
  Consultant Clinical Oncologist, Cambridge University Hospitals NHS Foundation Trust

- **Dr Tom Newsom-Davis**
  Consultant Medical Oncologist, Chelsea and Westminster Hospital NHS Foundation Trust

- **Professor Marianne Nicolson**
  Hon Professor of Oncology, Aberdeen University; Consultant Medical Oncologist, Aberdeen Royal Infirmary, NHS Grampian

- **Dr Anna Rich**
  Consultant Respiratory Physician, Nottingham University Hospitals NHS Trust

- **Mr Doug West**
  Consultant Thoracic Surgeon, University Hospitals Bristol NHS Foundation Trust

- **Professor Pieter Postmus**, Professor of Pulmonary Diseases, Leiden University Medical Centre, Leiden, the Netherlands

The group identified Denmark, France, the Netherlands and Sweden as the four countries to gather evidence from. These countries were chosen because:

- They have consistently recorded better five-year survival rates than the UK between 2000-2014 and a number have achieved greater increases within this period
- All countries are from Western Europe and have comparable levels of healthcare spending as a percentage of GDP (between 9.9 and 11.0 per cent in 2015), although they all spend more than the UK does
- Denmark, France and the Netherlands all have higher lifetime incidence rates for lung cancer than the UK

Within each of the countries, witnesses were identified by the expert group to be invited to give evidence about lung cancer in their country.

The clinical witnesses who agreed to give evidence were:

- **Professor Jacques Cadranel**, Head of the Chest Department and Expert Centre of Thoracic Oncology, Hôpital Tenon and Sorbonne Université, Paris, France
- **Professor Erik Jakobsen**, Associate Professor, OPEN and Thoracic Surgeon, Odense University Hospital, Odense, Denmark
- **Dr Karl Kölbeck, MD, PhD**, Lung Oncology Centre, Karolinska University Hospital, Stockholm, Sweden

The clinical evidence was gathered during a series of teleconferences. The first took place in April 2018. The witnesses from Denmark and the Netherlands were interviewed separately during 45-minute teleconference calls. Two subsequent calls took place in July, with the witnesses from France and Sweden.

If the expert group had further questions following the calls, then the witnesses were asked to answer short written questions or identify additional sources of information.

The key themes that the expert group asked the witnesses about were:

- Lung cancer outcomes
- National lung cancer policies
- Early diagnosis
- Diagnosis and staging
- Quality of, and access to, treatment and care
- Surgery
- Radiotherapy
- Systemic therapy
- Supportive and other care
- Patient involvement in decision-making
- Data collection

Following each of the interviews the expert group was able to refine the areas that it asked the witnesses about. This meant that not all of the witnesses were asked exactly the same questions. The later interviews featured more detailed questioning in some areas, although all interviews covered all of the topics from the list above.
Limitations

This report is intended to be a guide for policy-makers and support the delivery of the UKLCC’s aim to improve five-year survival rates to 25 per cent by 2025.

As a result, health systems which perform better than the UK in lung cancer survival were prioritised. It is notable that France, Denmark, the Netherlands and Sweden are all Western European countries. Future evidence gathering should consider lung cancer care in other European states, which both perform better and worse than the UK in outcomes and other epidemiological markers of successful lung cancer care. This could be done in conjunction with the ERS. Efforts to gather evidence from similarly advanced healthcare systems, outside Europe, should also be considered.

A further limitation was that for each of the countries only one witness was interviewed. Professor Cadranel and Dr Kölbeck highlighted that their experience was particularly detailed on a local level, due to the high degree of local autonomy in their healthcare systems. Further evidence gathering would allow a wider group of specialists to be interviewed, with expertise from different parts of the lung cancer care pathway and regions within their countries. This might allow for comparisons to be made between areas on a socio-economic level.

A final limitation to consider is the breadth of the report’s scope, which has meant that a high-level policy view has been taken. Further studies might choose to expand the detail in which they examine each area, to maintain a strong sense of the connected patient journey. However, it is possible for further small studies to be carried out on more specific areas.

Conclusion

While acknowledging the relatively poor lung cancer outcomes in the UK, this report has identified a great deal to be positive about.

It is important to note that many of the expert group’s recommendations align closely with the recommendations in NHS England’s 2017 NOLCP and Clinical Advice to Cancer Alliances for the Commissioning of the whole Lung Cancer Pathway.45,46 The Gaining perspective report’s recommendations have been developed following extensive independent research. They therefore serve as supporting evidence of the need for commissioners to continue implementing the specification, as a route to reducing variations in care and improving lung cancer outcomes.

There are certainly lessons to be learned from Denmark, France, the Netherlands and Sweden in improving diagnosis, referral and molecular testing. However, the UK has expertise in data collection, the role of CNSs and patients’ involvement in their care that should be more widely shared.

Many changes have been made in lung cancer care in the UK in recent years, the results of which may take some time to be seen in official statistics. However, it is clear that further action is needed to achieve the UKLCC’s ambition to raise UK five-year lung cancer survival rates to 25 per cent by 2025. We encourage all policy-makers to consider and act upon the recommendations in this report.
Glossary
**Adenocarcinoma**
A type of cancer arising from glandular tissue

**ALK**
A gene that makes the protein anaplastic lymphoma kinase (ALK), which may be involved in cell growth. Mutated (changed) forms of the ALK gene and protein have been found in some types of cancer, including non-small cell lung cancer

**Biomarker**
A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease

**Biopsy**
Removal and examination of tissue, usually microscopic, to establish a precise (pathological) diagnosis

**BRAF**
A gene that makes a protein called B-RAF, which is involved in sending signals in cells and in cell growth. This gene may be mutated (changed) in many types of cancer, which causes a change in the B-RAF protein. This can increase the growth and spread of cancer cells

**Clinical Nurse Specialist (CNS)**
A nurse with advanced practice qualifications who provides specialist care. They can specialise in a range of diseases including cancer

**Chemotherapy**
Medicines used in the treatment of cancer that can be given by mouth or by injection

**Clinical oncologist**
A doctor who uses radiotherapy and chemotherapy to treat and manage patients with cancer. They also use a range of other treatments to treat cancers, without using surgery

**Co-morbidity**
Medical condition(s) or disease process(es) that are additional to the disease under investigation (in this case, lung cancer). In the NLCA, this is recorded when a comorbidity restricts the type of treatment that can be given for lung cancer

**CT scan**
The abbreviated term for computerised tomography. These tests produce detailed images of the body using X-ray images that are enhanced by a computer

**Cytotoxic chemotherapy**
Anticancer drugs that kill cells, especially cancer cells

**Diagnosis**
Confirming the presence of the disease

**EGFR**
The gene that makes the protein found on the surface of some cells to which epidermal growth factor binds, causing the cells to divide. It is found at abnormally high levels on the surface of many types of cancer cells, so these cells may divide excessively in the presence of epidermal growth factor

**Epidemiology**
The study of patterns of health and disease in populations

**HER2**
The gene and protein involved in normal cell growth. HER2 protein may be made in larger than normal amounts by some types of cancer cells, causing them to grow more quickly and spread to other parts of the body

**IGRT**
A procedure that uses a computer to create a picture of a tumor to help guide the radiation beam during radiation therapy

**Immunotherapy**
A therapy that uses substances to stimulate or suppress the immune system to help the body fight cancer, infection, and other diseases. Some types of immunotherapy only target certain cells of the immune system. Others affect the immune system in a general way

**IMRT**
A type of three-dimensional radiation therapy that uses computer-generated images to show the size and shape of the tumor

**Incidence**
The number of new cases of a disease diagnosed each year

**Intracranial Stereotactic Radiosurgery/Radiotherapy (SRS/SRT)**
Methods of delivering precisely targeted radiotherapy treatment

**KRAS**
A gene that makes a protein called KRAS, which is involved in cell signalling pathways that control cell growth, cell maturation, and cell death. Mutated (changed) forms of the KRAS gene have been found in some types of cancer, including non-small cell lung cancer
**Large cell carcinoma**
Lung cancer in which the cells are large and look abnormal when viewed under a microscope

**Marker**
A diagnostic indication that disease may develop

**Medical oncologist**
A doctor who has special training in diagnosing and treating cancer in adults

**Molecular profiling**
The classification of biological specimens, like tissues, blood or urine, based on multiple molecule (like gene, protein, miRNA) expression patterns or genomic changes for diagnostic, prognostic, and predictive purposes

**Molecular testing**
Laboratory testing for certain genes, proteins, or other molecules in a sample of tissue, blood, or other body fluid, and/or for certain changes in a gene or chromosome that may cause or affect the chance of developing a specific disease or disorder, such as cancer

**Multidisciplinary team (MDT)**
Multidisciplinary team; a group of healthcare professionals working in a coordinated manner for patient care

**Mutation**
Any change in the DNA sequence of a cell. Mutations can be harmful, beneficial, or have no effect. Certain mutations may lead to cancer or other diseases

**Non-small cell lung cell cancer (NSCLC)**
A group of types of lung cancer sharing certain characteristics, which makes up 85-90 per cent of all lung cancers. Includes squamous carcinoma and adenocarcinoma

**Oncogene addiction**
A concept where a tumour contains multiple genetic abnormalities and is dependent on certain key abnormalities for its continued development

**PDL-1**
A gene that makes the protein (also PDL-1) that, when bound to another protein, PD-1 helps keep T cells from killing other cells, including cancer cells

**Peri-operative death**
Death around the time of surgery. This usually lasts from the time the patient goes into the hospital or doctor’s office for surgery until the time the patient goes home

**PIK3CA**
A gene which makes a subunit to the protein PI3K. Mutations to PIK3CA can result in unregulated production of the PI3K leading to uncontrolled proliferation of cells and the development of cancer

**Pleural Mesotheliomas**
A tumour affecting the thin layer of tissue that covers the lungs and lines the interior wall of the chest cavity

**Positron emission tomography (PET) scan**
A scan producing detailed three-dimensional images of the inside of the body, often combined with CT scanning to produce even more detailed images (PET-CT scanning)

**Radiotherapy**
The treatment of cancer using radiation, which is most often delivered by X-ray beams (external beam radiotherapy) but can be given internally (brachytherapy)

**Reflex testing**
Where molecular testing is run on an advanced sample prior to Multidisciplinary Team (MDT) review

**Screening**
Checking for disease when there are no symptoms. Since screening may find diseases at an early stage, there may be a better chance of curing the disease

**Small cell lung cancer (SCLC)**
A type of lung cancer making up around 10-15 per cent of all lung cancers

**Squamous cell cancer**
A type of cancer arising from cells that line body cavities

**Staging/stage**
The anatomical extent of a cancer

**Stereotactic ablative radiotherapy (SABR)**
A way of giving radiotherapy to a tumour from different directions
**Surgical resection**
An operation to remove abnormal tissues or organs

**Survival rate**
The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease, such as cancer

**Systemic anti-cancer therapy (SACT)**
Therapy comprising chemotherapy agents alongside targeted therapies and immunotherapy

**Systemic treatment**
Treatment using substances that travel through the bloodstream, reaching and affecting cells all over the body

**Targeted therapy**
A treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells. Some targeted therapies block the action of certain enzymes, proteins, or other molecules involved in the growth and spread of cancer cells. Other types of targeted therapies help the immune system kill cancer cells or deliver toxic substances directly to cancer cells and kill them
Gaining perspective

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Notes