Tackling emergency presentation of lung cancer:

An expert working group report and recommendations
This report, and the Expert Lung Cancer Working Group, have been financially supported by Bristol-Myers Squibb, who have had no editorial input.
Representatives of the following groups have contributed to this report, however its content and recommendations do not necessarily reflect the individual organisations’ views:

Nottingham University Hospitals NHS Trust  Guy’s and St Thomas’ Hospital NHS Trust  

The Clatterbridge Cancer Centre NHS  Walsall Hospitals NHS Trust  

Chelsea and Westminster Hospital NHS Foundation Trust  Richmond  Clinical Commissioning Group

England
Foreword By Dr Sanjay Popat

Compared to the European average, cancer survival in England is low. Studies investigating this disparity point to the diagnosis of many cancers late in their natural history, and higher rates of advanced stage disease which is often untreatable.

34% of all lung cancer patients in the UK are currently diagnosed as an emergency, a figure that is significantly higher than for other cancers. Despite a small drop in the number of lung cancer patients diagnosed via emergency routes, this figure remains far too high, especially as this is directly linked to poorer survival outcomes.

If we are to tackle poor lung cancer patient outcomes we must address the high numbers diagnosed through emergency presentations as a matter of urgency, as well as improving the care patients receive throughout the pathway. This thoughtful report by experts in their field of authority and its recommendations seek to do just that; identifying tangible ways in which to target high risk patients to aid earlier diagnosis, speed the diagnostic process by improving communication between clinicians, and improve patients’ experience of an emergency diagnosis.

Advances in molecular analysis and innovative new medicines have altered the treatment paradigm and, in turn, prognosis, for lung cancer patients. We must now all now focus on ensuring an optimum pathway exists in order to identify lung cancer earlier and prevent patients from being diagnosed as an emergency, if we are to truly improve patient outcomes.

Dr Sanjay Popat BSc PhD FRCP
Chair of the British Thoracic Oncology Group (BTOG).

Foreword By Dr Penny Woods

Lung cancer is the UK’s biggest cancer killer, accounting for more than 1 in 5 of all cancer deaths. Despite claiming so many lives, lung cancer has not been given the prioritisation of other common cancers such as breast and prostate, something which is necessary if we are to tackle the poor patient outcomes that make the UK one of the worst places to have lung cancer in Europe, if not the world.

At the British Lung Foundation, we hear patients say they feel stigmatised for having smoked, something which has been echoed in the conversations of this Working Group. Active and passive smoking are key risk factors for the disease, but non-smokers get lung cancer too, and this is something the general public and healthcare professionals need to become more aware of.

Many lung cancer patients also face a lack of understanding of the signs and symptoms of lung cancer when they do report them, with a recent report highlighting that many patients attend a number of consultations before they receive a diagnosis, which often leads to a worse experience of care and potentially worse outcomes.

It’s time for lung cancer patients to be prioritised, and for the stigma associated with the disease to be overcome. If we are to make progress and improve survival for lung cancer, then patients, healthcare professionals and the general public must become more aware of the signs and symptoms of the disease but also of the reality of who it affects and the fact that it can be treated. Other cancers have seen marked improvements in outcomes in recent years; we must ensure that lung cancer is not left behind.

Dr Penny Woods
Chief Executive of the British Lung Foundation.
## Recommendations

The Expert Lung Cancer Working Group has developed a series of recommendations on ways to improve both experience and outcomes for patients, which we hope will influence key decision makers to make the improvements needed to reduce lung cancer mortality rates across the UK.

<table>
<thead>
<tr>
<th>Recommendation 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding for a national campaign (such as Be Clear on Cancer, Detect Cancer Early or Be Cancer Aware) be maintained or increased, in order to raise public awareness of the signs and symptoms of lung cancer.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>A commitment be made to rapid adoption of a targeted, evidenced-based lung cancer screening programme, as deemed effective by the UK National Screening Committee, in order to reduce the number of lung cancer patients diagnosed late and via emergency routes.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer risk assessment/clinical decision support tools be tested and the most effective be made available in all primary care practices. Appropriate support be provided to enable GPs to utilise these tools at practice level and, where possible, a scaled-up version should be made available at CCG level.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>If proven to be effective and feasible, rapid access outpatient pathways should be introduced to prevent unnecessary emergency admissions.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation 5</th>
</tr>
</thead>
</table>
| A timed pathway for patients with suspected lung cancer admitted as an emergency, from time of initial presentation. This would include:  
  - Seeing a member of the Acute Oncology Service or lung team within 24 hours  
  - A CT scan conducted within 48 hours  
  - Review by the lung multi-disciplinary team (MDT) within a week.  
  - Being seen by a member of the lung MDT within a week. |

<table>
<thead>
<tr>
<th>Recommendation 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs be able to make direct access referrals for CT scans for patients with suspected lung cancer.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recommendation 7</th>
</tr>
</thead>
<tbody>
<tr>
<td>All chest x-rays and CT scans be formally reported within four days. The individual requesting the x-ray must acknowledge and act upon the result. Local mechanisms should be in place to ensure scans which suggest a possible diagnosis of lung cancer trigger referral to a specialist Rapid Access Lung cancer clinic.</td>
</tr>
</tbody>
</table>

---

4   Tackling Emergency Presentation of Lung Cancer: An Expert Working Group Report and Recommendations
Recommendation 8
Direct telephone or email access between GP practices and secondary care consultants to speed discussion about high risk cases.

Recommendation 9
Centralised systems be set up, either at GP federation, CCG or regional levels, in order to ensure data can be shared.

Recommendation 10
A Clinical Nurse Specialist (CNS) be available to all patients undergoing investigations for suspected lung cancer.

Recommendation 11
All patients diagnosed in an emergency setting be seen within 24 hours by an Acute Oncology Nurse, who then acts as the patients' key worker until they are safely handed over to the appropriate CNS.
Introduction by Dr Tom Newsom-Davis

In order to tackle the poor cancer survival in the UK, the reason for the high numbers of patients diagnosed via the emergency routes must be explored and acted upon. Between 2006 and 2010, 24% of all cancer patients and 39% of lung cancer patients in the UK were diagnosed as a result of an emergency presentation\(^v\). Rates have now decreased slightly, to around 34%\(^ix\), but this figure remains far too high, particularly as this route to diagnosis is associated with late presentation, when cancers are often less amenable to curative treatment, and therefore has a direct correlation with lower 1-year relative survival\(^vi\).

The emergency diagnosis of lung cancer is common across Europe\(^vii\), is associated with older age and greater social deprivation\(^viii\), and represents a significant burden on acute services, with an average length of hospital stay of 8.2 days, at a total cost of £26.5m to the NHS\(^ix\).

It has been an honour to chair this Working Group of lung cancer healthcare professionals and patient group representatives, all of whom have offered insight and expertise into this area. There is much work still to do, but I hope our recommendations can be implemented so that we can all improve outcomes for this important patient group.

Dr Tom Newsom-Davis BSc PhD FRCP
Chair of the Expert Lung Cancer Working Group
Individuals and groups working across lung cancer were drawn together in an Expert Lung Cancer Working Group, (ELCWG), to address the issue of the large number of lung cancer patients being diagnosed via emergency routes in the UK each year. The aim of the ELCWG was to develop recommendations to reduce the incidence of the emergency presentation of lung cancer in the UK and to improve the poor outcomes these patients typically face. Membership of the group includes patient advocacy groups, nurses, GPs, lung specialists and oncologists. Guidance for this report and its recommendations has also been sought from commissioners, members of the UK Lung Cancer Screening Trial Group (UKLS), those working on the Accelerate, Coordinate, Evaluate (ACE) project and, of course, patients themselves.

The ELCWG was established following a Guardian roundtable discussion in late 2014 entitled “It’s Time to Stop Ignoring this Curable Cancer”. This took place in response to the publication of data by the National Cancer Intelligence Network (NCIN) which highlighted that almost 40% of lung cancer cases in England were diagnosed as part of an emergency presentation between 2006 and 2010. Emergency presentation includes patients attending A&E, emergency GP referrals to an inpatient setting (non-two week wait referrals) and emergency admissions to either an inpatient or outpatient setting. This figure has since reduced to around 34% but this still remains significantly higher than for other cancer sites, which see around 20% of cases diagnosed via emergency routes. At the roundtable it was agreed that more action was required to improve outcomes for this group of patients across the whole patient pathway.

Overall survival for lung cancer is poor; just 10% of patients survive for five years post-diagnosis, in comparison with over 80% of breast and prostate cancer patients. For lung cancer patients diagnosed as part of an emergency admission the outlook is even worse, with patients having more advanced stage disease than those diagnosed through other routes, as well as poorer survival. Action must be taken to ensure patients are diagnosed as early as possible, and that those who present via emergency routes receive the best care and have their condition appropriately managed as quickly as possible.

Remit of the group

The ELCWG was tasked with specifically examining the following:

• Why lung cancer patients are diagnosed late;
• If the proportion of lung cancer patients who present via emergency routes can be lowered;
• How to ensure patients diagnosed via emergency routes receive the best possible treatment and quality of care;
• If it is possible to improve outcomes for lung cancer patients diagnosed through emergency routes.

Three full meetings of the ELCWG have taken place, along with two rounds of teleconferences focussing in on specific elements of the patient pathway: primary care; acute oncology; the interface between primary and secondary care; commissioning; and the overall patient experience.
A note about lung cancer

Much work is being done to improve early diagnosis of lung cancer, and the ELCWG has taken into account the efforts being made to increase public and primary care awareness of the disease, as well as the new treatment options that are rapidly becoming available. Despite being one of the most difficult-to-treat cancers, advances in surgery, chemoradiotherapy, and stereotactic radiotherapy have improved cure rates in both early stage and locally advanced disease. In advanced disease, where there are no curative treatments, the development of epidermal growth factor receptor (EGFR) and anaplastic lymphoma kinase (ALK) inhibitors has revolutionised prognosis. Meanwhile, newer agents, such as immuno-therapies which harness the immune system to target the cancer, have the potential to improve survival in patients whose tumours do not harbour the molecular targets necessary to benefit from personalised medicines.

The ELCWG welcomes the publication of Cancer Research UK’s Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020. There are a number of areas of alignment between the recommendations made by the Independent Cancer Taskforce and ours and, if we are to be successful in improving lung cancer incidence and mortality rates, both sets of recommendations should be considered and implemented as a priority.

Research is crucial to continuing progress in the prevention, diagnosis and treatment of lung cancer. Traditionally lung cancer has been underfunded in research terms compared to the overall burden of disease it has caused. Cancer Research UK has identified lung cancer as a cancer of unmet need, and has prioritised funding in this area, including work to develop and deliver more targeted treatments based on the genetic makeup of a patients’ cancer. It is essential that funding for lung cancer research continues, and that patients are given the opportunity to participate in clinical trials.

Key Facts

Lung cancer is the most common cause of cancer mortality in the UK amongst both men and women, and the second most common cancer diagnosed. There were 44,488 new diagnoses of lung cancer in the UK in 2012; 24,005 men and 20,483 women. Lung cancer has a direct correlation with socio-economic status; for males, lung cancer rates are 50.8% higher in the North East of England (116.7 cases per 100,000 males) compared to the South East. For females in the North East of England, the rates for lung cancer were double that of those in the South East (102.2 cases per 100,000 versus 50.5 cases). Lung cancer patients presenting via emergency routes tend to be older and of lower socio-economic status, and generally display poorer overall health, as well as being more likely to present with advanced stage disease when curative treatment may not be possible.
The ELCWG agreed there was a need to improve awareness of the symptoms of lung cancer, both common and atypical, amongst the public and healthcare professionals. Patient representatives stated they had reported to their GPs what they now know to be symptoms indicative of lung cancer, during repeat visits prior to being referred on for further investigation. A number of patients noted that they had not experienced the more common symptoms associated with lung cancer, such as a persistent cough and breathlessness, or that coughs had been temporary and had subsided quickly. Some had been diagnosed with pneumonia, and many had experienced recurring chest infections but this had not been followed up with investigations for lung cancer. Patients felt GPs were often reliant upon inappropriate tests, including ones measuring lung function, which had usually produced normal and even good results, especially for those who were fit and active.

Patients agreed it was vital to increase awareness of all the signs and symptoms of lung cancer - including less common ones such as back and shoulder pain, chest infections, weight loss and finger clubbing - amongst primary care clinicians, who are often the first point of contact for patients. It was also felt that the general public is not well informed about lung cancer symptoms, and that awareness campaigns should highlight the range associated with the disease, rather than just focussing on a recurrent cough as the primary indicator, as was the case in the 2012 Be Clear on Cancer lung cancer awareness campaign. Of note, Be Clear on Cancer has been run nationally more than once for lung cancer, with previous campaigns highlighting symptoms other than cough within their campaign materials.

Recommendation 1

Funding for a national campaign (such as Be Clear on Cancer, Detect Cancer Early or Be Cancer Aware) be maintained or increased, in order to raise public awareness of the signs and symptoms of lung cancer.
Raising awareness
In an evaluation of large-scale interventions on public awareness of lung cancer, Ironmonger et al. (2015) found that, following the 2012 Be Clear on Cancer lung campaign, there were “small decreases in spontaneous mentions of some lung cancer symptoms that were not the focus of the campaign.” This was thought to reflect a shift in the type or significance of symptoms that came to the forefront of the respondents’ minds. It was recommended that awareness interventions monitor for the potential impact of only focussing on select symptoms, as this could negatively change the public’s perceived significance of other symptoms.xixAwareness campaigns need to find a balance between communicating a comprehensive message, and one that is simple and clear enough to be understood and remembered. Research has shown that both the regional pilot and the national public awareness campaigns, such as Be Clear on Cancer, resulted in a stage-shift to earlier stage at diagnosis and an increase in the proportion of patients undergoing potentially curative surgery.xix

Echoing the call for an awareness campaign
Our recommendation for a commitment to the funding of a national campaign to raise awareness of the signs and symptoms of lung cancer chimes with the call within Achieving World-Class Cancer Outcomes: A Strategy for Cancer 2015-2020xiv. The Independent Cancer Taskforce report highlights the need for continued investment in the Be Clear on Cancer campaigns to raise awareness, and they state “campaigns should include lung, breast over 70s, and other cancer types where pilots prove effective.” They suggest the campaigns run for at least two years, and that NHS England, Public Health England and the Department of Health (DH) are jointly involved in planning in order to ensure an integrated roll-out.

A range of signs and symptoms
Lung cancer symptoms can include back and shoulder pain, finger clubbing (changes in the shape of the knuckles and/or nail area) and headaches as well as more typical symptoms such as recurrent coughs, weight loss and chest pain.

In order to improve patient outcomes, the general public, as well as healthcare professionals, need to be more aware of the signs and symptoms of lung cancer. Greater awareness of signs and symptoms, and an increased understanding of the potential of new treatments, would help speed diagnosis and maximise the potential for the disease to be caught at an earlier stage when there may be the potential for curative treatment.
**Recommendation 2**

A commitment be made to rapid adoption of a targeted, evidenced-based lung cancer screening programme, as deemed effective by the UK National Screening Committee, in order to reduce the number of lung cancer patients diagnosed late and via emergency routes.

The ELCWG had a number of discussions around the need for a national lung cancer screening programme, and consulted with Professor John Field, the Chief Investigator of the UK lung cancer screening trial, to develop a recommendation around this. The results of the US National Lung Screening Trial (NLST), published in 2011, are considered a landmark event in lung cancer research as they demonstrated a 20% decrease in mortality in patients screened for lung cancer with low-dose CT as compared to chest x-ray\[^{xxiii}\]. The pilot UK screening trial (UKLS) will report in 2015, and this data will be pooled with that from the NELSON trial in late 2016. There are also a number of smaller European studies, which have recently reported but were not fully powered to provide an answer about the mortality advantage from low-dose CT screening.

Screening programmes carried out in the UK have to be deemed clinically viable and cost-effective by the UK National Screening Committee, and should be targeted at those groups most at-risk, who would be most likely to benefit, with clear communication of the benefits and harms. In *Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020*\[^{xiv}\], the Independent Cancer Taskforce suggest that the Be Clear on Cancer brand be considered in attempts to improve uptake of screening programmes, particularly with disadvantaged groups. A well-known brand with a clear, straightforward message may resonate with hard-to-reach groups, making a lung cancer screening campaign more effective in reaching our key demographic.

**National Lung Screening Trial (NLST)**

The NLST was conducted in the United States, comparing low-dose helical computed tomography (often referred to as spiral CT) with standard chest X-ray. Helical CT uses X-rays to obtain a multiple-image scan of the entire chest, while a standard chest X-ray produces a single image of the whole chest in which anatomic structures overlie one another\[^{xxiv}\]. NLST trial participants had three rounds of screening and were randomised in a CT screen arm or a chest X-ray arm. The trial demonstrated a 20% decrease in mortality in the CT arm, providing the worldwide lung cancer community with evidence for a mortality benefit by CT screening. The randomised trial, of over 55,000 individuals, was stopped when the 20% decrease in lung cancer mortality was reported in the CT arm in current and former smokers of 55-75 years of age. The trial detected adenocarcinomas and squamous cell carcinomas more frequently at a very early stage of the disease, which were suitable for surgical resection. Small-cell lung cancers, which are very aggressive, were infrequently detected at early stages by either low-dose helical CT or chest x-ray\[^{xxv}\].

**US Preventative Services Taskforce (USPSTF)**

Five clinical professional groups in the USA have supported the implementation of CT screening and, more recently, the US Preventive Services Task Force (USPSTF) has also recommended implementation\[^{xxvi}\] with Medicare, the insurance group, agreeing to cover the screening costs for people who meet a certain criteria. The USPSTF recommends annual screening for lung cancer\[^{xxvii}\] with low-dose CT in adults aged 55 to 80 years who have a 30 pack-year smoking history and currently smoke, or have quit, within the past 15 years. They suggest that screening be discontinued once a person has not smoked for 15 years or if they develop a health problem that substantially limits life expectancy or the ability or willingness to have curative lung surgery.

[Pack-years are calculated by multiplying the number of packs of cigarettes smoked per day by the number of years the person has smoked, e.g. 1 pack-year is equal to smoking 20 cigarettes (1 pack) per day for 1 year\[^{xxviii}\].]

**NELSON Trial**

The situation in Europe is more complex, as it has been uniformly agreed to await the outcome of the NELSON trial and the pooling of the EU smaller trials in 2016, which will provide European mortality and cost effectiveness data\[^{xxix}\]. The NELSON\[^{xxi}\] trial investigated whether screening with low-dose CT could reduce lung cancer mortality by at least 25% compared to no screening at 10 years of follow up. Participants were
aged 50-75 and had smoked more than 15 cigarettes a day for more than 25 years, or more than 10 cigarettes a day for 30 years, and were still smoking or had quit less than 10 years earlier.

The NELSON trial introduced a completely new nodule care pathway, measuring the volume of the CT detected nodules and calculating the volume doubling time. This has provided a much more accurate methodology for identifying nodules which are suspicious but not considered suitable for referral to a MDT clinic. This, in turn, has made a major contribution to reducing 'false positives' to 3.6%xxx. The UKLS trial team also utilised this approach and have found a very similar false positive rate in the pilot trial.

**UK Lung Cancer Screening trial (UKLS)**
The pilot UKLS is the first lung cancer screening trial to take place in the UK. It aims to demonstrate that lung cancer CT screening can be undertaken by approaching individuals who are at a high risk of the disease and also implementing the volumetric based nodule care pathwayxxxi. The UKLS pilot provides in depth information on how to set up and plan for a national lung cancer CT screening programme, including using a risk prediction model to identify high risk individuals in the population, target age ranges, use of volumetric analysis of CT-detected nodules, and a pathway for the management of indeterminate CT nodules. The UKLS pilot will not provide mortality data as it is not a large enough trial, however, Professor John Field is currently organising pooling the UKLS data with the NELSON trial dataset (detailed above) in 2016/17. This will provide mortality data which will be submitted to the UK National Screening Committee, enabling a decision to be taken as to whether a programme of CT lung cancer screening is recommended and implemented in the UK.

Cost effectiveness modelling based on UK data as part of the UKLS pilot has shown that CT screening for lung cancer would be within NICE parameters. Currently the ACE programmexxxii (see page 16) is enabling Clinical Commissioning Groups (CCGs) to undertake ‘case finding’ projects in Manchester, as well as at University College London, Nottingham, Cheshire and Kings Hospital. These utilise a number of different approaches which focus on hard to reach populations, and some use mobile CT scanners to enhance uptake.

---

A recent (2015) Public Health England (PHE) reviewxxxiii of the UK National Screening Committee (NSC) concluded that the target population for any screening campaign should be sufficiently large to enable safe, clinically and cost effective screening. The cohort to be offered screening “would regard themselves as not necessarily having symptoms of the disease or to be at risk of the disease”xxxiii. They identified that, for a screening programme to be effective, the population to be screened should be proactively approached, for example by written invitation, or verbal invitation at the time of the contact with the health service, to encourage attendance and ensure that those offered screening are properly informed of the potential benefits and risks in order to help make an informed choice.
Primary care clinicians on the ELCWG thought that most GPs would value tools to help recognise patients at high risk of lung cancer, both when identifying them for initial check-ups and when deciding whether they should be referring them on for investigation. System-based tools for risk assessment are already in development and are being tested in certain areas. Clinicians felt that the focus should be on developing and rolling out simple tools which prompt all GPs and primary care clinicians to “think lung cancer”.

Two different lung cancer risk tools are available for differing clinical situations: system-based tools use patients’ current symptoms to provide an indication as to who should be referred for further investigations, whilst lung cancer risk prediction models identify high risk individuals without symptoms for future CT screening programmes. The Liverpool Lung Project (LLP) risk prediction model was used in the UKLS trial to select individuals, while in the Pan Canadian trial the PLCO2012 (a cancer screening programme for prostate, lung, colorectal and ovarian cancers) risk model was found to improve screening efficiency

Lung Cancer Risk Prediction Models
The LLP risk model is an individual risk prediction model for lung cancer that estimates the probability of an individual, with a specified combination of risk factors, developing lung cancer within a five year period. The LLP has been validated by three independent external data sets, two international and one UK-based, which demonstrate evidence of the benefits of stratifying patients for lung cancer CT screening.

Recommendation 3
Lung cancer risk assessment/clinical decision support tools be tested and the most effective be made available in all primary care practices. Appropriate support be provided to enable GPs to utilise these tools at practice level and, where possible, a scaled-up version should be made available at CCG level.

System-based tools
There are a number of system-based tools that can be used to calculate a patient’s risk of having cancer. QCancer uses annually updated and recalibrated algorithms developed by Dr Hippisley-Cox of Nottingham University, to calculate risk scores based on a number of parameters including symptoms, (for example; loss of appetite, coughing up blood (haemoptysis), night sweats and anaemia) body mass index (BMI) and family history of conditions such as cancer, diabetes and chronic obstructive pulmonary disease (COPD). QCancer is part of a wider research database, QResearch, which has already been used to identify patients at risk of cardiovascular disease (QRisk). A different approach, the cancer decision support (CDS) tool, is a collaboration between Macmillan Cancer Support and software manufacturer BMJ Informatica, and is part-funded by the Department of Health.

The CDS incorporates a Cancer Risk Assessment Tool (RAT) developed by Professor Willie Hamilton of Exeter University Medical School, which quantifies the risk of common symptoms being associated with cancer to help GPs decide which patients (below the NICE threshold) would benefit from investigation. The CDS also includes the QCancer algorithms, which alert the user to “red flag” combinations of risk factors, such as those listed above.

The CDS was tested in more than 500 GP surgeries across the UK to determine its usefulness and whether it could be incorporated into the 10 minutes (or less) standard GP consultation. An evaluation, coordinated by Cancer Research UK on behalf of the Department for Health, showed that in 54% of cases the cancer risk perceived by the GP was the same as that predicted by the tool. However in 31% of cases the tool calculated risk was higher than the GP had thought, whilst in 15% it was lower. Use of the CDS tool did not influence the decision to investigate or refer in the majority of cases (81%), but in 19% of consultations GPs indicated that they would not have done so had they not used the tool. A further tool, which was developed using logistic regression analysis (LRA) to identify the socio-demographic and clinical features associated with cancer up to two years before diagnosis, also merits consideration. This has the potential to identify people with cancer earlier and hence bring forward treatment options and improve outcomes.
Integrated versions of these and other tools are being developed and refined in partnership with clinicians and researchers across the country. Clinical champions within primary care should be invited to be involved in the roll out of tools across a CCG area or cluster of GP surgeries. The leadership and management skills of respiratory lead GPs with Special Interest (GPwSI) could be employed to ensure successful roll-out, and provide support to practices.

Sharing data
Certain CCG areas, such as Milton Keynes, operate via a single IT system with one central reporting unit. This creates the opportunity to analyse primary care records across an entire population, targeting high risk patients by inviting them for a consultation. Such an approach would minimise the potential “postcode lottery” of care for patients which can occur when GPs choose not to use system-based tool that are available.

The ELCWG felt that using and sharing data would provide value for money to the NHS, as well as delivering a more tailored service for patients. It was acknowledged that not all practice groups would be able to benefit from shared data systems, but that risk assessment tools or alerts could easily be added onto most primary care systems in order to identify patients with a high risk of lung cancer to pro-actively target. The ELCWG felt that traditional postal mail-outs asking patients to come in for check-ups tend to be ineffective, and that it would be more beneficial to engage patients by telephone. Data sharing was deemed to be the best way of targeting at-risk groups and those who do not usually visit the GP. To achieve this, information governance issues need to be addressed so that data can be shared within the NHS, something that many areas may find difficult given current data protection processes.
A wide range of initiatives are underway to try and increase early diagnosis of lung cancer.

Accelerate, Coordinate, Evaluate (ACE) Programme
The ACE (accelerate, coordinate, and evaluate) Programme is a collaboration between NHS England, Cancer Research UK and Macmillan Cancer Support, and is sponsored by Professor Sean Duffy, the National Clinical Director for Cancer. The aim of the ACE programme is to improve early diagnosis of cancer across a range of tumour types by learning from current best-practice and trialling new projects. It comprises around sixty projects - grouped into clusters - across the NHS. 12 projects are focussed on lung cancer, and another 10 have the specific aim of improving care pathways for patients who present with vague symptoms, some of whom will have lung cancer.

Lung Cancer Clusters
The 12 lung cancer projects fall within two distinct clusters:

1. The Lung Pathway Cluster
This cluster is focussed on streamlining lung cancer pathways from referral to diagnosis, with particular attention being given to arrangements for accessing CT scans. Some projects will be implementing more efficient straight-to-CT arrangements and others will be testing the impact of GP Direct Access to CT (when agreed criteria are met). The interface arrangements between primary and secondary care and the information and communication flow are also being examined; one project will look at the impact of local data analysis and clinically-led performance management arrangements.

2. The ‘Proactive Approaches’ Cluster
This cluster of projects explores the impact different proactive approaches can have on the identification and testing of high risk patients before they present with symptoms associated with lung cancer. Many of the projects offer low dose CT scans to such patients. One programme, called the Liverpool Healthy Lung Project, aims to identify hard-to-reach individuals by using the LLPv2 risk prediction model and offering them a CT scan. Any CT-detected nodules will then be assessed based on UKLS protocol. Another project aims to widen the availability of chest x-rays by establishing a self-referral service, in addition to public awareness and professional educational initiatives.

Vague Symptoms Cluster
The Vague Symptoms Cluster of projects explore and test different multi-disciplinary diagnostic centre models in order to identify which would work best within the UK NHS system.

Dr Tom Newsom-Davis is leading one of these projects: the Acute Diagnostic Oncology Clinic at Chelsea and Westminster Hospital provides next-day access to a diagnostic service for patients with suspected cancer who are medically unable to wait for an urgent (two week) cancer, with the aim of speeding up diagnosis and avoiding patients having to present via an emergency route.

The ACE Programme will begin to share practical materials and preliminary results from late 2015, with full evaluation reports becoming available in late 2016 or early 2017.

Recommendation 4
If proven to be effective and feasible, rapid access outpatient pathways should be introduced to prevent unnecessary emergency admissions.
Cancer Diagnosis in the Acute Setting (CADIAS)

Expert Lung Cancer Working Group members, including Dr Tom Newsom-Davis and Dr Cathy Hughes, have been involved in the Cancer Diagnosis in the Acute Setting (CADIAS) study, conducted on behalf of the London Cancer Alliance (LCA) and funded by NHS England. CADIAS was set up to investigate the issues surrounding the emergency presentation of lung and bowel cancer. Understanding why so many patients are diagnosed with their cancer through this route is important for policy to improve outcomes and patient experience, and reduce burden on services and costs. The study involved seven hospital across South and West London and data was collected from patients (using a semi-structured patient interview), from primary and secondary care.

Analysis of the lung cancer patient cohort found that 14% of the 111 patients who completed interviews had short histories of symptoms (<2 weeks), but nearly half reported symptoms for more than 12 weeks. 72% had seen a GP at some time since their symptoms started, and 22% had done so three or more times. About one in five patients had been referred by a GP to outpatients by the time the emergency presentation took place. About 16% of patients had delayed presentation to a doctor for more than 12 weeks; these patients were older and more likely to report fear of what the doctor might find.

The conclusions from the study were that interventions to reduce emergency presentations of lung cancer should focus on encouraging identification and referral of high risk patients in primary care, and improved access to secondary care services including imaging and acute oncology. It was also felt that there is a need to address barriers to symptomatic presentation, especially amongst older patients.

Care in the Emergency Department

The fact that 34% of lung cancer patients are diagnosed as a result of an emergency presentation may come as a surprise to many doctors working in Emergency Departments (ED). It is vital that the pathways of care for patients either diagnosed or suspected of a diagnosis of lung cancer in the ED receive faultless transition of care. Pathways should be agreed locally, ideally with the involvement of Acute Oncology Services, to ensure that patients are made aware of their possible diagnosis, and referred to a rapid access clinic to be seen within two weeks. The patient and their GP need to be fully informed throughout the process and contact details for the rapid access clinic should be made available.
GPs need to be equipped with the resources to diagnose lung cancer earlier and avoid emergency presentations. The ELCWG felt that this should include allowing all GPs to request CT scans for patients with suspected lung cancer, an approach being investigated as part of the ACE programme\textsuperscript{xii}. Currently, GPs have direct access to four major diagnostic tools for suspected cancer: chest X-rays for suspected lung cancer, non-obstetric ultrasound for ovarian cancer, flexible sigmoidoscopy for colorectal cancer and MRIs for brain cancer. However access to these varies by locality and availability to tests.

The ELCWG felt that direct GP access to CT would not result in large numbers of extra referrals for lower-risk patients, but instead would probably produce a reallocation of resources - from CT scanning of patients at the point of emergency admission to scanning earlier in the diagnostic pathway. Indeed GP access to CT could mean overall savings for the NHS by reducing emergency admissions and avoiding late diagnosis. Evidence of the benefit of direct GP referral to CT scan will be evaluated towards the end of 2015 through the ACE programme, however, the ELCWG felt a recommendation on this should be included within this report as the benefits of such a scheme have been demonstrated through similar approaches in Denmark\textsuperscript{xxxix}.

The Danish model
A new process of direct referral for CT was introduced in Denmark\textsuperscript{x} in 2008 in response to poor lung cancer survival rates and delays in presentation, diagnosis and treatment. This fast-track system allows GPs to refer patients who they believe to be at high risk of lung cancer for screening, within 72 hours of initial presentation. Evidence suggests that providing GPs with this direct access results in a greater number of lung cancers being diagnosed at an earlier stage, allowing for surgery and better patient outcomes.

Studies have demonstrated that Danish GPs are willing to use the direct referral system, and are confident in referring patients for CT. However, further research is required to link the referral system with a reduced mortality rate for lung cancer.

Impact on radiology services
The ELCWG considered the impact of additional CT scans requested directly by GPs on radiology services across the UK. As well as lung cancer, non-malignant diagnoses are likely to be made by the CT scans, requiring further radiological expertise to fully evaluate. This will have implications for the radiology workforce and equipment demands. A former radiologist on the

---

**Recommendation 6**

GPs be able to make direct access referrals for CT scans for patients with suspected lung cancer.

**Recommendation 8**

Direct telephone or email access between GP practices and secondary care consultants to speed discussion about high risk cases.

**Recommendation 7**

All chest x-rays and CT scans be formally reported within four days. The individual requesting the x-ray must acknowledge and act upon the result. Local mechanisms should be in place to ensure scans which suggest a possible diagnosis of lung cancer trigger referral to a specialist Rapid Access Lung cancer clinic.

**Recommendation 9**

Centralised systems be set up, either at GP federation, CCG or regional levels, in order to ensure data can be shared.
ELCWG, who now works in commissioning, highlighted there were already significant pressures on general radiology services, as well as recruitment issues into diagnostic radiology.

The Royal College of Radiologists (RCR) Clinical Radiology UK Workforce Census 2014 report\textsuperscript{xii} highlights the main reasons for these issues. It states, “These root causes are, in the main, an inadequate supply of resources, including availability of radiologists and at the same time a significant increase in demands made on radiology departments” (p.51). These findings have been echoed by the recent ‘Horizon Scanning’ report\textsuperscript{xxiii}, commissioned by Cancer Research UK.

**Communication between healthcare professionals**

The ELCWG felt that, in order to enhance communication between primary and secondary care, and to improve the patient journey, GP practices and secondary care consultants should have direct telephone access to each other without the need to speak to GP practice reception or consultants’ secretaries. This would include sharing phone numbers on radiology reports. If GPs are to have direct access to CT scans, results need to be accompanied by information about the significance of the results, ideally with the reporting radiologist contacting the GP directly when findings are suspicious for a new cancer diagnosis.

The RCR’s Standards for the Reporting and Interpretation of Imaging Investigations highlights the importance of direct telephone access: “Direct communication by telephone is clearly indicated if a patient has a medical condition requiring emergency treatment, for example pulmonary embolism or tension pneumothorax. Additional mechanisms for ensuring that the referrer receives the report in a timely fashion are also indicated when the usual method of reporting could lead to delays in treatment.”\textsuperscript{xi}

Emergency Department clinicians must work together with their Radiology colleagues when reviewing chest x-ray reports in order to ensure that all patients with suspected lung cancer are contacted as soon as possible, with provision being made for immediate follow-up and investigation and support.

**NICE Guidance**

The recently published NICE Guideline, Suspected cancer: recognition and referral (NG12)\textsuperscript{xlv}, provides updated advice for GPs on which patients to refer for investigations of possible cancer. It replaces the 2005 NICE guideline (CG27). With respect to lung cancer, the new guidance advises:

- Referral via the suspected cancer pathway for an appointment within 2 weeks if there are chest X-ray findings that suggest lung cancer or if the patient is aged 40 and over with unexplained haemoptysis.
- An urgent chest X-ray (within 2 weeks) for people aged 40 and over if they have 2 or more of the following unexplained symptoms, or if they have ever smoked and have 1 or more of the following unexplained symptoms: cough, fatigue, shortness of breath, chest pain, weight loss and appetite loss.
- An urgent chest X-ray (within 2 weeks) for people aged 40 and over if they have any of the following: persistent or recurrent chest infection, change in finger nail shape (clubbing), enlarged lymph nodes around the neck (supraclavicular or persistent cervical lymphadenopathy), clinical signs within the chest consistent with lung cancer or increased platelet count (thrombocytosis).

There is considerable concern amongst the ELCWG that this guidance specifically excludes an assessment of the composite risk prediction tools, and many feel it may not improve early diagnosis. Although mentioned in part of the guideline (away from the lung cancer recommendations), it is not stressed that even if a chest x-ray has been reported as normal or not showing possible cancer, there should still be prompt referral for individuals at high risk of developing lung cancer. Paradoxically, failure to refer in these circumstances might delay diagnosis in those more likely to benefit (a near normal chest X-ray could imply earlier stage cancer).
Specialist nurses

**Recommendation 10**

A Clinical Nurse Specialist (CNS) be available to all patients undergoing investigations for suspected lung cancer.

**Recommendation 11**

All patients diagnosed in an emergency setting be seen within 24 hours by an Acute Oncology Nurse, who then acts as the patients’ key worker until they are safely handed over to the appropriate CNS.

The ELCWG discussed the importance of patients undergoing investigation for lung cancer having access to a specialist nurse in order to support them through the diagnostic process. Lung cancer CNSs are key members of the multi-disciplinary team (MDT) and are well placed to support patients over this stressful period. The ELCWG recognised that, as well as lung cancer CNSs, there were other specialist nurses such as respiratory, palliative care and acute oncology, who could provide this service for patients.

**Key workers**

Patient representatives felt it was important to raise awareness of the role CNSs play as key workers, delivering information, accessing support services, providing continuity of care, following up investigations and helping obtain opinions from other clinicians. It is notable that in *Achieving World-Class Cancer Outcomes: A Strategy for Cancer 2015-2020* the Independent Cancer Taskforce stress the need to systematise patients having access to a CNS, or other key worker, to help coordinate their care and “establish patient experience as being on a par with clinical effectiveness and safety”.

**Variation**

There is significant variation in the provision of oncology CNSs across the UK, with an average of only one lung cancer nurse for every 161 people diagnosed with lung cancer in England. Patients on the ELCWG noted that there was a need to ensure more equitable access to lung CNSs, or their equivalent, across the UK. The point at which a CNS becomes available to a patient was discussed. The ELCWG felt that patients undergoing investigation for lung cancer would have particular benefit from CNS input because the nurse could support the patient through investigations, helping them understand the process and findings. There would then be continued care post-diagnosis from that CNS or a colleague. Nurses on the ELCWG reported that there is a current trend towards making CNSs work on wards and in Acute Oncology Services (AOS) instead of focusing on their primary role, something which could negatively impact on patient experience and their ongoing care. It was felt by the ELCWG that all patients who are diagnosed in the emergency setting should be seen within 24 hours by an Acute Oncology nurse, who should act as the patients’ key worker until they are safely handed over to the appropriate tumour-site specific CNS. Acute Oncology is moving toward a seven day service, therefore the AOS nurse role will be pivotal in the management of patients diagnosed via emergency routes.

**Case studies**

Examples of the positive impact of nurse specialists can be seen across the country. Macmillan Cancer Support have highlighted the potential of the CNS in reducing unplanned emergency admissions, saving money and supporting patients to recover at home. An economic modelling analysis focussing on Manchester found that up to 10% of cancer-related NHS expenditure could be released into the system through service improvements created by a CNS for breast and lung cancer patients diagnosed through the two-week wait pathway.

**North Tees**

An analysis of patient experience in North Tees Hospital suggested lung cancer patients and carers were encountering problems following admission to the Emergency Assessment Unit. These included unnecessary investigations, poor symptom management, lack of recognition of end of life, delays in discharge and inadequate communication. This resulted in worse patient experience and increased costs from lengthy hospital stays and needless tests. To tackle the
problems, the CNS team at North Tees used its specialist knowledge of lung cancer to support patients admitted as emergency cases to reduce the length of inpatient stay (from 10.8 to 9.7 days) and help the patient and their carers understand and manage their symptoms.

**East Anglia**

The East of England Strategic Clinical Network and Macmillan Cancer Support jointly funded the *Transforming Community Cancer Care Programme (TCCC)*. This was launched in 2011 and involves a team of primary care nurses providing patient care at home and in the community, with their work being closely coordinated with that of the hospital-based teams. The programme offers personalised support to patients and carers throughout the patient pathway from the point of diagnosis, and TCCC won the “Living with and Beyond Cancer” category of the Quality in Care Oncology Awards 2014.

**The support TCCC provides includes**

- providing treatments at home (where clinically appropriate);
- early assessment of emergency symptoms with the hospital acute teams;
- access to information and education;
- help and advice on managing symptoms;
- answering questions about treatment options;
- developing skills to help patients maintain their independence;
- fast-tracking/efficient access to hospital and other services.
Members of the expert lung cancer working group

Dr Tom Newsom-Davis,
Consultant Medical Oncologist, Chelsea and Westminster Hospital
Ms Nicky Adams,
Acute Oncology Nurse Consultant, Walsall Healthcare NHS Trust
Professor David Baldwin,
Consultant Respiratory Physician
Lead Clinician, Nottingham University Hospitals Nottingham Lung Cancer and Mesothelioma Centre
Ms Ashley Burns,
Information Officer, Roy Castle Lung Cancer Foundation
Dr Matthew Callister,
Consultant Respiratory Physician, Leeds Teaching Hospitals NHS Trust
Ms Paula Chadwick,
Chief Executive, Roy Castle Lung Cancer Foundation
Ms Alice Devitt,
Director of Fundraising and Communications, British Lung Foundation
Dr Shelley Dolan,
Joint Clinical Director, London Cancer Alliance
Dr Kate Haire,
Consultant in Public Health Medicine, London Cancer Alliance
Dr Cathy Hughes,
Consultant Nurse in Gynaecology and Oncology, Imperial College London Healthcare Trust
Dr Luke James,
General Practitioner, Newport Pagnell Medical Centre
Professor Sam Janes,
Professor of Respiratory Medicine, University College London
Ms Philippa Jones,
Macmillan Associate Acute Oncology Nurse Advisor and UKONS Acute Oncology Forum Lead.
Dr Jeff Keep,
A&E Lead Clinician for Acute Oncology Services, London Cancer Alliance
Dr Ernie Marshall,
Macmillan Consultant in Medical Oncology, Clatterbridge Cancer Centre
Ms Sue Maughn,
Clinical Advisor, PAN London Transforming Cancer Services Team
Mr Mike McKeivitt,
Head of Patient Services, British Lung Foundation
Mr Andy McMeeking,
Team Manager, PAN London Transforming Cancer Services Team
Dr Mick Peake,
Clinical Lead, National Cancer Intelligence Network, Public Health England
Dr Richard Roope,
Clinical Lead for Cancer, Royal College of General Practitioners
Mr Ollie Scott,
Information Services Manager, Roy Castle Lung Cancer Foundation
Ms Rachel Sharkey,
Deputy Acute Oncology Lead Nurse, Chelsea and Westminster Hospital
Ms Rachel Thomas,
Lung Cancer Nurse Specialist, Guy’s Hospital
Ms Heather Walker,
Policy Manager, Cancer Research UK
Ms Laragh Walton,
Director of Financial Strategy Implementation, The Royal Marsden
Dr Christopher Watts,
York Medical Practice, Twickenham
Mr Martin Whitehead,
National Oncology and Access Manager, Bristol-Myers Squibb
Dr Penny Woods,
Chief Executive, British Lung Foundation

Huge thanks go to our patients and patient representatives, some of whom are sadly no longer with us:

Brian, Caroline, Denise, Jenny, Peter, Stewart.

Contributions were also received from the following:

Barbara Gill,
Programme Lead, ACE, NHS England/Cancer Research UK
Professor John Field,
Clinical Professor of Molecular Oncology, University of Liverpool, Chief Investigator of the UK lung cancer Screening trial (UKLS)
Dr Nav Chana,
Chairman, National Association of Primary Care (NAPC)
References


References


xxx Background to the UKLS. Available at: https://www.ukls.org/index.html. Accessed: August 2015.


One person in five in the UK is affected by lung disease. Millions more are at risk.

We are the UK’s lung charity and we are here for every one of them, whatever their condition.

Lung disease can be frightening and debilitating. We offer hope and support at every step so that no one has to face it alone.

We promote greater understanding of lung disease and we campaign for positive change in the nation’s lung health.

We fund vital research, so that new treatments and cures can help save lives.

We are the British Lung Foundation.

Leading the fight against lung disease.

British Lung Foundation
73–75 Goswell Road London EC1V 7ER
Helpline: 03000 030 555
www.blf.org.uk
enquiries@blf.org.uk

Registered charity in England and Wales (326730) and Scotland (038415) and the Isle of Man (1177)
© British Lung Foundation 2015

Supported by