



Royal College  
of Physicians

National Lung  
Cancer Audit

# National Lung Cancer Audit 2017 Key findings for patients and carers

Published March 2018



## What does this booklet include?

This booklet provides a summary of key results from the 2017 National Lung Cancer Audit (NLCA) annual report, which looked at patients who were diagnosed with lung cancer between 1 January and 31 December 2016. The results are based on data from 140 English NHS trusts and 13 Welsh hospital sites.<sup>1</sup> Full details of the findings can be found at [www.nlcaudit.co.uk/AnnualReport](http://www.nlcaudit.co.uk/AnnualReport).

The data in this booklet are based on patient-level information that is collected by the NHS as part of the care and support of patients with lung cancer. English NHS trusts submit patient data via the Cancer Outcomes and Services Dataset (COSD). These data<sup>2</sup> are then sent to the National Cancer Registration and Analysis Service (NCRAS) (which is part of Public Health England (PHE)), where they are combined with different datasets to make the information as complete as possible, to better analyse the patients' entire pathway. The data are collated, maintained and quality assured by the NCRAS. In Wales, data are collected through the Cancer Network Information System Cymru (CaNISC), and an extract of the data is then submitted to the NLCA. More details about the data collection process can be found on page 29.

This booklet specifically looks at how organisations performed in key areas of the patient pathway. It does not include information on the types of treatment or drugs that are available to patients with lung cancer.

**We would like to thank Roy Castle Lung Cancer Foundation for working with us on this project, and for providing guidance and their expertise in writing this booklet.**

<sup>1</sup> The results in this booklet also include 40 cases from Guernsey that contributed towards the work of the NLCA.

<sup>2</sup> We use the plural 'these data' because this term is considered to be an abbreviation of 'datasets'.

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## What is the NLCA?

The NLCA was developed after it was found that UK patients with lung cancer had worse outcomes than comparable countries that spend a similar amount on healthcare. There was also considerable variation between UK healthcare organisations. The NLCA began to collect data on patients with lung cancer in 2004, in order to review the quality of lung cancer care and to identify areas for improvement and reduce variation in practice. We produce annual reports that analyse the NLCA results and set recommendations for clinical teams in England and Wales.

The NLCA strives to raise standards across all lung cancer clinical teams in order to improve treatment and outcomes for patients with lung cancer.

The NLCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh government.

Commissioned by:





## Foreword by Janette Rawlinson, patient advocate

This second annual NLCA patient and carer booklet evidences several key improvements, based on the previous audit's recommendations. The information in this booklet highlights areas where the patient pathway differs between one organisation or part of the country and another. Examining this information in detail provides an essential tool for clinical teams and managers to identify the reasons for the differences and to learn where change might deliver improvements.

The increased access to lung cancer nurse specialists (LCNSs) is particularly welcome because in coordinating and communicating many treatment aspects, LCNSs provide a vital part of the patient pathway. Likewise, the increase in the recording of patients' disease stage and performance status for daily life (PS) are encouraging because this information helps to determine the most appropriate care. An increase in surgical treatment along with the increase in earlier detections of lung cancer is also welcome.

To achieve further improvement, it is essential to reduce variation and to understand what constitutes high-quality care from patients' and carers' perspectives. There is more to do, but the results to date (demonstrated by research and clinical collaboration) offer patients and their carers confidence in light of the collective willingness to improve patient care.

## Foreword by Neal Navani, NLCA clinical lead

I am delighted to introduce our second NLCA booklet for patients and carers. The data used to compile this report have been collected by trusts in England that, for the first time, were able to validate their data for our annual report. We continue to be impressed by the high level of engagement that organisations maintain with the NLCA. The results for individual organisations are available online: [www.nlcaudit.co.uk/AnnualReport](http://www.nlcaudit.co.uk/AnnualReport).

In total, 39,041 patients were diagnosed with lung cancer in 2016, which was higher than ever before. This likely reflects the comprehensive data collection processes that feed into the NLCA. We know that high rates of surgery for lung cancer are associated with better survival, and it is therefore excellent news that 17.5% of patients underwent surgery. This is the highest surgical rate reported by the NLCA and it represents a significant improvement from 9% in 2006.

In a first for the NLCA, we ran a spotlight audit in 2017, in order to clarify why some patients with early-stage disease did not have surgery. The results highlighted the emergence of radiotherapy as an alternative to surgery in patients at high risk and also the importance of communication and patient choice.

The NLCA annual report continues to demonstrate variation in outcomes between providers across England and Wales. A key aim of the audit is to improve the care provided by poorly performing organisations so that they achieve the standards of the best performing organisations. Therefore, in another first for the NLCA, the audit team has compared organisations according to key performance measures and identified organisations that are statistically performing worse or better than the national average. Outlier organisations that are performing significantly worse than others have been notified. They have been asked to investigate their data and to provide an action plan to address their performance. We aim to publish the responses from the outlier organisations as an appendix to the annual report in March 2018.

In 2017 we also focused heavily on quality improvement work by running workshops across the country. We aim to continue this work in 2018 with further workshops and webinars. Improving the quality of different aspects of care in hospitals will translate into improved outcomes for patients with lung cancer, which will be measured by future editions of this patient booklet.

## Key findings and recommendations

The NLCA focuses on the following areas to assess lung cancer care:

- > data completeness
- > the proportion of patients with pathological confirmation of lung cancer
- > the proportion of patients where the pathology code is non-small-cell lung cancer not otherwise specified (NSCLC NOS)
- > LCNS input
- > the proportion of patients who receive a positron emission tomography-computerised tomography (PET-CT) scan before curative-intent treatment
- > the curative-intent treatment rate for patients with stage I–II non-small-cell lung cancer (NSCLC) and a PS of 0–2
- > the use of chemotherapy in patients with small-cell lung cancer (SCLC)
- > the proportion of patients with SCLC who receive chemotherapy within 2 weeks of pathological diagnosis
- > the use of systemic anti-cancer treatment rates in patients with NSCLC
- > surgical treatment for patients with NSCLC
- > the proportion of patients with lung cancer who are alive 1 year after diagnosis.

The key findings in this booklet are taken from the 2017 NLCA annual report, which looked at patients who were diagnosed between 1 January and 31 December 2016. The results are measured against the recommendations that were set in the previous year's annual report.

Each section begins with the targets that were set for 2016, followed by the key findings from the 2016 audit. Where necessary, the booklet reviews the recommendations for the next audit period (of patients who were diagnosed in 2017), in order to enable continuous improvement.

## Glossary

**Small-cell lung cancer (SCLC)** is a subtype of lung cancer, making up around 10–15% of all lung cancers.

**Non-small-cell lung cancer (NSCLC)** is a group of types of lung cancer, which makes up 85–90% of all lung cancers. It includes squamous carcinoma and adenocarcinoma.

**Not otherwise specified (NOS)** in this context this term implies that the pathological diagnosis has not been subclassified to a particular cell type.

**Stage** refers to the extent of the cancer, such as how large the tumour is and whether it has spread. Stage I indicates early-stage disease and stage IV is the most advanced stage.

**Lung cancer nurse specialists (LCNSs)** are nurses who have expert knowledge and experience in lung cancer. They are often called the key worker: they form an important part of the team of healthcare professionals who provide support, information and advice during investigations, diagnosis and treatment.

**Performance status (PS)** describes how active a patient is in terms of their ability to care for themselves, their daily activity and their physical ability. Zero is the most active level and 4 is the least active level.

**Positron emission tomography-computerised tomography (PET-CT) scan** is a combined scan including a PET and a CT to produce a three-dimensional image of the body.

## Data completeness

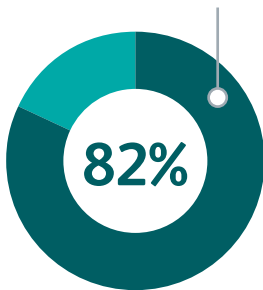
The NLCA relies on organisations giving us accurate data in order to allow us to carry out the most accurate casemix adjustment. The following three data fields should be collected because they help clinical teams to determine the best treatment for patients, which will ultimately improve their outcomes: performance status (PS); disease stage; and forced expiration volume in 1 second percentage (FEV1%) predicted.

In 2016, we made the following recommendations for data completeness.

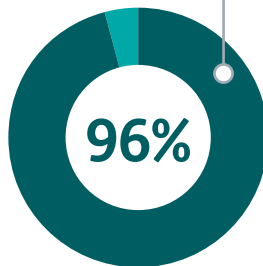
- > Both PS and disease stage should be recorded in at least 90% of cases.
- > FEV1% predicted should be recorded for at least 75% of patients.

### Key findings

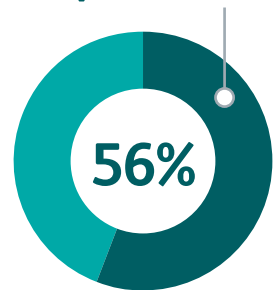
#### Performance status



#### Disease stage



#### FEV1% predicted



**Performance status (PS)** – Overall, 82% of patients had their PS recorded.

**Stage** – Overall, 96% of patients had their disease stage recorded. This continues the upward trend and is the best result that the NLCA has seen for this measure of care. The target was exceeded in both England and Wales, with English trusts recording disease stage in 96% of patients and Welsh hospital sites recording disease stage in 98% of patients.

**FEV1% predicted** – In England, only 54% of patients had this measure of care recorded. In Wales, FEV1% predicted was recorded for 94% of patients.

## Recommendations for the 2017 audit period

- > We have kept the same recommendation for both PS and disease stage, which should be recorded in at least 90% of cases.
- > FEV1 and FEV1% should be recorded in at least 75% of patients who have stage I–II disease and a PS of 0–1.

## Glossary

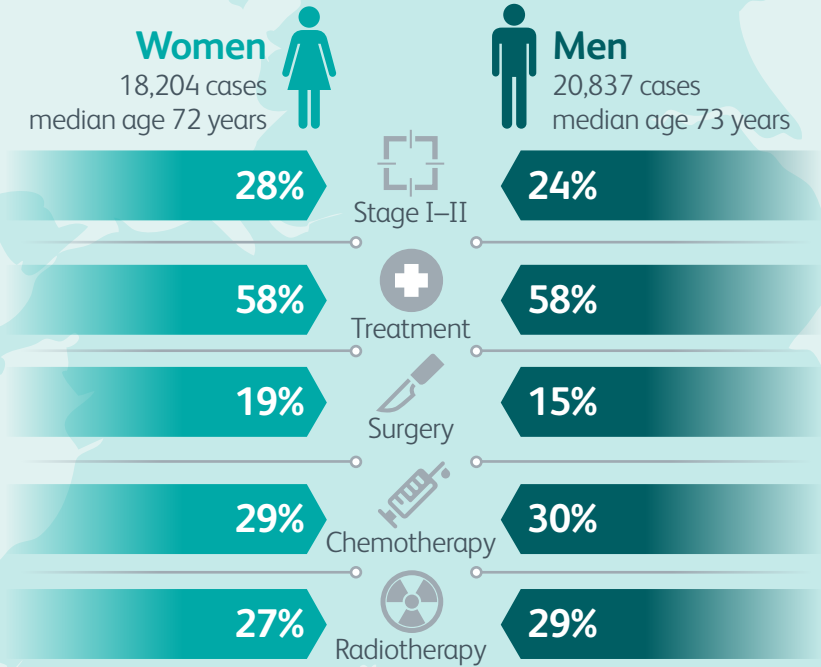
**Case-mix adjustment** is a statistical process of comparing the quality of care between organisations that takes into account important and measurable patient characteristics, eg age, sex, disease stage, social deprivation and general health.

**FEV1** is a measurement of lung capacity to determine the health of a patient's lungs. It measures the amount of air a patient can blow out of their lungs in 1 second.

**FEV1% predicted** is a patient's actual lung capacity compared with what would be expected for someone of their age, weight, gender and race.

# Demographics

## Comparison of men and women



Our analysis found that women are more likely than men to present with early-stage disease and to have surgical treatment.

The median age of patients who were diagnosed with SCLC in 2016 was 70 years. The median age was 73 years for patients who were diagnosed with NSCLC. This is the same median age as the 2015 patient cohort.



## Patient story: Pat Crawford

I was diagnosed with lung cancer in August 2012. I had a bad chest infection and my GP sent me for a scan. A tiny 'insignificant' nodule was found on my right lung. As a precaution I had a follow-up scan 6 months later; the nodule had grown to 1 cm. I was able to have surgery because the nodule was still small enough and had good margins contained in one lobe, and it had been detected early. I had open surgery for an upper-right lobectomy in September. Being told I was able to have surgery made me feel like there was going to be a positive outcome.

After surgery I experienced breathlessness, which I had not previously had; this was the most worrying thing for me. After attending my local lung cancer support group, which was run by our lead LCNS with support from Roy Castle Lung Cancer Foundation, I realised that this was common. My pre-surgery experience was very stressful. There was a really bad breakdown in communication between the medical and nursing staff, which resulted in misinformation being passed to my husband. This was eventually resolved thanks to my surgeon and a matron. The staff at the hospital were very sorry and assured me that they would make sure this never happened again.

About a year after my operation, I started swimming again and I started going to the gym too. I even abseiled down Liverpool Cathedral on 5 August 2017! I'm grateful that I had the chance to do it: there are far too many people who do not. I did not tell many people about my diagnosis, mainly because of people's attitude to this disease. People say things like: 'it's your fault for smoking'. I had a friend who more or less said this to me just before my operation! Recently I decided to tell everyone: I am now 'Miss July' in Roy Castle Lung Cancer Foundation's #HeadHigh calendar.

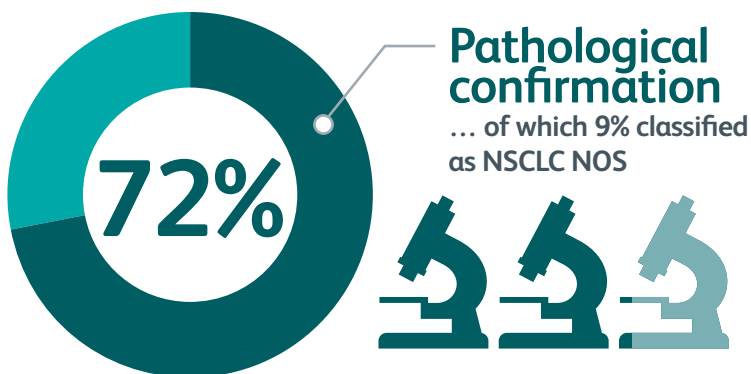
## Pathological confirmation

Lung cancer is usually diagnosed based on the findings of an X-ray/scan, and by finding cancer cells when examining tissue or fluid under a microscope (called a pathological confirmation). This is the preferred means of diagnosis, as it is more accurate and helps to determine the most appropriate form of treatment.

In some frail patients, biopsies are not appropriate, so pathological confirmation may not be possible.

In 2016, we made the following recommendations.

- > Pathological confirmation should be performed for at least 80% of patients.
- > Non-small-cell lung cancer not otherwise specified (NSCLC NOS) should not be recorded for more than 15% of patients.



## Key findings

The rate of pathological confirmation fell short of the recommended 80%, with 72% of patients having their lung cancer confirmed pathologically, which was the same result as in the 2016 report.

Only 9% of patients who had pathologically-confirmed NSCLC had a recorded subtype of NSCLC NOS; this shows a steady improvement for this measure over the past 10 years and is a further improvement on the 11% from last year.

For patients whose lung cancer has been pathologically confirmed, a more precise diagnosis is preferred (ie the cancer should be subtyped), as this helps to determine the most appropriate form of treatment.

## Recommendations for the 2017 audit period

The recommended rates for pathological confirmation have been altered for the 2017 round of audit.

- The proportion of patients with stage I–II disease and a PS of 0–1 with pathological confirmation of lung cancer should equal or be greater than 90%.
- The proportion of patients with a PS of 0–2 with pathological confirmation of lung cancer should be equal or greater than 80%.
- Non-small-cell lung cancer not otherwise specified (NSCLC NOS) rates of more than 15% should be reviewed by lung cancer clinical teams.

## Glossary

**Pathological confirmation or diagnosis** is a diagnosis of cancer based on examination of tissue or fluid.

**Biopsy** refers to the removal and examination of tissue, usually by microscope, to establish a precise (pathological) diagnosis.

**Comorbidities** are medical condition(s) or disease process(es) that are additional to the disease that is 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.

## Chemotherapy rates in patients with SCLC

Small-cell lung cancer (SCLC) is a particularly aggressive cancer, which is nearly always advanced at the time of diagnosis. Surgery is therefore often not appropriate. These tumours are, however, very sensitive to chemotherapy (and radiotherapy), which can improve survival and quality of life. Similarly, alternatives to surgery are used if a cancer has spread: surgery aims to remove the tumour and its margins.

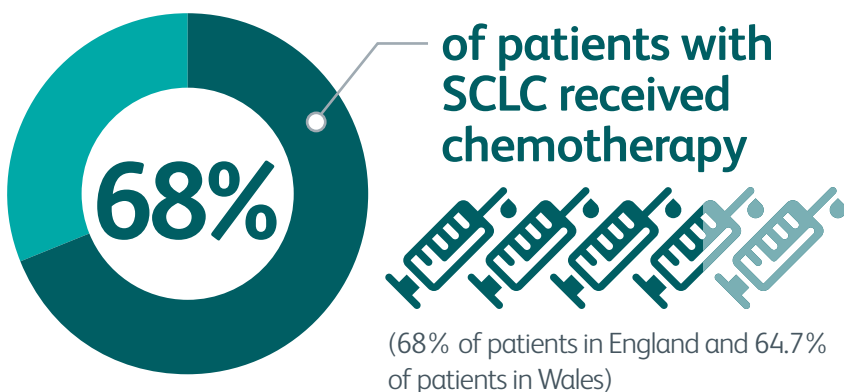
Due to the likelihood of the late-stage presentation of lung cancer, it is especially important that treatment begins as soon as possible.

In 2016 we set the following targets.

- > At least 70% of patients with SCLC should receive chemotherapy.
- > At least 80% of patients with a pathological diagnosis of SCLC should receive chemotherapy within 2 weeks of their diagnosis.

### Key findings

Across both England and Wales, 34% of patients with pathologically-diagnosed SCLC received chemotherapy within 2 weeks of diagnosis, with England achieving 33% and Wales achieving 40%. The overall result was consistent with last year's result.



## Recommendations for the 2017 audit period

For the 2017 round of audit we have set the following standards.

- > The proportion of patients with SCLC who receive chemotherapy should exceed 70% of cases.
- > The proportion of patients who receive chemotherapy for SCLC who begin treatment within 2 weeks of their pathological diagnosis should be equal to or greater than 80%.

### Glossary

**Chemotherapy** refers to a set of medicines used in the treatment of cancer that can be given by mouth or by injection.

**Radiotherapy** refers to the treatment of cancer using radiation, either internally or externally.

## Systemic anti-cancer treatment rates in patients with NSCLC

Over the past few years, there have been considerable developments in the treatment options for patients with lung cancer. Previously, patients with advanced NSCLC were offered palliative chemotherapy to improve their quality of life and extend survival. Since then, advancements have allowed for this category of patients to receive other anti-cancer treatments, such as biologic therapies and immunotherapies, in addition to chemotherapy. Therefore, chemotherapy is included as part of systemic anti-cancer treatment (SACT).

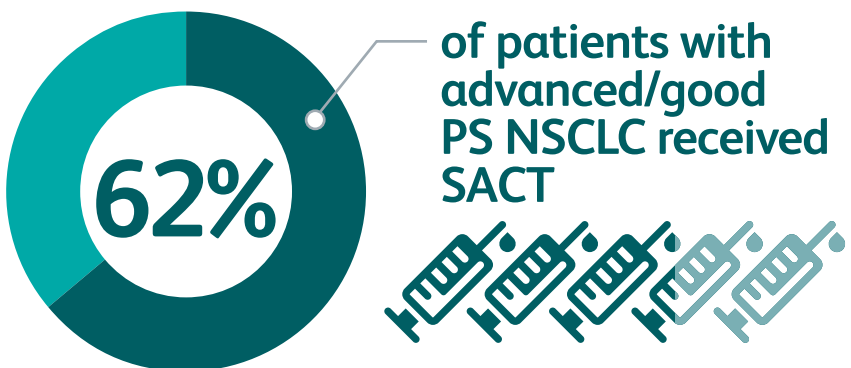
In 2016 we set the following recommendation.

- Overall, 65% of patients with advanced NSCLC (stage IIIB/IV) and a good PS (0–1) should receive SACT.

### Key findings

For this measure, NHS trusts in England achieved a result of 62.5% and hospital sites in Wales achieved 55.6%. This result is just slightly lower than in the previous year, when 64% of patients in this category received SACT.

In total, 85 organisations failed to meet the target, but 15 organisations were identified as 'good practice' sites.



## Recommendations for the 2017 audit period

For the 2017 audit, we have kept the target for 65% of patients with advanced stage NSCLC, with a good PS, to receive SACT.

Multidisciplinary teams (MDTs) should also review how they treat certain groups of patients, such as older patients or those with comorbidities, to ensure their outcomes are in line with best practice.

### Glossary

**Palliative care** (sometimes referred to as 'supportive care') refers to treatment that eases pain and improves quality of life.

**Systemic anti-cancer treatment (SACT)** is a group of cancer treatments given by mouth or injection, including chemotherapy, immunotherapy and biologic therapy.

**Immunotherapy** refers to systemic treatments that boost the immune system to fight cancer.

**Biologic therapy** is a set of medicines used in the treatment of cancer, often directed against a specific molecular target in the cancer.

**Multidisciplinary teams (MDTs)** are groups of healthcare professionals (often from different organisations) who work in a coordinated manner for patient care. For lung cancer, MDTs include surgeons, physicians, oncologists, pathologists, radiologists and LCNSs.

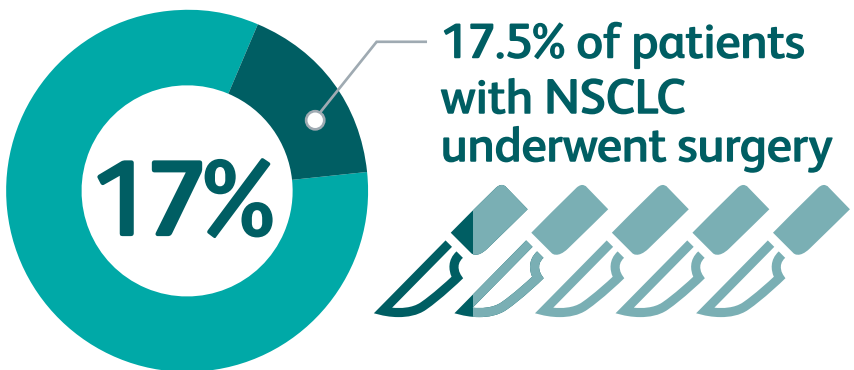
## Surgical treatment for all patients with NSCLC

Surgery is the preferred treatment for early-stage lung cancer because it offers the best chance of long-term survival. The number of patients in the UK who receive treatment has been historically low but there has been a gradual increase over the past decade as more patients are being detected at an earlier stage and surgical techniques (including the use of keyhole surgery) have spread.

In 2016, we set an audit standard for 17% of patients with either histologically confirmed or presumed NSCLC to undergo surgery.

### Key findings

Both England and Wales exceeded the 17% target. This is an encouraging result, and an increase from the 16.7% seen in the 2016 annual report. It also continued the rising trend from the 9% seen in 2006. Many factors determine whether a patient is offered an operation, including the stage of the disease, and their PS and lung function measurements.



## Recommendations for the 2017 audit period

- > MDTs with lower-than-expected surgical resection rates for patients with NSCLC should perform a detailed case-note review to determine why each suitable patient with a good PS did not receive an operation.
- > At least 17% of patients with NSCLC should have surgical operations.

### Glossary

***Surgical resection*** is an operation to remove abnormal tissues or organs. For lung cancer, this could be a whole lung, a lobe or a wedge. It can be performed as open surgery, keyhole surgery and even with robotic techniques.

***Case-note reviews*** provide an independent expert opinion on whether the management of a series of cases has met the relevant standards of care.

## Patient story: Graham Thomas

In 2014 I was diagnosed with pneumonia. Just when my consultant thought I would have the all clear, they could see that cancer was present under the shadow of the pneumonia. I had SCLC. I was told this was the worst kind to have, and that the cancer had spread to my bones. It was only a few months later when I was told that I was stage IV, but they could not give me a prognosis because I was responding well to my treatments. Following treatment at Velindre Hospital, a specialist cancer hospital, I was referred to St David's Hospice Care, which also discharged me after a few months.

I had five sessions of radiotherapy as an inpatient for the tumour on my spine, which could have paralysed me, then four sessions of chemotherapy as an outpatient. My treatment at Velindre was outstanding: the staff are very special people. Everything was explained and my questions were answered. Treatment was also holistic: we had music on the ward most evenings and there was always laughter, and even the odd dance with a nurse.

My diagnosis came as a great shock. My family were devastated and they supported me. Other people always seemed to have a story about someone they knew who had had lung cancer; they also had the old chestnut: 'I expect you were a smoker'. People say I look well but I sometimes feel like I have the Sword of Damocles hanging over my head. I joined Roy Castle Lung Cancer Foundation's #HeadHigh campaign to help raise the profile of this disease.

## Curative-intent treatment rate for stage I–II NSCLC, PS 0–2

This measure combines the rate of surgical treatment and radical radiotherapy in early stage NSCLC patients with good PS – calculation requires the Radiotherapy Dataset (RTDS) which is only available for England. To align with new NHS England commissioning guidance ([www.roycastle.org/how-we-help/lung-cancer-information/information-for-healthcare-professionals/commissioning-guidance](http://www.roycastle.org/how-we-help/lung-cancer-information/information-for-healthcare-professionals/commissioning-guidance)), a target of 70 % was set by the NLCA in 2016.

### Key findings

Overall, 80.4 % of patients in this cohort received curative-intent treatment in 2016. This figure may look high but, in England, one in five patients in this category did not receive treatment with curative intent. This is the subject of the spotlight audit (page 25).

### Recommendations for the 2017 audit period

- > Overall, 80% of patients with NSCLC disease stage I–II and a PS of 0–2 should receive curative-intent treatment.
- > MDTs should consider whether their approach to cohorts such as older patients, and patients with comorbidities, is in line with best practice guidelines (National Institute for Health and Care Excellence (NICE): [www.nice.org.uk/guidance/cg121/chapter/1-Guidance#treatment](http://www.nice.org.uk/guidance/cg121/chapter/1-Guidance#treatment) and British Thoracic Society (BTS) radical treatment guidelines: [www.brit-thoracic.org.uk/document-library/clinical-information/lung-cancer/radical-lung-cancer/btsscts-guidelines-on-the-radical-management-of-patients-with-lung-cancer/](http://www.brit-thoracic.org.uk/document-library/clinical-information/lung-cancer/radical-lung-cancer/btsscts-guidelines-on-the-radical-management-of-patients-with-lung-cancer/)).

## Lung cancer nurse specialist (LCNS) input

In our 2016 report we set the following targets.

- > At least 90% of patients should be seen by an LCNS.
- > An LCNS should be present at the point of diagnosis in at least 80% of cases.

### Key findings

Overall, 71% of patients across England and Wales were seen by an LCNS. The specific results were: 70% for England, 86% for Wales and 32.5% for Guernsey. In England, 58% of patients had an LCNS present at the point of diagnosis (this measure is not recorded in Wales).

This was a great improvement on the results from the 2016 annual report, where only 57% of patients were seen by an LCNS, although we acknowledge that there were problems with uploading these data for patients who were diagnosed in 2015.

### Recommendations for the 2017 audit period

- > At least 90% of patients should be seen by an LCNS.
- > An LCNS should be present at the point of diagnosis in at least 80% of cases.

## One-year survival

One-year survival was 37%, across England and Wales. This is similar to the 2015 cohort when it was 38%, and increased from 2010 when it was 31%. As our analysis of patients diagnosed in 2016 had to take place before the end of 2017, the results presented here only include patients who were diagnosed between January and September 2016, inclusive.

There remains unacceptable variation in casemix adjusted survival between trusts. In accordance with the NLCA outlier policy ([www.nlcaudit.co.uk/AnnualReport](http://www.nlcaudit.co.uk/AnnualReport)), organisations that performed significantly worse than the national average have been notified of their results and will submit action plans to improve their outcomes for patients.

## Organisational audit

The NLCA ran its first organisational audit in 2014, which highlighted significant variations in the workloads of lung cancer specialist teams and the services that were available. We ran the second organisational audit for organisations in Wales and England in June 2017, to reassess these measures.

To undertake the audit, we created an online portal that asked organisations questions that specifically focused on on-site provisions such as equipment to diagnose patients and the availability of LCNSs.

### Results

Overall, 86% of providers participated in the second organisational audit. The number of providers with an MDT that met specifically for diagnosis purposes had increased from 29% to 43%; however, one-third of providers discussed more than 30 patients per MDT meeting, which is more patients per meeting than we recommend.

The provision of on-site endobronchial ultrasound (EBUS) has increased from 44% to 67% in the past 3 years. Access to both on-site pulmonary rehabilitation (81% to 67%) and smoking cessation services (86% to 67%) has decreased since the 2014 audit.

## New key recommendations

These recommendations are based on the above findings, to address the national variation in lung cancer services. We plan to repeat the organisational audit in 2019, using these recommendations as the benchmark.

- 1 All patients should have access to local smoking cessation and pulmonary rehabilitation services.
- 2 All core MDT members should have dedicated time to attend a weekly MDT meeting, at which they discuss no more than 30 patients in 2 hours.
- 3 All MDTs should ensure that there is adequate specialist time commitment, with a particular focus on LCNSs.
- 4 All providers that do not have a separate diagnostic MDT meeting should implement one during the next 12 months.

## Glossary

**Organisational audit** refers to short-term, or snapshot, audit that looks at an organisation's staffing levels and the level of patient access to diagnostics and types of treatment.

**Endobronchial ultrasound (EBUS)** is a minimally invasive method of diagnosing lung cancer that allows for tissue samples to be removed from glands within the chest with a similar instrument to that used in a bronchoscopy.

**Bronchoscopy** is a procedure that allows for the examination of the windpipe and airways via the nose or mouth.

**Pulmonary rehabilitation** is a physical exercise programme that is designed to improve a patient's breathlessness.

## Spotlight audit

Data from our 2016 annual report, which looked at patients who were diagnosed in 2015, showed that 58% of patients with early-stage disease and a good PS had surgery. In August 2017 we ran our spotlight audit in England to determine why this treatment rate was so low ([www.brit-thoracic.org.uk/document-library/clinical-information/lung-cancer/radical-lung-cancer/btsscts-guidelines-on-the-radical-management-of-patients-with-lung-cancer/](http://www.brit-thoracic.org.uk/document-library/clinical-information/lung-cancer/radical-lung-cancer/btsscts-guidelines-on-the-radical-management-of-patients-with-lung-cancer/)) and whether national guidelines relating to assessment of early-stage lung cancer were being followed. In total, we analysed the results of 755 patients.

### Key results

A surprising result was that 31% of patients did not have surgery due to patient choice; 66% of patients underwent radiotherapy instead of surgery. The audit has also identified that guidelines for radical treatment are poorly followed. Only 2% of the 755 patients who did not receive surgery had a second surgical opinion and the number of patients who received pre-surgery tests, to measure suitability and eligibility for an operation, was very low. This may reflect the necessity to achieve treatment timescales or a lack of knowledge of the clinical guidelines.

Another key finding showed that both stereotactic ablative body radiotherapy (SABR) and radical radiotherapy improved survival for patients, compared with those who received best supportive care: these three treatment plans were all alternatives to surgery.

We plan to link these data with the organisational audit and LCNS data in order to further understand the factors behind patient choice.

## Glossary

**Spotlight audit** refers to an audit that focuses on a small cohort of patients to understand a specific issue in treatment or care.

## What do the results mean for me?



First and foremost, we believe it is important that patients and their carers and families know that we have an outstanding level of engagement from clinical teams (we have 100% participation from teams in England and Wales). Not only does this mean that our analysis is based on all lung cancer cases but it reiterates the commitment from lung cancer teams to work towards better outcomes for patients.

We are pleased to see an increase in the number of patients seen by an LCNS, who undergo specific training and provide speciality care for patients with lung cancer. A nurse specialist can improve a patient's pathway and offers an additional point of contact during their treatment.

Another important result is the continued increase in the number of patients who are receiving surgery. For early-stage disease, and when it is appropriate, this treatment offers a better chance of survival. We have seen this trend increase over the past decade and we hope to see this again next year. However, as our spotlight audit highlighted, not enough patients are receiving a second opinion on surgery as a treatment option, or they are not undergoing tests such as a cardiopulmonary exercise test or an echocardiogram. While surgery may not be suitable for some patients, it is crucial that clinical teams adhere to guidelines and that patients who are eligible for surgery are offered it.

Going forward, the audit aims to work more closely with clinical teams across the country. This includes teaching quality improvement techniques that teams can implement in their hospital to improve or speed up the patient pathway. We also want to encourage more collaborative working between organisations, to align organisations that have poorer results with the best performing organisations, and to create opportunities to share examples of good practice. We have already begun this work by holding workshops for lung cancer teams.

In 2017 we implemented a new outlier policy that identifies the best and worst performing organisations compared with the median. We are asking the worst-performing outliers to create action plans that will be reviewed by the NLCA and published on our website. We will work with these organisations to support their improvement plans.

Roy Castle Lung Cancer Foundation ([www.roycastle.org](http://www.roycastle.org)) is our key partner, and we work with the Foundation to ensure that patients continue to be at the centre of everything we do. There is no denying that there is a lot of stigma surrounding lung cancer and its association with smoking. In fact, one in four people in the UK have less sympathy for people with lung cancer than those with other types of cancer. However lung cancer can affect anyone: men and women, young and old, smokers and non-smokers. In November 2017, Roy Castle Lung Cancer Foundation launched its #HeadHigh campaign. Featuring a diverse group of patients, including Pat and Graham, the campaign aimed to challenge the shame and stigma that people with lung cancer can experience. The charity took the #HeadHigh campaign to Westminster, where it was praised by several MPs and journalists who pledged their support to make lung cancer a higher priority. Roy Castle Lung Cancer Foundation will continue to maintain pressure on the government to ensure that appropriate research and innovation is undertaken and it will push for the implementation of a national lung health check programme.

More details can be found at [www.roycastle.org/how-we-help/our-campaigns/hold-your-head-high-this-november](http://www.roycastle.org/how-we-help/our-campaigns/hold-your-head-high-this-november).

## Glossary

**Cardiopulmonary exercise test** is a non-invasive test that measures the performance of the heart and lungs both during exercise and at rest.

**Echocardiogram** is a type of ultrasound scan that looks at the heart and surrounding blood vessels.

**Outlier** refers to an organisation that has results that are significantly different to the median of all organisations' results.

**Quality improvement** is the process to make changes that will lead to better patient outcomes and healthcare systems performance.

## Information on available treatments

This booklet touches on some of the treatment options that are available, such as chemotherapy, radiotherapy, targeted therapies and surgery. Further information on treatment can be obtained from a variety of sources, including:



Roy Castle Lung Cancer Foundation

0333 323 7200

[www.roycastle.org/how-we-help/lung-cancer-information/information-about-treatments](http://www.roycastle.org/how-we-help/lung-cancer-information/information-about-treatments)

## Notes

We hope that you have found this booklet useful and informative. For further details on the results for your region and local trust, Roy Castle Lung Cancer Foundation has created an interactive map for patients with lung cancer, and their families and carers:

[www.roycastle.org/how-we-help/our-campaigns/improving-treatment-and-care/interactive-map](http://www.roycastle.org/how-we-help/our-campaigns/improving-treatment-and-care/interactive-map)

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## How do we collect our data?



**English hospital trusts** collect the Cancer Outcomes and Services Dataset (COSD) in their cancer database; these data are then submitted to ...

### Example additional NCRAS datasets:

- > systemic anti-cancer treatment (SACT)
- > Radiotherapy Dataset (RTDS)
- > death certificate data
- > pathology report data

**The National Cancer Registration and Analysis Service (NCRAS) at Public Health England (PHE)**, which combines the COSD data with additional datasets to produce a full pathway for each patient. After this has been done, a pseudo-anonymised extract of patient-level data is securely transferred to ...

In Wales, data are collected through the **Cancer Network Information System Cymru (CaNISC)**. From there, a pseudo-anonymised extract of patient-level data is then submitted to the NLCA for analysis.

**The University of Nottingham**, which carries out analysis for the NLCA.





## Further information

For further information on the NLCA and to see our annual reports, please visit [www.nlcaudit.co.uk](http://www.nlcaudit.co.uk).

You can follow us on Twitter: [https://twitter.com/RCP\\_NLCA](https://twitter.com/RCP_NLCA)

The NLCA regularly posts blog articles on different aspects of our work and what the team does. Stay up to date at [www.nlcaudit.co.uk/Home/Blog](http://www.nlcaudit.co.uk/Home/Blog).

If you have any other specific queries about the work of the NLCA, please email us at [NLCA@rcplondon.ac.uk](mailto:NLCA@rcplondon.ac.uk).

## Roy Castle Lung Cancer Foundation

Roy Castle Lung Cancer Foundation is the only charity for patients with lung cancer in the UK. It provides information for patients, their families and their carers. The Foundation has many online resources and holds patient information days across the country.

**For further details contact:**

**0333 323 7200**

**[www.roycastle.org](http://www.roycastle.org)**

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