



Royal College
of Physicians

National Lung
Cancer Audit

National Lung Cancer Audit 2016

Key findings for patients and carers



What does this booklet include?

The information in this booklet for patients and carers is a summary of key results from the 2016 National Lung Cancer Audit (NLCA) annual report, which looked at patients diagnosed from 1 January to 31 December 2015. The results are based on data from 142 English trusts and 13 Welsh sites.¹ Full details of the findings can be found at www.rcplondon.ac.uk/nlca2016

This booklet, the first from the NLCA aimed at patients and carers, 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 available to lung cancer patients.

In England, this was the first year that the audit used multiple data sources from the National Cancer Registry and Analysis Service (NCRAS) compared with previous years when we only used the data submitted by trusts.

In Wales, data are collected through the Cancer Network Information System Cymru (CANISC), and an extract of data is then submitted to the NLCA.

Data for this booklet are based on patient-level information collected by the NHS, as part of the care and support of cancer patients. The data are collated, maintained and quality assured by the National Cancer Registration and Analysis Service, which is part of Public Health England (PHE).

When discussing data, we use the plural ‘these data’ as it is considered an abbreviation of datasets.

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

¹The results in this booklet include 37 cases from Guernsey that contribute towards the work of the NLCA.

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What is the NCLA?

The National Lung Cancer Audit (NLCA) was developed after it was found that outcomes for lung cancer patients in the UK lagged behind other comparable countries that spend a similar amount on healthcare and there was considerable variation between organisations. The NLCA began collecting data on lung cancer patients in 2005 in order to review the quality of lung cancer care, to highlight areas for improvement and to reduce variation in practice. We produce annual reports analysing the results of our audit and setting recommendations for hospital teams in England and Wales.


The NLCA strives for improved standards across all lung cancer clinical teams for better treatment and outcomes for lung cancer patients.

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



Commissioned by:





Foreword by Martin Grange, patient advocate

The latest National Lung Cancer Audit annual report indicates that 2015 was yet another year of improvement in the delivery of care for people with lung cancer and we are rewarded with improving survival. The number of people receiving specialist treatment has increased across all measures; this is a tremendous achievement.

Through the National Lung Cancer Audit we are able to look closely at how people with symptoms of lung cancer are detected, diagnosed and treated. We can see the organisation and communication behind the clinical skills required to run an effective lung cancer service. This complex process is a sequence of simpler steps, done in the right order, so it is important to recognise the centres that exceed or meet their targets and encourage them to share their expertise to further reduce the variation between centres.

From the public perspective, confidence that people with lung cancer will be diagnosed and receive the best and most appropriate treatment is greatly enhanced by this report.

Foreword by Neal Navani, NLCA clinical lead

While scientific advances in lung cancer care are regularly reported in the press, it remains vitally important to measure the quality of care that patients actually receive in every hospital in the country. This is a key goal of the National Lung Cancer Audit and allows us to learn from the best-performing hospitals. If the quality of care provided in the best-performing hospitals could be matched by all hospitals then we would have one of the best healthcare systems in the world for treating patients with lung cancer.

This booklet provides important information about lung cancer services in England and Wales for patients and carers. It shows that significant progress is being made. There are real improvements in treatment rates including chemotherapy and surgery and this is having a significant benefit on overall survival for patients with lung cancer.

However, there is more to be done. We need to increase the number of patients who see a lung cancer nurse specialist to help support people better through their cancer journey. In addition, there remains wide variation in standards of lung cancer care across the country. Reducing this variation will go a long way to further improving outcomes for patients with lung cancer. There is a great deal of optimism now in treating people with lung cancer and I hope that future editions of this booklet for patients and carers will be able to demonstrate this.

Key findings and recommendations

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

- > data completeness
- > pathological confirmation
- > specialist nursing input
- > overall anticancer treatment rates
- > use of chemotherapy in small-cell lung cancer (SCLC) patients
- > use of anticancer therapies in patients with advanced non-small-cell lung cancer (NSCLC)
- > surgical treatment for NSCLC patients
- > survival

The key findings presented in this booklet are from the 2016 NLCA annual report which looked at patients diagnosed between 1 January and 31 December 2015. The results are measured against the recommendations in the previous year's annual report.



Each section begins with the target set for 2015 followed by the key findings from the 2015 audit. The clipboard icon demonstrates the overall success for a recommendation. A tick indicates that a target was met or exceeded whereas a cross indicates that the target was missed.

We then review the recommendations, if necessary, for the next audit period which looks at patients diagnosed in 2016.

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 sharing certain characteristics, which make up 85–90% of all lung cancers.

Data completeness

We rely on organisations giving us accurate data. In 2015, we made this recommendation for data completeness:

- > Both performance status and stage should be recorded in at least 90% of cases.

Key findings



Performance status (PS)

Overall, 76 % of patients had their PS recorded. 119 trusts failed to meet this recommendation. However, feedback from trusts in England suggested that although they were recording PS, there were problems in uploading this data.



Stage

Overall, 95 % of patients had stage recorded. Only 18 trusts failed to meet this recommendation. This is the best result that the NLCA has ever achieved, and is to be welcomed.

Recommendations for the 2016 audit period

- > We have kept the same recommendation for both PS and stage, which should be recorded in at least 90% of cases.

Glossary

Performance status (PS) describes how active a patient is in terms of their ability to care for themselves, their daily activity, and physical ability. 0 is the most active level and 4 the least active.

Stage refers to the extent of the cancer, such as how large the tumour is and whether it has spread.

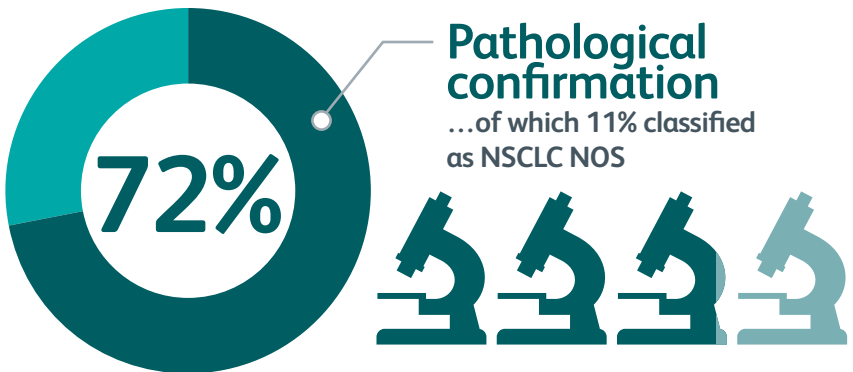
Pathological confirmation

Lung cancer is usually diagnosed based on the findings of an X-ray/scan, or by finding cancer cells when examining tissue (a biopsy) 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 very old or frail patients, biopsies are not appropriate so pathological confirmation may not be possible.

In 2015, we made the following recommendations:

- > Pathological confirmation rates below 75 % should be reviewed by the lead lung cancer clinician in each trust.
- > Non-small-cell lung cancer, not otherwise specified (NSCLC NOS) rates of more than 15 % should be reviewed.



Key findings



In 2015 pathological confirmation fell short of the recommended 75%.

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



11% of patients who had their lung cancer pathologically confirmed as NSCLC had a recorded subtype of NSCLC NOS. There has been a steady improvement in this measure over the past 10 years, and this national performance is probably very close to optimal as some cancers cannot be subtyped. Just 29 trusts failed to achieve the suggested standard.

Recommendations for the 2016 audit period

The recommended rate for pathological confirmation has been increased.

- > Pathological confirmation rates of less than 80% should be reviewed to determine whether best practice is being followed.
- > Non-small-cell lung cancer, not otherwise specified (NSCLC NOS) rates of more than 15% should be reviewed.

Glossary

Pathological diagnosis refers to a diagnosis of cancer based on examination of tissue or fluid.

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

NOS stands for not otherwise specified. In this context it implies that the pathological diagnosis has not been subclassified to a particular cell type.



Patient story: Jane Holmes

At diagnosis in June 2014, I was told my cancer was inoperable and incurable. However, following chemotherapy and radiotherapy I became eligible for surgery and had a right upper lobectomy in June 2015. I started fundraising for the Roy Castle Lung Cancer Foundation and raised £4,000 within a couple of weeks. I think people were shocked by my story as I don't fit the image of someone with lung cancer.

I have a very good clinical team and feel that I am working with them rather than just being told what I should do. My friends and family have been amazing and I have been so fortunate to receive all the support that I have over the last 3 years.

Lung cancer unfortunately does have a high recurrence rate so I do have concerns that I may not have seen the last of it. I think that because I was fit at the time of diagnosis, I was able to have some radical treatment and it also helped with my recovery from the surgery.

Specialist nursing input

In the 2015 annual report, we made the following recommendation:

- > At least 90% of patients should be seen by a lung cancer nurse specialist (LCNS); at least 80% of patients should have an LCNS present at the time of diagnosis.

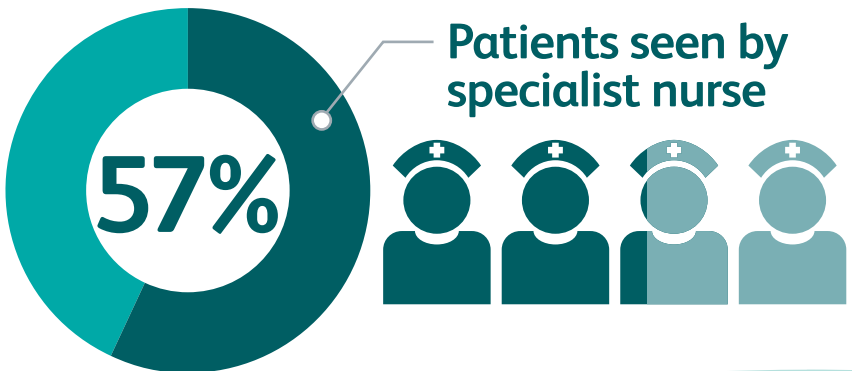
Key findings



Although this figure is low, data on whether a nurse was 'present at the time of diagnosis' were only available for England and were too incomplete to be interpreted.

Specialist nurses need to work with their data managers to ensure that the data are more reflective of their activity.

We have kept the same recommendations as the 2015 report.



Overall anticancer treatment rates

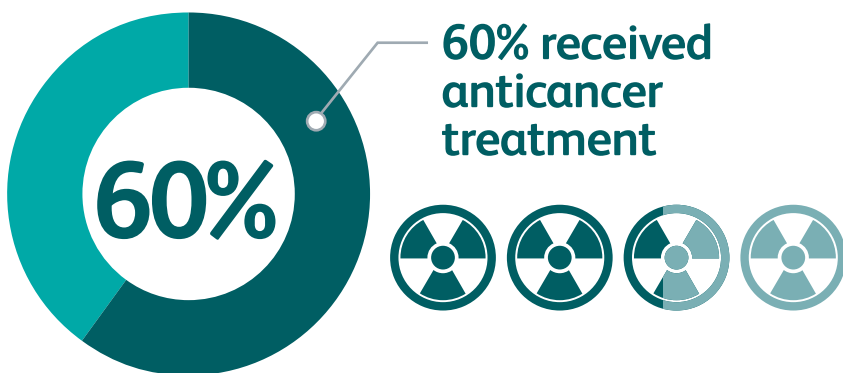
Anticancer treatment refers to therapies that work against the cancer itself, rather than just against the symptoms.

Patients with lung cancer are often older and have other conditions, which can sometimes make treatments challenging.

In our 2015 report we made the following recommendation:

- > MDTs with active anticancer treatment rates of less than 60% should perform detailed case-note review. This should be reviewed by all members of the multidisciplinary team in a meeting where detailed patient information can be discussed.

Key findings



This is a welcome improvement compared with the rate of 58% seen in 2013 and 2014. However, 85 trusts still failed to achieve the suggested standard.

Recommendations for the 2016 audit period

For 2016 we decided to keep the 60% recommendation, due to two opposing trends.

The population of lung cancer patients is getting older, which means that treatment becomes more challenging. On the other hand, patients previously considered unsuitable for treatment may now be eligible due to the emergence of more targeted therapies. We suggest that these two factors will lead to similar anticancer treatment rates for at least one more round of audit.

Glossary

Anticancer treatment (active treatment) is a term used to define treatments for cancer that have an effect on the tumour itself (active treatment), not just on symptoms. In lung cancer patients, these are most often surgery, chemotherapy, biological agents, radiotherapy or a combination of these.

MDTs are multidisciplinary teams; a group of healthcare professionals working in a coordinated manner for patient care. For cancer they include surgeons, physicians, oncologists, pathologists, radiologists and nurse specialists.

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

Use of chemotherapy in small-cell lung cancer patients

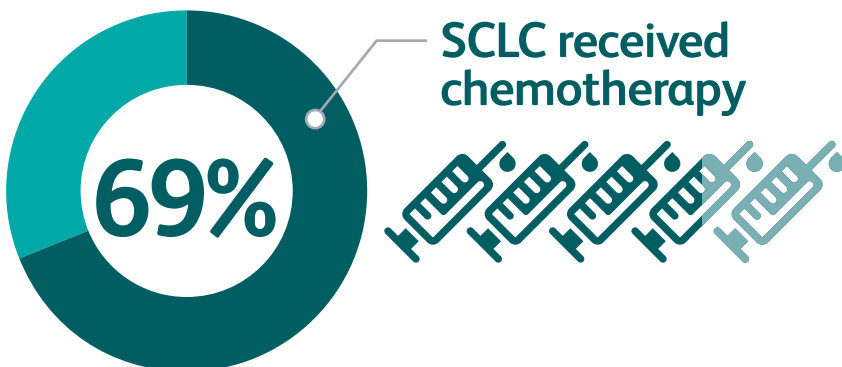
In our 2015 report we recommended that:

- > MDTs with chemotherapy rates for SCLC of less than 70 % should perform detailed case-note review.

Key findings



We found that, in 2015, 69% of SCLC patients received chemotherapy, although 72 trusts failed to achieve the suggested standard. Despite missing the target, this result signifies an improvement over the previous 2 years.



Recommendations for the 2016 audit period

- > MDTs with chemotherapy rates for SCLC of less than 70 % should perform detailed case-note review.

We have also introduced a new recommendation for organisations:

- > 80% of patients receiving chemotherapy for SCLC should start treatment within 2 weeks of pathological diagnosis.



Patient story: Evelyn Campbell

In February or March 2013, I went to see my GP suffering from a cold and cough. I was prescribed antibiotics and steroids, which did not help. My GP then sent me for an X-ray and the result was terrible news; a ‘shadow’ had been found on my right lung. I was devastated; it was a double blow for me as I was diagnosed with cervical cancer 10 years ago.

A CT scan and bronchoscopy revealed that I had lung cancer. The consultant advised that an operation was not possible and the proposed treatment would be radiotherapy and chemotherapy. At the consultation I met Anita and Kay, both lung cancer nurse specialists. They have offered great help and support, explaining how the treatment would work and assuring me that I could ring them with my concerns.

I attend the Wirral support group and have gained strength from other members’ experiences. I take part in various fundraising activities to support the Roy Castle Lung Cancer Foundation. I found it very hard to adjust to having lung cancer at first, and found it difficult to accept. I still dread the scans, but my oncologist is very kind and makes me feel reassured. My husband, sister and her family and our friends were wonderful and helped me a great deal. They are always there when I need them, which is very comforting.

Use of chemotherapy in non-small-cell lung cancer

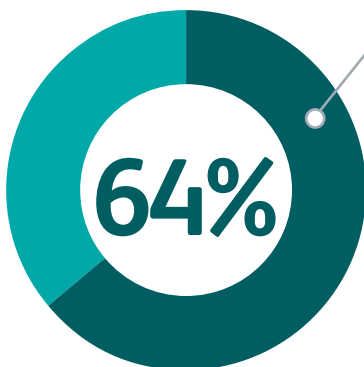
In 2015 we made the following recommendation:

- > MDTs with chemotherapy rates of less than 60 % for patients with good PS and stage III or IV NSCLC should perform detailed case-note review.

Key findings



Although 58 trusts failed to meet the suggested standard, this result is still very encouraging and continues the upward trend of increasing treatment rates since they were first reported at 48% in 2008. We would expect that more patients with advanced NSCLC will be suitable for treatment as new treatments with less toxicity become available.



**advanced/good
PS NSCLC received
chemotherapy**



Recommendations for the 2016 audit period

- > MDTs with chemotherapy rates of less than 65 % for patients with good PS and stage III or IV NSCLC should perform detailed case-note review.

Surgical treatment for non-small-cell lung cancer patients

In 2015 we recommended that:

- > MDTs with surgical resection rates for NSCLC of less than 16% should perform detailed case-note review, including determining whether a second opinion was offered to patients who have not been accepted for surgery.

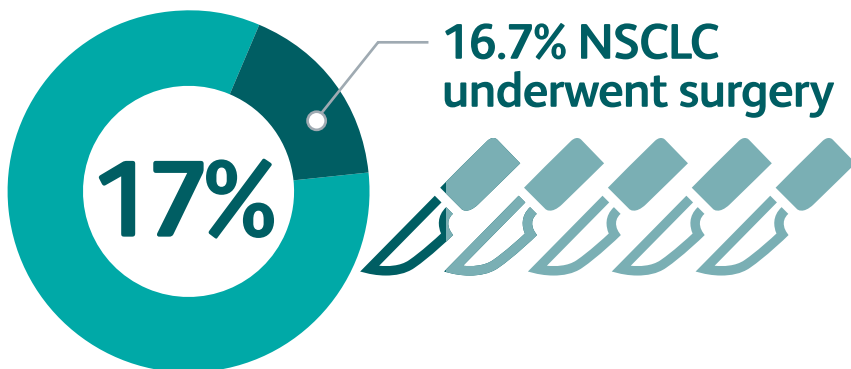
Key findings



This is a promising result and shows a continuation of the rise in surgical operations over the past decade. However, 83 trusts still failed to achieve this standard.

There remains scope to increase the surgical resection rate, particularly in those organisations reporting very low rates.

As there is an increasing use of radiotherapy as a curative treatment we also set a standard to achieve a 'radical treatment rate'.



Recommendations for the 2016 audit period

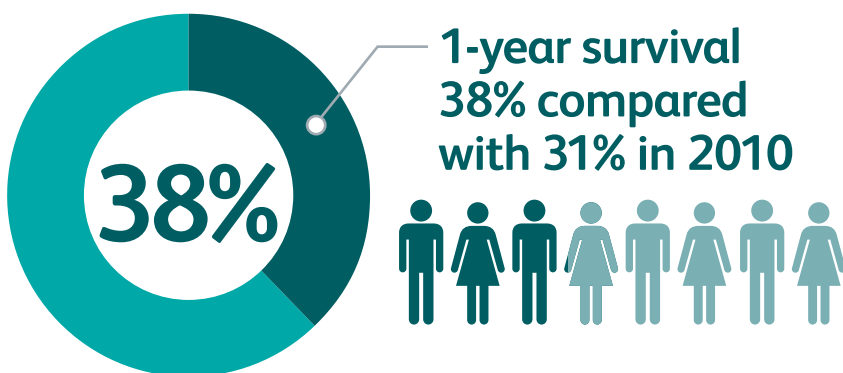
- > MDTs with surgical resection rates for NSCLC of less than 17% should perform detailed case-note review.
- > MDTs with radical treatment rates for NSCLC of less than 30% should perform detailed case-note review.

Survival

We do not set a specific target for survival as we expect that attention to individual targets will deliver improvements.

Key findings

The audit has shown steady improvements in both 1-year and 5-year survival rates in lung cancer. This finding is extremely welcome, and is in keeping with other published analyses. However, there is still unacceptable variation in survival across trusts.



Glossary

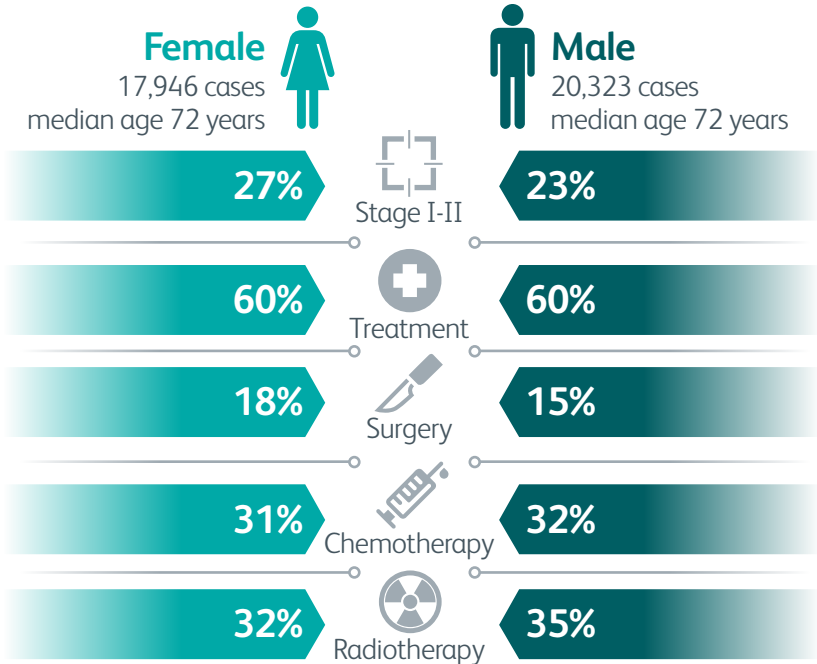
Chemotherapy is a set of medicines used in the treatment of cancer that can be given by mouth or by injection.

Surgical resection is an operation to remove abnormal tissues or organs.

Radical treatment rate is the proportion of patients who have had treatment with the intent to cure the patient of lung cancer. This is usually with surgery or radiotherapy.

Demographics

Comparison of males and females in the NLCA



The median age of patients diagnosed with NSCLC in 2015 was 73, and the median age for those with SCLC was 70.

The number of younger patients with lung cancer is going down. For example, the number of patients diagnosed with lung cancer in the age range of 60–69 decreased by 1.3% between 2008 and 2015, whereas the number of patients aged 80 and over increased by 2.8%.

This could be due to a change in smoking habits over the last few decades, and it also reflects our ageing population, as well as better access to techniques for diagnosis such as CT scanning.

What do the results mean for me?



Patients, their families and their carers should be reassured by the engagement of clinical teams with the audit process. We have a 100% participation rate from trusts in England and Wales.

We now incorporate the data submissions from trusts with registry data collected from the NCRAS, which creates a much more detailed and accurate picture of each patient's pathway.

The results from our 2016 report indicate steady improvements for lung cancer patients. 1-year survival has seen a 7% increase in the 5 years between 2010 and 2015.

There are also more patients receiving treatment, both in chemotherapy and surgery. Chemotherapy as a treatment has seen a slow but steady increase over the past few years. 16.7% of patients now receive surgery, which is an encouraging result and continues the upward trend over the past 10 years.

It is certainly important for patients to be seen by a lung cancer nurse specialist. Current numbers of patients receiving this service are low. However, the data from trusts may not be as complete as they could be.

Nevertheless, there are still wide variations in results between organisations and therefore marked differences in the standard of care that they deliver. The number of patients undergoing surgery has increased, but in 2015 there were still 83 trusts that failed to meet the 17% target. This is similar to chemotherapy, where many trusts still fail to meet our recommendations.

Glossary

Patient pathway refers to the process of care that a patient experiences, from the point of diagnosis through to and following treatment.

Registry data refers to the processed data that the NCRAS produces from a variety of sources, including information submitted via the Cancer Outcomes and Services Dataset (COSD).

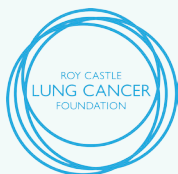
Patients should be confident in asking the clinicians looking after them about the level of care that they can expect from their organisation. We want patients and their families to be informed about the level of care they can expect when facing a lung cancer diagnosis. This information can also be used to demonstrate where there have either been improvements or where more work needs to be done to improve lung cancer outcomes.

Moving forward, the NLCA is looking at why some organisations might have lower treatment rates. We have recently run an organisational audit which looks at data items such as how many nurse specialists a trust has, whether there is a surgical unit on site and what treatments can be offered on site. In examining this we aim to see if there is a link between low levels of access and poorer treatment outcomes. This could also help to explain the continuing regional variation in treatment and outcomes that triggered the start of this audit.

We run our audit every year to set standards and monitor an organisation's performance. This helps us to drive improvements in standards of lung cancer care and to track progress both nationally and locally. It also gives organisations the chance to critically review their results and work to improve their services. Clinical teams can use these results to understand where they can improve and adopt quality improvement techniques to deliver change. Chief executives in hospitals should take time to discuss results with their clinical teams as managers working with clinicians are the key to a greater understanding of how to improve services. Commissioners in England should look at their results alongside the National Service Specification to ensure that the services they commission provide the highest quality care.

Information on available treatments

This booklet touches on some of the treatment options available, such as chemotherapy 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

Notes

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

www.roycastle.org/how-we-help/our-campaigns/improving-treatment-and-care/interactive-map

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 Registry and Analysis Service (NCRAS) at Public Health England (PHE) combines the COSD data with additional datasets to produce a full pathway for each patient. Once 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 here, 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 National Lung Cancer Audit.

Further information

For further information on the National Lung Cancer Audit and to see our annual reports, please visit www.rcplondon.ac.uk/nlca

You can follow us on Twitter @RCP_NLCA

The NLCA regularly posts blog articles looking at different aspects of our work and what the team does. Keep up to date at www.rcplondon.ac.uk/nlcablog

If you have any other specific queries about the work of the NLCA, please email us at NLCA@rcplondon.ac.uk

Roy Castle Lung Cancer Foundation

The Roy Castle Lung Cancer Foundation is the only charity for lung cancer patients 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

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