



Leading the information revolution in cancer intelligence: why the National Lung Cancer Audit is the key to transforming lung cancer outcomes

January 2014



Roy Castle Lung Cancer Foundation

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Acknowledgment

The Roy Castle Lung Cancer Foundation would like to thank all those who have lent their support and expertise in the development of this report: Dr Paul Beckett; Rhona Buckingham; Dr Paul Cane; Dr Matthew Hatton; Sebastian Hinde; Professor Richard Hubbard; Aamir Khakwani; Dawn McKinley; Dr Emma O'Dowd; Mr Richard Page; Dr Mick Peake; Dr Helen Powell; Dr Anna Rich; Dr Berkan Sesen; Dr Roz Stanley; Dr Laila Tata; and the members of the UK Lung Cancer Coalition. We would also like to thank MHP Health, whom we commissioned to compile this report.

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Contents

○ Foreword	4
○ Executive summary	5
○ Introduction	8
○ History of the NLCA	10
○ Content of the NLCA	12
○ Value of the NLCA	14
○ Future of the NLCA	27
○ References	29

Foreword



Having been involved from the conception of the National Lung Cancer Audit through its gestation, birth and now maturity, I am absolutely delighted that the Roy Castle Lung Cancer Foundation has taken upon itself to commission this review and to seek the views of such a wide range of knowledgeable individuals. I am very proud of what the audit has achieved and the impact that it has had, but must stress that this has been very much a team effort from the start. Without the support, advice and encouragement of a wide range of people including clinicians, academics, analysts, members of the lay public and bodies such as the Royal College of Physicians, the British Thoracic Society and the Health and Social Care Information Centre, this project would not have got beyond the paper on which the first ideas were written. More than the various members of the project team and clinical advisory group however, this audit would not have been successful without the hard work and personal commitment of an army of clinicians and administrative staff in lung cancer multi-disciplinary teams across the UK; it is a real testament to the strengths of the NHS and the extent to which its employees care about providing the best standards of care for their patients.

In the end it is, of course, all about patients and driving up the quality of their treatment so that their experience of care, their chances of long term survival and the control of their symptoms are all as consistently good as is humanly possible.

I am also very pleased that the National Lung Cancer Audit has stimulated so much research, since there is a history of major under-funding of research into lung cancer compared with many other cancers. It is very good news that this shortcoming is now being addressed by a number of funding bodies and I would like to think that the NLCA has been a factor in raising the profile of the disease.

The work of the NLCA is not done; there is still unacceptable variation in standards of care and in patient outcomes. New treatments and diagnostic tools for lung cancer are appearing with increasing frequency and new sources of data on cancer are becoming available. All these issues mean that it is essential that this successful audit programme is maintained for the long term, but all of us involved recognise the need for it to develop and adapt to these changes. We very much hope that the Government continues to recognise the value of programmes such as the NLCA and make the funding available for it to continue to drive up the quality of care for the large number of people who are unfortunate to fall victim to this disease.

Dr Mick Peake

**Clinical Lead, National Lung Cancer Audit and National Cancer Intelligence Network
Consultant and Senior Lecturer in Respiratory Medicine, University Hospitals of Leicester NHS Trust**

“In God we trust. All others bring data.”

William Edwards Deming (1900-1993)

“We can only be sure to improve what we can actually measure.”

Professor the Lord Darzi of Denham, High Quality Care for All, June 2008

Executive summary

Introduction

Reducing mortality from the big killers remains a key priority for the NHS. Lung cancer is still the most common cause of death from cancer in the UK. The UK fares poorly compared to its European neighbours for lung cancer survival with a five year survival rate of nine per cent, while the European average is 13 per cent¹. Ensuring the UK is fully equipped to tackle lung cancer in the most effective way is dependent on having first class data on clinical practice and how this is affecting patient outcomes. Central to this is the National Lung Cancer Audit (NLCA), which was one of the first national comparative audits of cancer services and now includes data for approximately 98 per cent of the expected number of new lung cancer cases in the UK. The NLCA is an invaluable source of data on lung cancer and the key to transforming outcomes for people living with the disease, costing a fraction of the £2.4 billion that lung cancer costs the UK economy.

The Department of Health's 2012 policy paper, *The power of information*, states that information helps health professionals to understand “the needs of the population they serve, how well different services and treatments work, and the needs and health history of the people they treat”². There is no better exemplar of this than the NLCA. At this time of NHS reform, it is more important than ever that we have an accurate understanding of the outcomes that are being delivered by our health services.

At the time of writing, it is not clear where responsibility for commissioning and funding of the NLCA will lie beyond the end of 2014. As the UK's only national lung cancer charity, the Roy Castle Lung Cancer Foundation is calling for the NLCA to continue to be commissioned and to receive support and resources to maintain its high quality data collection and intelligence outputs. Without this, there is the possibility that lung cancer services will fall back rather than move forward, putting lives at risk. This report examines the value of the NLCA, highlighting the contribution it has made to improvements in lung cancer services to date, and the vital importance of it being continued in future years.

History and content of the NLCA

The NLCA has taken around 20 years from conception to its establishment as a gold standard national clinical audit. The first discussions around the need to audit services and patient outcomes took place among a small group of clinicians with an interest in lung cancer in 1994. Since then, the NLCA has developed into a national audit which captures information on almost every case of lung cancer and mesothelioma that reaches hospital in the UK. The clinical expertise and commitment that has driven the NLCA's development must continue to be fostered and supported if the UK is to remain a leading light in relation to lung cancer intelligence and if we are to improve survival rates for people with lung cancer.

The NLCA captures data on a range of demographics, clinical features and key process measures in treatment and care, spanning the patient journey. We believe it is essential that all the measures currently included in the audit continue to be captured, but that the NLCA also allows for new indicators to be added when appropriate, to keep pace with new advances in research, technology and treatment.

Value of the NLCA

The NLCA is used by a wide variety of stakeholders within the lung cancer community to understand how care is being delivered across the country and to drive improvements in services. The fact that the audit includes data which are as close to real-time as possible and that it covers a remarkable 98 per cent of lung cancer cases in the UK makes it an invaluable resource in understanding trends in lung cancer services and outcomes.

We sought insights from healthcare professionals, patient groups, researchers, industry representatives and policymakers about the different ways the NLCA is used in practice. Our key findings include the following:

- **Improving clinical practice**

- Average rates of active treatment, surgery, histological diagnosis and access to lung cancer nurse specialists have improved during the lifetime of the audit. The variation between trusts for these key measures has also improved over time, most significantly for the proportion of patients seen by a lung cancer nurse specialist
- Data from the NLCA have been used to underpin large-scale national projects relating to lung cancer, including the Improving Lung Cancer Outcomes Project and LungPath project
- There are hundreds of examples of how the NLCA has been used for service improvement projects at local trust or hospital level³, including identifying the need for an additional lung cancer nurse specialist at Burton Hospital, and improving surgical resection rates for Welsh patients at the Liverpool Heart and Chest Hospital
- Lung cancer clinicians report that they take ownership of the collection of data for the audit locally and are responsive to the results, looking closely at how their trust compares with others. Making sure that they compare well with their peers is an additional incentive on top of wanting to do the best for patients

- **Supporting clinical research**

- 175 clinical journal articles published between 2006 and 2013 reference the NLCA
- 13 of the 214 new research projects presented at the British Thoracic Oncology Group conference in 2013 reference the NLCA
- There are at least 13 clinical research projects currently ongoing across the UK which are making use of NLCA data to understand more about lung cancer outcomes and clinical practice

- **Leading the way in international lung cancer research and audit**

- The NLCA is the model that other countries now look to replicate when it comes to lung cancer research and audit
- Projects such as the European Initiative in Quality Management of Lung Cancer Care have come about due to international recognition of the quality of the NLCA
- Looking beyond Europe, the NLCA has been used to inform policy on improving lung cancer care as far afield as New Zealand and the United States

- **Informing cancer policy and guidelines**

- The National Institute for Health and Care Excellence (NICE) references the NLCA at least 36 times in documents ranging from guidance, implementation guides, and audit tools to briefings. It has also used the NLCA to inform at least three of its clinical pathways and to develop indicators within the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS)
- The Health Technology Assessment Programme, which informs the NICE assessment process, has used the NLCA as evidence in six of its assessments
- The National Cancer Peer Review programme uses exclusively the NLCA headline indicators as its clinical lines of enquiry for lung cancer. These are then used as part of the Care Quality Commission's assessment of local hospital services
- The National Cancer Intelligence Network (NCIN) references the NLCA 32 times in the documents currently available on its website and uses most of the NLCA's headline indicators in its online lung cancer service profiles
- The NLCA has been used almost exclusively to evaluate the major clinical impact of the 2011 and 2012 national public awareness campaigns relating to persistent cough as an early warning symptom of lung cancer

- **Raising awareness of lung cancer issues**

- The annual NLCA report helps to raise awareness of lung cancer issues among national and local decision-makers and the general public
- The Roy Castle Lung Cancer Foundation has used data from the NLCA to raise awareness of lung cancer, and variations in lung cancer care and outcomes, across England and Scotland, through the publication of two reports⁴ and an accessible interactive map of variations in lung cancer care across the country

Future of the NLCA

The NLCA has enormous value and more than delivers on the investment of approximately £400,000 that is made to fund it each year, through the provision of incomparable data that can be used to inform and improve lung cancer care in the UK. There is a risk that the NLCA will be incorrectly perceived to have served its purpose – in fact, we are at a tipping point in the life of the NLCA and its usefulness is likely to increase exponentially over the coming years. There are a number of potential ‘spin-off’ projects which are dependent on NLCA data, some already in progress, which will only deliver additional value and improve lung cancer services and outcomes further. These include:

- deep-dive audits on specific aspects of the lung cancer pathway
- the development of tailored audit tools to address specific problems in some trusts
- linking the NLCA data to other datasets to improve understanding of the whole patient pathway
- collaborating internationally to improve our global understanding of lung cancer care and outcomes

It is vital that the NLCA continues to be resourced in the future and that the data it uncovers continue to be used to tackle lung cancer in the UK and beyond. The NLCA has led the way in undertaking an information revolution in cancer intelligence and should be rightly recognised as the gold standard when it comes to national disease audits. The publication of the annual NLCA report, providing close to real-time data on lung cancer services and outcomes, is a resource that we cannot afford to lose. The NLCA must be continued if the UK is to remain a leading light in relation to lung cancer intelligence and if we are to improve survival rates for people with lung cancer.

The Roy Castle Lung Cancer Foundation therefore calls on the Secretary of State for Health and NHS England to recognise the true value of the NLCA and to commit the necessary resources for its future. Any reduction of this gold standard audit would be an enormous step backwards in the UK’s information revolution in cancer intelligence. This would have significant ramifications for patients’ care and outcomes. The 41,500 cases of lung cancer that we see each year in the UK mean that this is simply not a viable option. The NLCA is the key to understanding more about lung cancer, improving services, and ultimately saving lives. Its value is therefore hugely significant and must not be underestimated.

Introduction

Reducing mortality from the big killers remains a key priority for the NHS. Lung cancer is still the most common cause of death from cancer in the UK. Yet the UK continues to lag behind the best countries in Europe in terms of lung cancer survival⁵. The NHS is looking to implement an ‘information revolution’, opening up data and intelligence to commissioners, clinicians and users of NHS services. There is no better exemplar of this than the National Lung Cancer Audit (NLCA).

Understanding what is happening in clinical practice and how this is affecting patient outcomes depends on having first-class data collection. National comparative audit aims to help managers and clinicians assess both the quality of cancer care and patient outcomes delivered by their teams. The purpose of the NLCA is to provide an annual report on the quality of care provided to people diagnosed with lung cancer or mesothelioma in the UK.

The NLCA was one of the first national comparative audits of cancer services. It is commissioned by the Healthcare Quality Improvement Partnership (HQIP), and managed by the Health and Social Care Information Centre (HSCIC) in partnership with the Royal College of Physicians. Every health trust in the UK now submits data to the audit, and it includes data for approximately 98 per cent of the expected number of new lung cancer cases. This is thought to represent all cases of lung cancer presenting to secondary care.

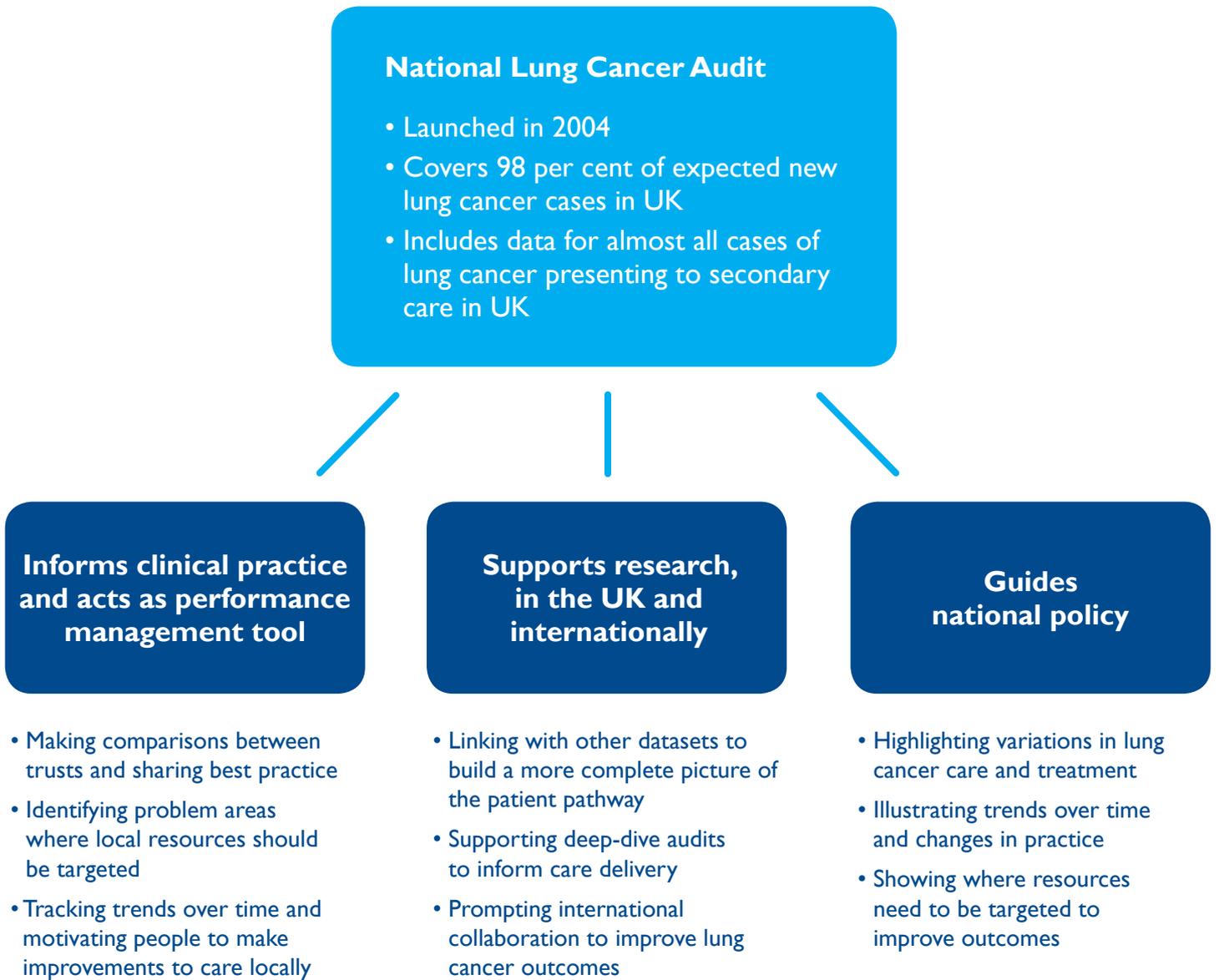
The Roy Castle Lung Cancer Foundation has supported the audit since its inception. As the only charity in the UK wholly dedicated to the defeat of lung cancer, we believe that the NLCA holds the key to transforming lung cancer services for people living with the disease. By looking at the services, treatment and care received by past and current patients, we will be able to assess what works, what needs to change and, ultimately, improve care and survival.

We therefore felt it was timely to review how the NLCA has been, and continues to be, used by the lung cancer community. In compiling this report, we have:

- Assessed the different ways in which NLCA data are used by healthcare professionals, patient groups, researchers, industry and policymakers
- Sourced illustrative examples of the NLCA’s contribution to changes in clinical practice, service redesign and improved patient outcomes
- Demonstrated why the enormous value of the NLCA needs to be recognised and why resources must be committed to secure its future

This report examines how the NLCA is used by the lung cancer community in the UK (and beyond) and why it is often referred to as the gold standard of clinical audits. Figure 1 provides an overview of the different ways the NLCA is currently used and how it informs clinical practice, supports research and guides national policy. Each of the different elements set out below are explored in more detail in the report.

Figure 1: The uses and reach of the NLCA



History of the NLCA

The NLCA has taken around 20 years from conception to its establishment as a gold standard national clinical audit. It has benefitted from the input of representatives from across the lung cancer community, from a range of disciplines, together with patient and lay representatives and has at the same time played an active role in binding the clinical community together. Clinicians took ownership of the NLCA from its early days, believing in its value and constantly pushing it in the right direction so that it became a vital tool, relied upon by all those involved in lung cancer care and research.

The first discussions around the need to audit service performance and patient outcomes were held among a small group of clinicians with an interest in lung cancer, hosted by the British Thoracic Society (then the Thoracic Society) in 1994.

In parallel, the Royal College of Physicians (RCP) secured funding from the Department of Health to do a lung cancer snapshot audit. Around 50 hospitals were asked to record their data on patients diagnosed with lung cancer between 1995 and 1996. The findings of this were shared with the hospitals that took part, but not published externally. However, the lessons from the snapshot audit formed the basis for establishing the first dataset in lung cancer and then, towards the end of 1999, plans for creating a full scale national audit.

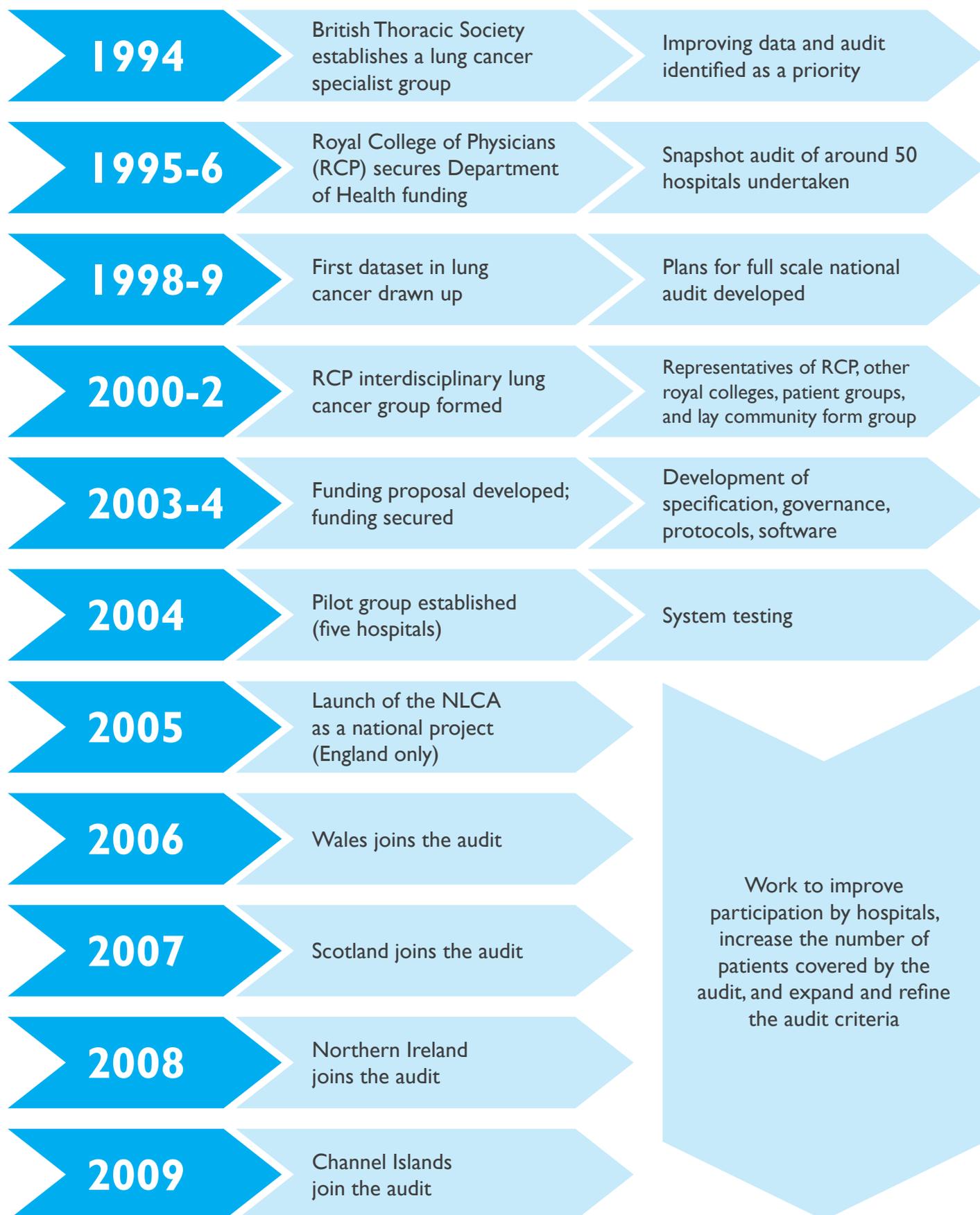
The first Intercollegiate Lung Cancer Committee was established in 2000, hosted by the RCP and with representation from the Royal College of Surgeons, Royal College of Radiologists, Royal College of Pathologists, and Royal College of Nursing, as well as patient advocacy groups and lay people. This group secured funding from the Department of Health's National Clinical Audit and Patient Outcomes Programme to develop the audit in 2003 and, by 2004, had put in place the necessary governance and software infrastructure.

In 2004, the audit was piloted with a group of five early adopter hospitals. It was then launched as a national project in England in 2005. In 2006, Wales came on board, followed by Scotland (2007), Northern Ireland (2008) and the Channel Islands (2009). Each year the report of the audit has been published, enabling commissioners, providers and other interested stakeholders to analyse the findings and identify variations between different hospitals.

From 2005 onwards efforts were made to increase year on year the number of hospitals entering data, the number of patients covered and the completeness of data. The audit now captures information on almost every case of lung cancer and mesothelioma that reaches hospital in the UK.

A timeline of development of the audit is shown in Figure 2.

Figure 2: The development of the NLCA



Content of the NLCA

Data submitted by hospitals are collated by a team based at the Audit Support Unit in the Health and Social Care Information Centre. The most recent NLCA report, published in December 2013, collected data on 40,216 patients in Great Britain, representing approximately 98 per cent of the expected number of new lung cancer cases⁶. This is thought to represent all cases of lung cancer presenting to secondary care. It is a remarkable achievement that data are collected for such a high proportion of lung cancer cases.

The fields in the NLCA have been expanded and refined to ensure that the data captured can be cross-referenced to provide meaningful intelligence on variations in lung cancer treatment and care across the nations. Importantly, it includes a measure of completeness for key fields (expected and actual cases, multidisciplinary team discussion, staging, treatment recorded, seen by a specialist nurse etc) to ensure that the data are comprehensive.

The audit captures data on a range of key process measures in treatment and care, spanning the patient journey. These are set out in figure 3, along with an explanation of why they are essential to record:

Figure 3: Overview of NLCA metrics

Metric	Importance
Actual number of cases	Enables commissioners to see which hospitals are treating the most patients. Helps to identify those centres which may be more specialist than others. Supports workforce planning.
% of cases discussed at an MDT	NHS guidelines state that everyone diagnosed with lung cancer should be under the care of a multi-disciplinary team (MDT). The MDT discussion means that the patient is more likely to be considered for all treatment options.
% of cases with a histological diagnosis	A histological diagnosis, which confirms the tumour type and stage of disease, is essential in determining what kind of treatment is likely to work best for the patient.
% of patients seen by a lung cancer specialist nurse	Lung cancer nurse specialists (LCNSs) form an important link between patients and their families and the MDT. Patients report a better experience of care when they are seen by a LCNS. The audit also shows that patients seen by a LCNS are more likely to receive active treatment.
% of patients with a lung cancer specialist nurse present at diagnosis	Ideally, patients should have access to a LCNS during the diagnostic process, but it is vital that they are supported at the time of definitive diagnosis, when they may find it difficult to take in the news. A LCNS can provide ongoing personalised support to answer questions, explain treatment options and their risks and benefits etc.
% of patients having active treatment	Active treatment is intended to control or cure the cancer, rather than simply manage the symptoms. A low percentage of patients receiving active treatment may suggest problems with early diagnosis or with access to specialists.
% of patients receiving a CT before bronchoscopy	Patients should undergo the minimum number of investigations to establish an accurate tissue diagnosis, stage of disease and their fitness for treatment. Bronchoscopy should only be carried out after a CT scan to improve patient experience, save time and potentially reduce the cost to the NHS.

Metric	Importance
% of patients receiving surgery	Surgery still offers the best hope of curing lung cancer, if the tumour is caught early. However, there are only around 70 specialist thoracic surgeons in the UK. A low resection rate may indicate lack of access to a thoracic surgeon, overly cautious practice, or problems with late diagnosis meaning that surgery is not an option.
% of patients receiving radiotherapy	Radiotherapy is an important option for people with lung cancer, both as a potentially curative treatment and as a therapeutic option to ease the symptoms of the disease. Recent years have seen the development of more advanced and targeted techniques, which should be widely available.
% of expected cases	Enables assessment of whether a hospital's data returns are likely to be complete, as well as whether they are under or over-subscribed. Hospitals submitting data for fewer than expected cases may not be supplying all their records.

The NLCA also contains data which breaks down the outcomes depending on the type of lung cancer – non small cell lung cancer (NSCLC and its sub-types) or small cell lung cancer (SCLC) – and differentiates it from data on mesothelioma. This is important as the treatments offered to patients will be different depending on which type of cancer is diagnosed.

SCLC, which accounts for roughly 12 in every 100 lung cancers, is mostly treated with chemotherapy. It tends to spread rapidly, meaning that surgery is usually not an option by the time the cancer is diagnosed. Chemotherapy is usually the main treatment, followed by radiotherapy (or at the same time if the patient is fit – combination chemoradiotherapy).

NSCLC can be treated with surgery, chemotherapy, radiotherapy or a combination of these, depending on the stage when the cancer is diagnosed. Some people with advanced lung cancer may have biological therapy.

Breaking down the audit findings by tumour type means that it is possible to analyse variations and see whether some centres are treating people with SCLC or NSCLC differently, or whether outcomes are varied.

The Roy Castle Lung Cancer Foundation welcomes the development of other clinical audits to capture information and intelligence on performance in other common and rarer cancers. However, we believe it is essential that all the measures above continue to be captured for lung cancer services. Any contraction in the data captured by the NLCA could seriously harm the value and utility of the audit. It is also important that the NLCA allows for new indicators to be added when appropriate, to keep pace with new advances in research, technology and treatment.

“The database is now massive. [It has] more than 230,000 patients in it – bigger than anything else in the world. It really does give you the power and the scope to see...we’re not doing quite as well as we thought we were or there is a group of patients we are not so actively treating. And it does allow us to reflect on our own practice and see how we stand compared with the national average or other trusts within our network and share good practice.”

(Dr Anna Rich, Nottingham University Hospitals NHS Trust)

Value of the NLCA

The NLCA is used by a wide variety of stakeholders within the lung cancer community to understand how services are being delivered across the country and to drive improvements to services. As part of our research for this report, we sought insights from healthcare professionals, patient groups, researchers, industry representatives and policymakers about the different ways the NLCA is used in practice. This chapter provides an overview of our findings, demonstrating how the NLCA is valued by different parts of the lung cancer community.

Improving clinical practice

During the lifetime of the NLCA, significant improvements across key areas of lung cancer care have been recorded. When looking at the average rates for several of the most important measures in the audit – those related to active treatment – there has been an increase of around 5 per cent across all areas since 2008. This is illustrated in Figure 4. The picture is also very positive when looking at the number of lung cancer patients who have access to a nurse specialist. This has risen from just over half of patients in 2008 to over 80 per cent in 2012.

Figure 4: Improvements over time across key measures included in the National Lung Cancer Audit, 2008 to 2012⁷

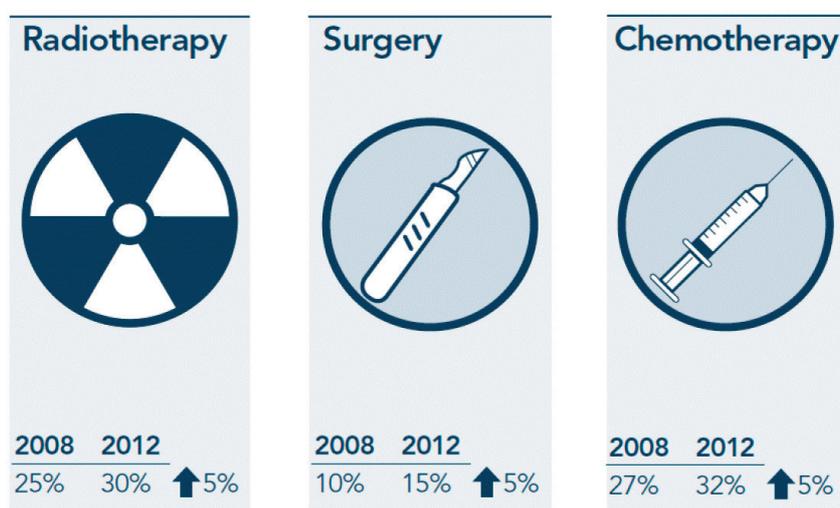
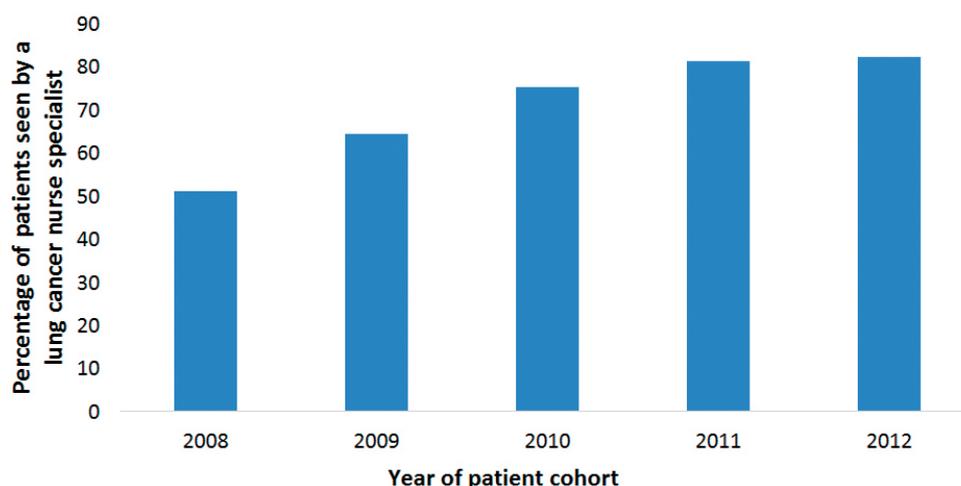


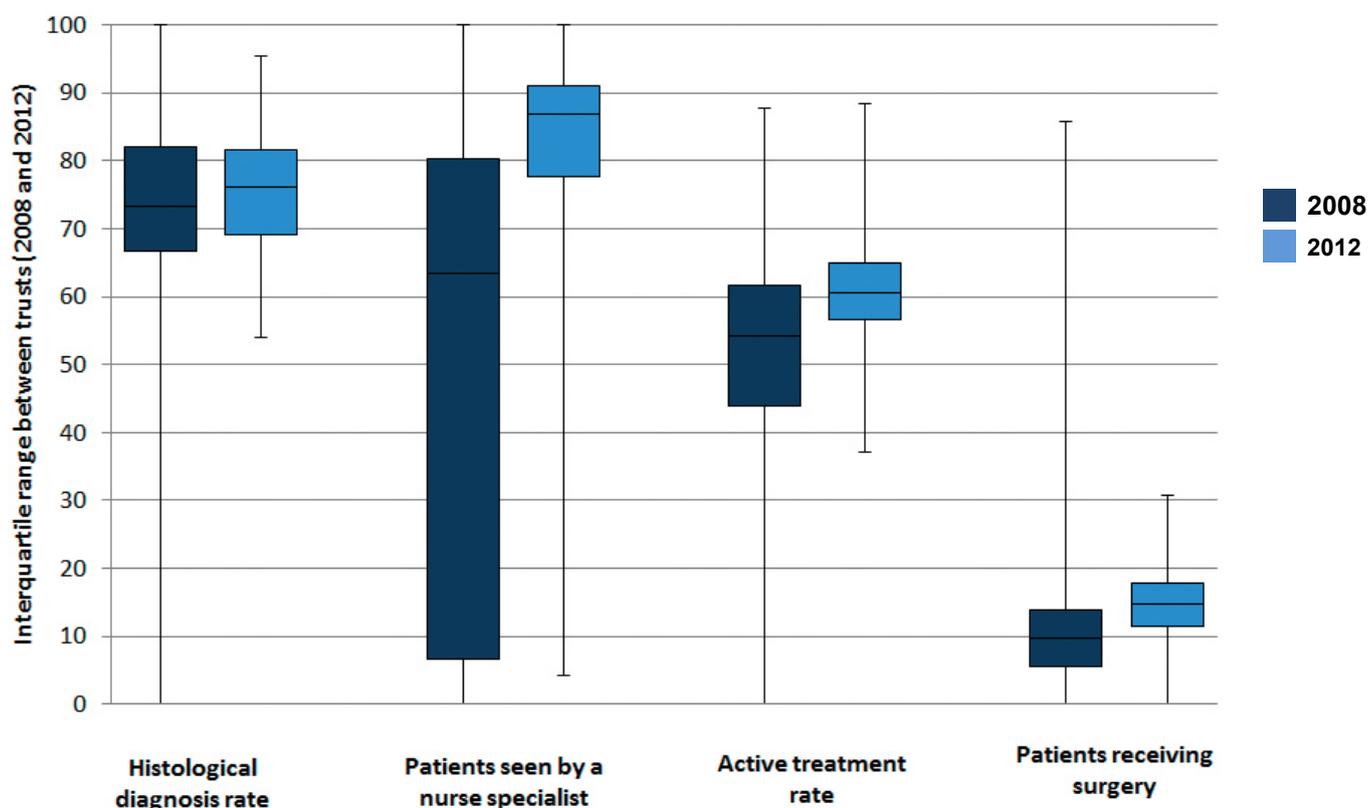
Figure 5: Improvement over time in the number of lung cancer patients seen by a nurse specialist, England and Wales, 2007 to 2012⁸



While it is very encouraging to see improvements across the board in the average rates for these measures across all trusts, crucially the level of variation between trusts has also improved. As illustrated in Figure 6, the level of variation between trusts for the four chosen measures reduced in all cases between 2008 and 2012. The starkest improvement was for the percentage of patients seen by a lung cancer nurse specialist. The interquartile range across trusts for this measure reduced from 73.6 per cent in 2008 to 13.4 per cent in 2012.

In our discussions with lung cancer clinicians, it became clear that part of the reason for these improvements is that clinicians really believe in the data captured through the NLCA. Clinicians take ownership of the collection of data for the audit locally and are responsive to the results. One leading clinician described how everyone in the lung cancer community looks closely at how their trust compares with others, in particular around active treatment and surgical resection rates. He described clinicians wanting to make sure that they compare well with their peers as an additional incentive on top of wanting to do the best for patients. The NLCA's findings are also published rapidly after collection compared to other disease areas. For example, findings of the National Diabetes Audit can be published up to two years after collection while the NLCA is published a year after collection. This means that data from the NLCA are more relevant to local trusts and other healthcare bodies. In addition, efforts are underway to reduce the time from data collection to the NLCA and publication of the findings.

Figure 6: Variation between trusts for key measures included in the National Lung Cancer Audit, 2008 and 2012⁹



There are hundreds of examples of how the NLCA has been used for service improvement projects at trust or hospital level¹⁰. The detail included in the NLCA allows clinicians to see how their trust compares with others in their region, or across the UK, in relation to key measures included in the audit, for example active treatment rates, access to lung cancer specialist nurses and resection rates. This means clinicians, and commissioners, are able to target attention and resources towards problem areas to improve the quality of care for the patients in their charge.

A good example of how NLCA data have been used to inform and change lung cancer service delivery is illustrated by the Improving Lung Cancer Outcomes Project (ILCOP). ILCOP, which was set up in 2010, was funded by the Health Foundation, clinically led by Dr Ian Woolhouse (Consultant in Respiratory Medicine at University Hospitals Birmingham NHS Foundation Trust) and managed by the Royal College of Physicians. The project aimed to:

- Identify the reasons for variations in lung cancer outcomes
- Apply proven quality improvement methods to target specific problems
- Collect patient experience data
- Assess the impact of the changes

It did this through using the NLCA to identify where there are variations and to support multi-disciplinary teams to make the changes that would improve clinical outcomes for people with lung cancer. Key outputs from the project are illustrated in box A.

Box A: Key outputs from the Improving Lung Cancer Outcomes Project (ILCOP)

- Engagement of over 200 healthcare professionals working in lung cancer in a programme of quality improvement activities, eg workshops and peer-led service reviews
- Academic articles on improving patient involvement and using peer-review for quality improvement
- Development of a patient experience questionnaire for people with lung cancer
- Publication of recommendations on a collaborative approach to improving the quality of care for people with lung cancer

The NLCA allows not only the identification of unexplained variation between trusts, but also highlights areas of good practice from which other trusts may learn. The LungPath project is a good example of this in action. This project, led by Dr Paul Cane (Consultant Histopathologist at Guy's and St Thomas' in London) was commissioned by HQIP and aims to gather information about pathological aspects of lung cancer diagnosis and staging within England. The project has led to some trusts being highlighted as centres of excellence from which others can learn. For example, University Hospital Birmingham has been identified as a centre of excellence through the project, based on its performance in the NLCA. Dr Ian Woolhouse commented on the LungPath project in a statement from the trust saying:

“The National Lung Cancer Audit isn't about collecting data for its own sake. The audit supports many service improvement initiatives within participating trusts and helps them identify their strengths and weaknesses. The audit provides a local action plan template to facilitate this process. The audit also allows organisations to learn from each other. UHB is leading the way with its excellent biopsy service and the LungPath project will allow us to share our practices with other hospitals across the UK who aren't performing so well in this area”¹¹.

“At trust level, everyone takes note of the LUCADA return – everyone is keenly looking at how they are doing, in particular around active treatment rates, surgical resection rates and it's an additional incentive on top of wanting to do best for patients to make sure that they compare well with their peers.”

(Dr Paul Cane, Guy's and St Thomas' NHS Foundation Trust)

Further details of the LungPath project are summarised in box B.

Box B: LungPath project – improving the pathological diagnosis of lung cancer

Phases I and II of LungPath focused on describing and mapping the current performance of 20 lung cancer multi-disciplinary teams (MDTs) across England. It found variations in waiting times for tests, such as biopsies, and recommended that waiting times for such tests should only be two weeks. It also called on trusts to regularly audit the proportion of people with lung cancer receiving a number of tests.

Phase III looked at the challenges faced by MDTs in achieving a high level histological confirmation rate. It recommended that in every instance a clear diagnostic pathway should be in place and to ensure that pathologists are an integral part of MDTs.

The NLCA was a vital part of informing this project, providing key evidence on performance across the country.

In addition to projects like the ILCOP and LungPath, there are also less well known local examples of where the NLCA has been used to identify specific issues and provide the evidence to support the changes that were needed. For example, Mr Richard Page, consultant thoracic surgeon at Liverpool Heart and Chest Hospital, told us that he had seen comparison of surgical resection rates between England and Wales, which showed that rates were lower in Wales compared to just over the border in Liverpool. Since then, measures have been put in place which have significantly increased the number of resections being carried out in Wales, leading to better outcomes for people with lung cancer in the area.

The NLCA allows trusts to assess their ongoing performance over time meaning that trends in the quality of care can be identified. Dr Paul Beckett, consultant chest physician at Burton Hospital (recently moved to Derby), told us that his team had identified the need for the appointment of an additional lung cancer nurse specialist. Information from the NLCA supported the application for appointing an additional lung cancer nurse specialist and was then used to show how care and outcomes had improved following their appointment.

Dr Beckett also gave an example of where the NLCA had been used to identify a lag between initial lung cancer diagnosis and being seen by an oncologist, in which time the patient's condition had deteriorated so much that anti-cancer treatment was not possible. The trust put measures in place, using the NLCA to underpin the pathway, to reduce the time between diagnosis and being seen by an oncologist and thus increase the chance of receiving curative treatment.

The value of the NLCA in assessing the quality of outcomes at trust level is further highlighted through its inclusion in the Department of Health Quality Accounts reporting process. All health service providers have to submit a report each year about the quality of their services in the previous financial year – a Quality Account. Each report is required to be submitted to the Secretary of State and published on the NHS Choices website where it is made available to the public. Providers are required to include a statement in their Quality Account which details the national clinical audits they have participated in during the year. HQIP publishes a list each year of the national clinical audits that are included in this process. The NLCA has been included in this list for several years and has recently been included in the list for 2014/15¹².

Supporting clinical research

The breadth and depth of the NLCA dataset (referred to as the LUCADA dataset) makes it an incomparable resource for all those interested in lung cancer. The wealth of information collated by the NLCA has meant that it is often relied upon by researchers whose work focuses on various aspects of lung cancer care, treatment or service delivery.

The wide use of the LUCADA database by researchers, both in the UK and globally, is reflected in the numerous times it is referenced in clinical journals. We conducted a review of research articles which were published in relevant journals between 2006 and 2013 and uncovered a total of 175 articles which referenced the NLCA or LUCADA.

These included publications from the UK (eg British Journal of Cancer and British Medical Journal), Europe (eg European Journal of Cardio-thoracic Surgery and European Respiratory Journal) and the US (eg Journal of Cardiothoracic and Vascular Anesthesia and American Journal of Respiratory and Critical Care Medicine).

As the NLCA has grown in breadth and depth, so has its reach among the clinical research community. The British Thoracic Oncology Group (BTOG) is a UK lung cancer and mesothelioma research group which aims to improve the care of patients through multidisciplinary education and clinical and scientific research. BTOG holds an annual conference at which new research findings are shared

among the lung cancer research community. We were interested to see how often the NLCA had been referenced in the various poster abstracts that were collated at each BTOG conference since the inception of the NLCA.

An analysis of the abstracts published over the last seven years uncovered a significant increase in those that referenced the NLCA over time. In 2007, just two of the 90 published abstracts referenced the NLCA, whereas at the 2013 conference, 13 of the 214 abstracts referenced the NLCA. Some examples of the most recent abstracts are included below.

Examples of research abstracts referencing the NLCA from the BTOG conference held in January 2013¹³

A retrospective study of changing performance status and staging in all patients presenting with lung cancer to the Northern Health and Social Care Trust over the past decade

A. McShane, S. McNeill, W. Anderson, C. Butler, J. Legget, E. Murtagh, R. Donnelly,
Northern Health & Social Care Trust, Antrim Area Hospital, UK

Lung cancer resection rates have become more controversial as the publication of the national lung cancer audit has shown such geographical variation and then national improvement over a small number of years. This could be due to differences in patients, disease, recording of information or real differences in treatment. As well as initiatives to optimise treatments of patients after they present, there have been efforts to encourage patients to present earlier such as the national awareness early diagnosis initiative.

Aim: To assess if patients presenting with Lung Cancer in the Northern Trust are different in performance status or stage to those presenting a decade ago.

“I believe [the NLCA] is incredibly valuable with the amount of detail that is collected. The key issue is that all cancers are very different in terms of their cause, their presentation and their treatment, and so detailed information is needed that is tailored to each type of cancer. This is crucial for audit data to be useful for improving patient care and outcomes – the lung cancer audit is doing this well and is improving.”

(Dr Laila Tata, University of Nottingham)

Methods: We used previously published data (BTS, Winter 2003) to compare patients from 2001/2002 with patients from 2009/2010 (data collected from the Regional Northern Ireland Cancer Patient Pathway System). The catchment area over this ten year period had increased from 350,000 in 2001 to 450,000 in 2010 as the Causeway hospital has since been included. We compared numbers presenting, patient demographics, performance status at presentation, histology and staging.

Results and Conclusions: A total of 563 patients were studied. Allowing for the change in population served by the MDT, similar numbers of patients presented each year with similar demographics. The histology of the groups was also similar however more patients are now being given a histological diagnosis rather than a clinical diagnosis. Our data also showed that patients were presenting at a statistically significant earlier stage of disease for both Small Cell Carcinoma (chi-square, $p = 0.0004$) and Non-Small Cell Carcinoma (chi-square, $p = 0.01$). Patient Performance Status at presentation had statistically improved between 2001 and 2010 (chi-square, $p = 0.01$). We also found a non-significant trend of higher surgical referral rates in 2010 compared to 2001. These results may well vary with geography and might be improved by further health promotion in the future.

Management of stage I and II non-small cell lung cancer at Plymouth Hospitals NHS Trust

S. Iyer, A. Roy, A. Marchbank, Plymouth Hospitals NHS Trust, UK

Background: Surgery remains the most effective curative treatment for early stage lung cancer (stage I and II). In 2010 our trust's resection rate for this group was lower than the National Lung Cancer Audit's (NLCA) recommended resection rate of 52% and in view of this the aim here was to analyse our unit's management of primary early stage lung cancer including surgical resection rates and whether this was appropriate for our population.

Methods: Data was collected retrospectively for patients diagnosed with Stage I and II lung cancer between April 2011 and 2012 from their notes/MDT outcomes.

Results: 62 patients were diagnosed with Stage I or II lung cancer of which 48.3% (n 30) were females. The mean age was 71.9 years. 50% (n 31) of these patients underwent surgical resection. There was no in-hospital post-operative mortality in this group. Of the 50% (n 31) who did not have surgery, 19% (n 6) were operable by Performance Status (0 or 1), half of whom refused surgery. 2 patients had poor FEV1s and had radical radiotherapy while 1 patient was diagnosed with metastatic disease during further investigations. In the no surgery group overall 22.55% (n 7) had radical radiotherapy and the overall mortality in this group was 35.4% (n 11).

Conclusion: Our surgical resection rate for 2011-2012 for early primary lung cancer has increased from 2010 and is comparable with the average for England and Wales. This may be a real increase or due to data entry for the NLCA. There are various reasons why patients may not be offered radical surgical treatment. Most of our patients not undergoing surgery had a poorer performance status and inadequate pulmonary function tests. This audit suggests that the treatments given for early stage lung cancer in our trust is appropriate for our population.

Higher resection rates in non-small cell lung cancer are associated with better survival

P. Beckett, R.B. Hubbard, R.A. Stanley, I. Woolhouse, M.D. Peake. Royal College of Physicians, UK, University of Nottingham, UK, NHS Information Centre for Health and Social Care, UK

Introduction: Outcomes for lung cancer patients in the UK appear to be worse than comparable healthcare systems and whilst late presentation is an important contributor, variability in radical treatment rates, in particular surgery in non-small cell lung cancer (NSCLC) may be important. Evidence from the National Lung Cancer Audit and the Society of Cardiothoracic Surgeons shows that the number of curative resections is increasing, but there is debate about whether this is appropriate and whether in some cases resection rates may be too high.

Methods: Using data from the National Lung Cancer Audit (England only, 2008 2011 inclusive) we have looked at all cases of stage I and II NSCLC (confirmed and presumed). We have allocated every patient to a trust based on the recorded “place first seen” and divided the trusts into quintiles according to their resection rates in this group of patients. We excluded organisations with <25 cases (Stage I/II) in the study period (some private hospitals and nonacute specialist trusts, also where PCT had been recorded rather than acute trust). The resection rate quintiles were used in a Cox proportional hazards model, adjusted for age, stage, sex, PS, deprivation and co-morbidity to assess the influence of resection rate on survival.

Results: The table shows the results for Stage I/II combined. There was a statistically significant trend towards increased survival with a higher trust resection rate.

	Resection rate	1 year survival	3 year survival	Median survival	Hazard Ratio	p	95% CI
Q1	20.4–42.9	72.4%	45.1%	889	1.0	-	-
Q2	43.3–48.6	73.7%	47.8%	993	0.87	<0.001	0.81–0.93
Q3	48.6–53.3	74.4%	49.0%	1056	0.96	0.254	0.89–1.03
Q4	53.5–58.5	75.8%	51.6%	1155	0.91	0.016	0.85–0.98
Q5	59.4–82.0	78.1%	55.9%	1409	0.84	<0.001	0.77–0.90
Total	50.8	74.9%	49.9%	1090			

Conclusion: In patients with Stage I and Stage II NSCLC, higher resection rate is associated with longer median survival, 1 year survival and 3 year survival. This improved survival is independent of variation in case-mix factors. This real world data, whilst lacking the rigour of a randomised controlled trial, lends support to the hypothesis that lung cancer survival in the UK would increase if a larger proportion of patients underwent surgical resection.

There are at least 13 major clinical research projects currently ongoing across the UK which are making use of NLCA data to understand more about lung cancer outcomes and clinical practice. In order to understand more about the types of research projects that have made use of the NLCA data, we spoke to a number of leading researchers about their work. An overview of the projects they discussed with us is set out in figure 7.

As illustrated, the projects focus on different aspects of the lung cancer pathway, from diagnosis to survival. Many of the projects are only made possible, and their value made far greater, by the use of data from the NLCA. Every health trust in the UK now submits information to the audit and, as a result, the NLCA database includes information for approximately 98 per cent of the expected number of new lung cancer cases. The projects that are being undertaken by the researchers we spoke to have been made possible by data

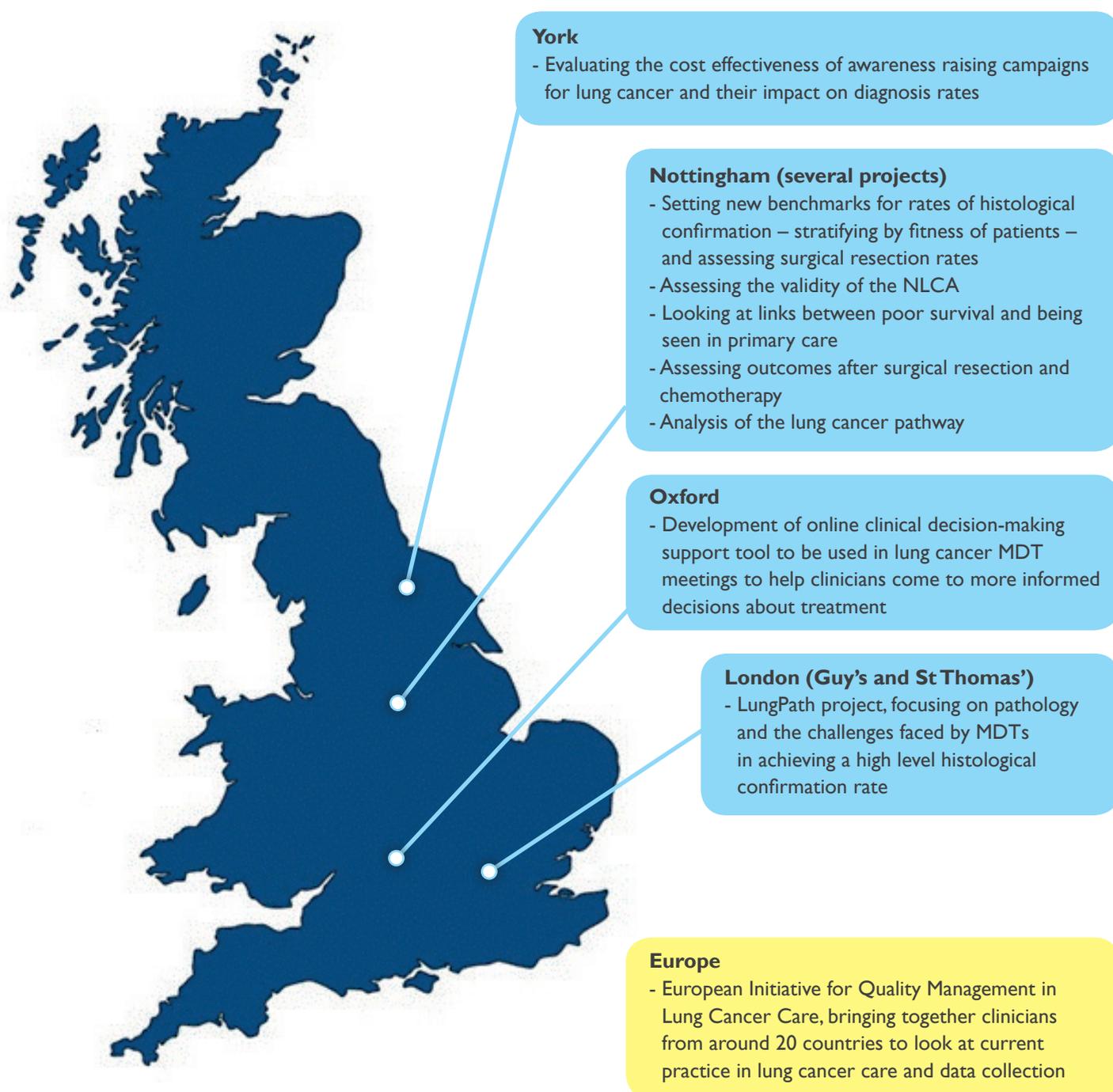
“A database of this size does not exist anywhere else so I really commend the clinical leads of the project. It potentially opens up a lot of doors and I think it is very useful.”

(Dr Berkan Sesen, Oxford University)

sharing agreements which allow access to the NLCA database. The range and scale of the projects are testament to the value of the NLCA as a vital data source in understanding and tackling lung cancer. Initiatives such as the LungPath and ILCOP projects demonstrate how clinical practice is already changing through research. All of the various projects we have discussed are looking at key aspects of the lung cancer pathway and have the potential to alter our understanding of the disease and improve patient outcomes.

We believe it is vital that the value of the NLCA is recognised and maintained so that these projects can continue to uncover new findings which will help to inform the delivery of high quality lung cancer care in the UK and, ultimately, save lives.

Figure 7: Examples of research projects using NLCA data



Leading the way in international lung cancer research and audit

The NLCA is the model that other countries now look to replicate when it comes to lung cancer research and audit. Projects such as the European Initiative for Quality Management in Lung Cancer Care have come about due to international recognition of the quality of the NLCA. This project has been led by a European Respiratory Society taskforce, which was formed in 2010 and constituted a group of interested physicians from a number of European countries. The taskforce was co-chaired by Anna Rich (Consultant Respiratory Physician at Nottingham University Hospitals NHS Trust).

The aim of the taskforce was to sustainably improve the quality of lung cancer care across Europe. The first step in this process has been to perform a systematic and thorough evaluation of the patterns of lung cancer services throughout Europe. The second year of the taskforce focused on a pilot study in more than 20 European countries collecting basic prospective data on lung cancer patients. Six national registries or audit programmes were involved alongside an online data entry tool in the remaining 23 countries. This aspect of the project drew largely on the NLCA and highlighted that very few other European countries have anything close to the NLCA in terms of valuable data on lung cancer.

Looking beyond Europe, the NLCA has been used to inform policy on improving lung cancer care as far afield as New Zealand¹⁴ and the United States¹⁵. There is also scope for further international collaboration on lung cancer research with other potential collaborative projects in the pipeline involving Australia, Canada, Denmark, Poland and the USA.

Informing cancer policy and guidelines

The Department of Health, its agencies and arm's-length bodies produce an enormous amount of valuable information on cancer every year. The National Institute for Health and Care Excellence (NICE) alone currently has 32 separate pieces of guidance relating to lung cancer on its website¹⁶. These documents require robust evidence to underpin them, such as that provided by the NLCA.

The NLCA is also used widely by policymakers to inform the development of national and regional policy relating to improving the treatment of people with lung cancer. At this time of NHS reform, it is more important than ever that we have an accurate understanding of the outcomes that are being delivered by our health services and the policy developments that are necessary to effect change. A wide range of organisations contribute to the process of developing and delivering innovative policy. The NLCA highlights those areas and fields where improvements may need to be made at a national policy level, for example addressing low resection rates or high rates of diagnoses at emergency admission.

The **National Cancer Peer Review** programme has, in recent years, added outcome measures to its process of assessing the quality of cancer services. These measures are called 'Clinical Lines of Enquiry'. Because of the NLCA, lung cancer was the first cancer in the Peer Review process to have these outcome measures included and now all of the lung cancer 'Clinical Lines of Enquiry' are derived from the NLCA. The results of the Peer Review Programme form part of the way that the Care Quality Commission assesses the quality of hospital services in England.

The **National Cancer Intelligence Network** (NCIN) aims to improve clinical outcomes for cancer across the country through using the information collected about cancer patients. In the documents currently available on its website, the NCIN has referenced the NLCA 32 times, including in presentations, reports and briefings. The NCIN now publishes service profiles for lung cancer showing a range of activities and performance outcomes for every hospital trust in England, with the large majority of the outcome measures used derived from the NLCA. These service profiles are available via the Cancer Commissioning Toolkit (via www.ncin.org.uk). Likewise, the **Healthcare Quality Improvement Partnership** (HQIP), which uses audit data across a wide range of disease areas, including lung cancer, has referenced the NLCA 30 times in documents currently available on its website.

NICE references the NLCA no less than 36 times in documents ranging from guidance, implementation guides, audit tools and briefings. It has also used the data to inform at least three of its clinical pathways which set out the recommended routes clinicians should take when delivering care for patients. Indeed, the NLCA has also been used to develop indicators within the Clinical Commissioning Group Outcomes Indicators Set (CCGOIS) to monitor and assess the quality of care for patients with lung cancer¹⁷.

Similarly, the **Health Technology Assessment Programme**, which itself informs the NICE assessment process, has used the NLCA as evidence in six of its assessments, including, for example, a review of the clinical effectiveness and cost effectiveness of topotecan for small-cell lung cancer.

Professional bodies, including the **Royal College of Physicians, the Royal College of Surgeons** and the **National Lung Cancer Forum for Nurses**, have used the NLCA to support their own guidance and documents. For example, the Royal College of Surgeons used it to inform

“Having the sheer numbers that the audit has makes the information that you get from it difficult to ignore. It's a very powerful resource. And we have seen an awful lot of things improve just because we've been collecting the data and people have had to self-reflect. I think that can only be a good thing.”

(Dr Anna Rich, Nottingham University Hospitals NHS Trust)

its report on promoting innovation in surgery¹⁸. The NLCA has also been used by charities such as Cancer Research UK, the UK Lung Cancer Coalition and Macmillan to support their campaigning activities to improve the quality of care people with cancer receive.

In Parliament, government ministers have also used the NLCA to support their answers to questions on lung cancer. Even as recently as July 2013, the then health minister, Anna Soubry MP, responded to a question from Sir Paul Beresford MP (Conservative, Mole Valley) on lung cancer outcomes, noting:

“We know from the National Lung Cancer Audit 2012 that there have been increases in curative surgery for lung cancer patients. The audit report supports providers and commissioners and NHS England to reduce variation in services and drive improvement locally.”¹⁹

Over the last two years the Government has been trying to increase public awareness of persistent cough as a symptom of lung cancer as part of its ‘Be Clear on Cancer’ campaign. The regional pilot from autumn 2011 and the 2012 national campaign have recently been evaluated and data from the NLCA have been crucial in demonstrating the positive impact of the campaign.

Beyond England, NHS Wales has used data from the NLCA to support improvement in care for people with lung cancer in its jurisdiction.

Raising awareness of lung cancer issues

Lung cancer remains one of the UK's biggest killers and early diagnosis is vital to ensure that curative treatment is possible and to improve clinical outcomes. Yet despite this, recent research has shown that 40 per cent of all lung cancer diagnoses occur after an emergency admission – the highest for any cancer²⁰. Sadly, clinical outcomes amongst these patients are very poor as the disease has advanced beyond a level at which curative treatment is possible. Only 8.9 per cent of lung cancer patients diagnosed through an emergency admission survive for one year post diagnosis²¹.

Organisations such as the Roy Castle Lung Cancer Foundation (RCLCF), which are passionate about improving lung cancer practice and outcomes, have been able to use the findings of the NLCA to raise awareness of lung cancer issues and campaign for policy measures to improve these poor survival rates.

The Government's cancer outcomes strategy, *Improving Outcomes: a Strategy for Cancer*, set out a challenging ambition to save an additional 5,000 lives per year by 2014/15²². This equates to halving the gap between the survival rates in England and those in the best countries in Europe. To help meet this target, the Department of Health has identified one and five year survival from lung cancer as an improvement area within the NHS Outcomes Framework²³.

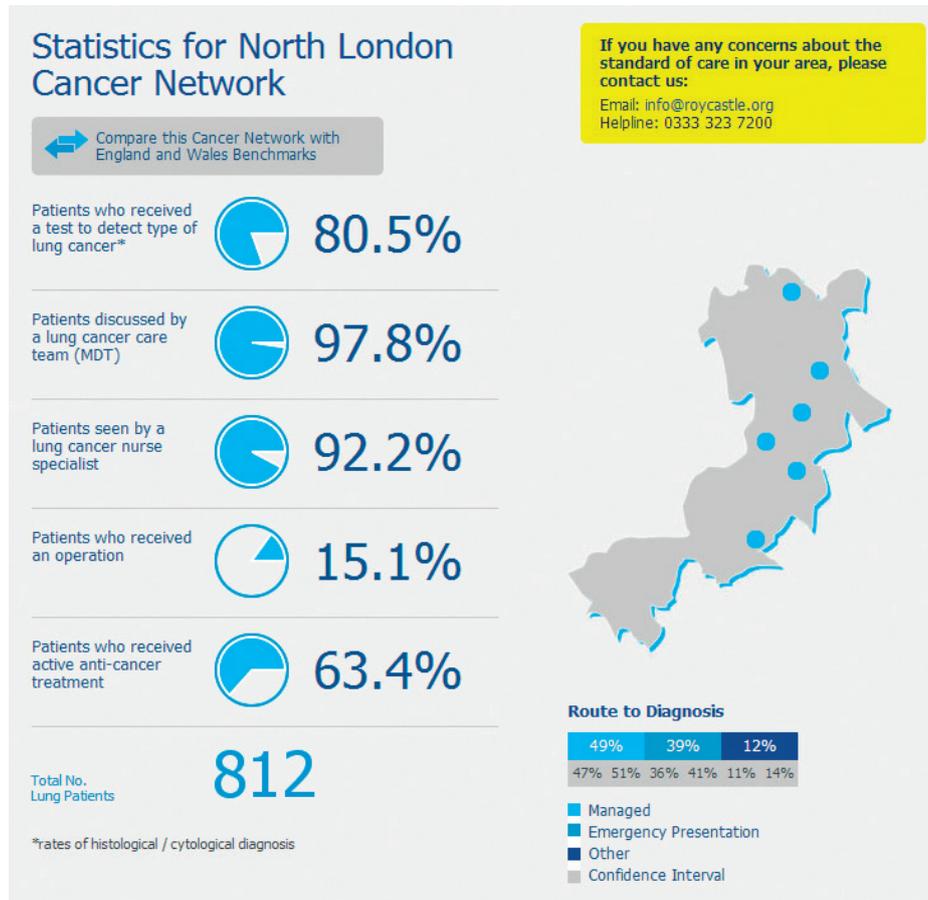
RCLCF has used data from the NLCA to raise awareness of lung cancer, and variations in lung cancer care and outcomes across England and Scotland, through the publication of two reports²⁴. The RCLCF has also recently gone a step further by using the data to create an accessible interactive map of variations in lung cancer care across the country. Figure 8 shows the outcomes for the North London Cancer Network.

The interactive map has received much attention and its usage has been increasing steadily showing that more people are accessing it to get information on lung cancer in their area. In 2013 (up to 20 November), 6,000 people had used the interactive map, an increase of 25 per cent on the previous period in 2012.

The map has also been an important tool in engaging with parliamentarians and ministers. The then health minister, Anna Soubry MP, commented on the latest version of the map, saying:

“This interactive cancer map is a great source of information which empowers lung cancer patients to make better informed choices about the care and treatment they receive. I'd like to commend the Foundation's commitment to diagnosing lung cancer earlier and identifying the best treatments available in order to save as many lives as possible.”²⁵

Figure 8: Snapshot from RCLCF interactive lung cancer map



Beyond the charity sector, industry has also been using the NLCA to raise awareness of lung cancer nationally and locally. During Lung Cancer Awareness Month 2012, Lilly UK used data from the NLCA, and from the RCLCF interactive map, to highlight in the media, particularly local media, the variations in care between different parts of the country with regards to lung cancer. Pfizer has also used data from the NLCA in its press briefings, and has used it to inform its response to technology appraisals and assessing the quality of diagnostic services.

The examples above illustrate that the NLCA has multiple uses across the lung cancer community, from informing clinical practice and supporting research to guiding national policy and guidelines. It is a resource that is relied upon by a variety of different stakeholders and should therefore be maintained and resourced appropriately so that these different uses may be continued.

Future of the NLCA

Insights from those in the lung cancer community have made it very clear that the NLCA has enormous value and more than delivers on the investment of approximately £400,000 that is made to fund it each year, through the provision of incomparable data that can be used to inform and improve lung cancer care in the UK. Fears have been expressed, however, about the future of the NLCA and whether its true value is recognised by those decision makers at a national level who will be responsible for its future. At the time of writing, it is not clear whether responsibility for the commissioning and funding of the NLCA will reside in the NHS or what form it will take. Funding is secure to the end of 2014 but, beyond this, there is uncertainty.

There is also the possibility that other organisations may take on some of the data collection that has historically been part of the NLCA. What is vital is that, regardless of these potential changes, an amalgamated annual report setting out close to real-time data on lung cancer services and outcomes continues to be produced and is of the same standard as the current NLCA annual report. This is a resource that we cannot afford to lose.

There is a risk that the NLCA will be incorrectly perceived to have served its purpose – in fact, we are at a tipping point in the life of the NLCA and its usefulness is likely to increase exponentially over the coming years. Many of the clinicians and researchers we spoke to expressed views to this effect, explaining that we have not yet seen the full potential of the NLCA. Indeed, there are a number of potential ‘spin-off’ projects from the NLCA, some already in progress, which will only deliver additional value to the NLCA and seek to improve lung cancer services and outcomes further. These are summarised below:

• Deep-dive audits

Dr Mick Peake (Consultant and Senior Lecturer in Respiratory Medicine for the University Hospitals of Leicester), the NLCA lead, has highlighted the potential around further ‘deep-dive’ audits, such as the aforementioned ILOP and LungPath projects. Since the recently implemented Cancer Outcomes and Services Database (COSD) collects a broad range of data items across all cancer subtypes, there is inevitably overlap with the NLCA dataset, and as the former becomes embedded into local services, there will be scope to collect more in-depth data on specific areas of care. In his interview with us to discuss the NLCA, Dr Peake discussed the potential for more work to look at the quality of nursing, why patients with limited disease are not getting surgery or curative treatments, and to uncover the reasons for variation between trusts. He explained that what the NLCA has done to date is to define what the issues are, where the benchmarks are, and what the levels of variation are. There is more work to be done, however, to explain in more detail what the real causes for these differences are and to use this information to care more effectively for people with lung cancer.

• Tailored audit tools

There is also scope to make the audit more detailed on specific issues and more tailored so that trusts can audit particular problem areas that they have, rather than conducting exactly the same audit across the country. If, for example, a trust has a very good resection rate but an issue with nursing, there could be scope to develop an audit tool which addresses this problem so that hospitals are not using precious resources to collect information on areas where they are performing well.

“I think it is a great dataset...I think its usefulness will increase exponentially. So you put all this resource and effort in and you don't get much out, but then you reach a tipping point where it will suddenly start to become massively useful. And it has reached that tipping point...I think it is a great data resource but we haven't seen its full potential yet. That will come.”

(Professor Richard Hubbard, Nottingham University Hospitals NHS Trust)

• Linking to other datasets

Another area for development that was highlighted in our research was the value in being able to link data from the NLCA with other datasets. By matching NLCA data with data in the National Cancer Registration Service plus hospital episode statistics (HES) and GP databases, it is possible to gain a clearer idea of the whole patient pathway. It is possible through HES and GP data, for example, to see what happened before a patient received a diagnosis of lung cancer, which helps to identify where interventions may have been possible to prevent a person's lung cancer from advancing. There is certainly more work to be done in this area to fully understand why the UK continues to lag behind other countries in rates of lung cancer survival. Other emerging datasets containing rich information about systemic treatments and radiotherapy will allow more detailed analysis and practice variation and outcome in these areas.

• International reach

Lastly, the NLCA now has an international reach and there is scope for further international collaboration to improve our understanding of lung cancer care and outcomes. Projects such as the European Initiative in Quality Management of Lung Cancer Care, which is led by Anna Rich (Consultant Respiratory Physician at Nottingham University Hospitals NHS Trust), have come about due to international recognition of the quality of the NLCA. Currently in the pipeline are other potential collaborative projects involving Australia, Canada, Denmark, Poland and the USA.

What needs to happen?

It is vital that the NLCA continues to be resourced in the future and that the data it uncovers continue to be used to tackle lung cancer in the UK and beyond. For this reason, it is important that policy makers fully understand the true value of the NLCA and ensure that it is embedded in the structures of the new NHS. The NLCA has led the way in undertaking an information revolution in cancer intelligence and should be rightly recognised as the gold standard when it comes to national disease audits. The NLCA has also brought the UK lung cancer community together and its success has relied on committed clinical leaders to drive new and existing projects. This expertise and commitment must continue to be fostered and supported if the UK is to remain a leading light in relation to lung cancer intelligence and if we are to improve survival rates for people with lung cancer.

“I think we have defined the problem and we have made inroads into some of the key things but we have not had the ability to dig down into the real detail of the cause of variation and the best methods of improving it. I think we have got to develop the audit to really hone down the reasons for the variation and to have the resources and the ability to intervene.”

(Dr Mick Peake, National Cancer Intelligence Network)

The Roy Castle Lung Cancer Foundation therefore calls on the Secretary of State for Health and NHS England to recognise the true value of the NLCA and commit the necessary resources for it to be continued beyond the end of 2014, keeping intact its breadth and depth in terms of its content and reach. The alternative is the loss of the gold standard of cancer audits and an enormous step backwards in the UK's information revolution in cancer intelligence. This would have significant ramifications for patients' care and outcomes. The 41,500 cases of lung cancer that we see each year in the UK mean that this is simply not a viable option.

The journey from the early beginnings of the NLCA two decades ago to its current status as a world leader in cancer intelligence has been a remarkable one. Credit must go to all those who have championed the NLCA, developed it into such an invaluable tool, and those who use it on a daily basis to improve lung cancer care and save lives. This vital work must continue and it is only by recognising the true value of the NLCA that we can be sure that this will happen.

References

- ¹ De Angelis R, Sant M, Coleman MP et al, 'Cancer survival in Europe 1999-2007 by country and age: results of EURO CARE-5 – a population-based study', *The Lancet*, 2013
- ² Department of Health, *The Power of Information: Putting all of us in control of the health and care information we need*, May 2012
- ³ Beckett P, *National Lung Cancer Audit: Past, present and future*, slides presented at National Cancer Intelligence Network lung cancer site specific clinical reference group workshop, 25 September 2013
- ⁴ The Roy Castle Lung Cancer Foundation, *Explaining variations in lung cancer in England*, July 2011
- ⁵ Coleman MP et al, 'Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK 1995-2007 (the international Cancer Benchmarking Partnership): an analysis of population-based cancer registry data', *The Lancet*, Vol. 377, January 2011
- ⁶ Health and Social Care Information Centre, *National Lung Cancer Audit Report 2013: Report for the audit period 2012*, December 2013
- ⁷ Beckett P, *National Lung Cancer Audit: Past, present and future*, slides presented at National Cancer Intelligence Network lung cancer site specific clinical reference group workshop, 25 September 2013
- ⁸ Health and Social Care Information Centre, *National Lung Cancer Audit annual reports from 2007 to 2011*, accessed on 25 September 2013 via: <http://www.hscic.gov.uk/lung>
- ⁹ Health and Social Care Information Centre, *National Lung Cancer Audit Report 2012: Full report, December 2012*, and *National Lung Cancer Audit Report 2009: Full report, January 2009*
- ¹⁰ Beckett P, *National Lung Cancer Audit: Past, present and future*, slides presented at National Cancer Intelligence Network lung cancer site specific clinical reference group workshop, 25 September 2013
- ¹¹ University Hospitals Birmingham NHS Foundation Trust, *Excellence in lung cancer care recognised*, accessed on 15 August 2013 via: <http://www.uhb.nhs.uk/news/uhb-recognised-for-excellence-in-lung-cancer-care.htm>
- ¹² Healthcare Quality Improvement Partnership, *2014/15 Quality Accounts list confirmed*, December 2013
- ¹³ British Thoracic Oncology Group, 'Poster abstracts, 11th Annual British Thoracic Oncology Group Conference', *Lung Cancer*, Volume 79, Supplement 1, January 2013
- ¹⁴ New Zealand Ministry of Health, *Standards of Service Provision for Lung Cancer Patients in New Zealand*, 2011, accessed on 11 August 2013 via: [http://www.moh.govt.nz/moh.nsf/Files/cancer/\\$file/lung-cancer-service-standards-aug11.pdf](http://www.moh.govt.nz/moh.nsf/Files/cancer/$file/lung-cancer-service-standards-aug11.pdf)
- ¹⁵ United States of America Department of Health and Human Services, *Lung Cancer: The diagnosis and treatment of lung cancer*, accessed on 11 August 2013 via: <http://www.guideline.gov/content.aspx?id=34282>
- ¹⁶ National Institute for Health and Care Excellence, *Cancer – Guidance by topic*, accessed on 15 August 2013 via <http://www.nice.org.uk/guidance/index.jsp?action=byTopic&o=7165>
- ¹⁷ National Institute for Health and Care Excellence, *Clinical Commissioning Group Outcomes Indicator Set Indicator Rationale*, accessed on 15 August 2013 via: http://www.nice.org.uk/media/073/F5/090713_CCG_OIS_Indicator_Rationale_Final_postGE.pdf
- ¹⁸ Royal College of Surgeons, *From theory to theatre: Overcoming barriers to innovation in surgery*, June 2011
- ¹⁹ Hansard, *Column 472W*, 1 July 2013
- ²⁰ Wilcock A, Crosby V, et al, 'Lung cancer diagnosed following emergency admission: a mixed methods study protocol to improve understanding of patients' characteristics, needs, experiences and outcomes', *BMC Palliative Care*, 12:24, 2013
- ²¹ National Cancer Intelligence Network, *Routes to Diagnosis, NCIN Data Briefing*, November 2010
- ²² Department of Health, *Improving Outcomes: A Strategy for Cancer*, January 2011
- ²³ Department of Health, *The NHS Outcomes Framework 2014/15*, November 2013
- ²⁴ The Roy Castle Lung Cancer Foundation, *Explaining variations in lung cancer in England*, July 2011
- ²⁵ The Roy Castle Lung Cancer Foundation, *Smart Map launch offers new approach in the battle against Britain's biggest cancer killer*, accessed on 11 August 2013 via: <http://www.roycastle.org/news-and-campaigning/Media-Centre/Latest-News-and-Developments/News-Articles/Smart-Map-launch-offers-new-approach-in-the-battle-against-biggest-cancer-killer>





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