

UK Lung Cancer Coalition Commissioning Communications Toolkit

Supporting clinicians to engage with and strengthen lung cancer commissioning

Humber and Yorkshire Coast Cancer Network

Introduction

This toolkit has been developed by the UK Lung Cancer Coalition (UKLCC) to help lung cancer clinicians to make a constructive and effective contribution to the commissioning of services. Whether you are a pathologist, radiologist, oncologist, respiratory medicine doctor, nurse, or are involved in lung cancer services in another capacity, it will provide you with the tools to speak to your local commissioner of lung cancer services and highlight the areas where you believe improvements should be made.

The UKLCC is a partnership of charities, clinicians, senior NHS professionals and healthcare companies campaigning for improvements in lung cancer care. We believe that getting the commissioning of lung cancer services right will help to reduce the postcode lottery in access to diagnostic and pathology services, treatment and specialist nursing. To do this lung cancer clinicians need to sit at the heart of commissioning.

Our soundings from the front line tell us that clinicians want to make a contribution but are not certain about how to best engage with local commissioners and to help in the commissioning process. This toolkit has been developed to help fill this knowledge gap. We believe that with experts like you engaging with cancer commissioning, we can make a real difference towards achieving our goal of doubling lung cancer survival.

The toolkit includes:

- Background on the UK Lung Cancer Coalition and the actions that we believe must be prioritised to improve lung cancer care
- Data on how your area performs on lung cancer, and how this compares to the rest of the country
- Contact details for your local commissioner of lung cancer services
- A template e-mail to approach your local commissioner for a meeting
- Things to consider when engaging with your local commissioner of lung cancer services, and advice on making your case as convincing as possible
- Other sources of information on lung cancer

About the UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) is the nation's largest multi-interest group in lung cancer – a powerful partnership of the leading lung cancer charities, clinicians, healthcare professionals and healthcare companies with a commitment to lung cancer issues. You can read more about us at www.uklcc.org.uk

Our challenge

Lung cancer is the country's biggest cancer killer.¹ In the UK, someone dies from lung cancer every 15 minutes.² Despite some recent improvements in service provision, there are still wide variations in standards across the country, including diagnosis, treatment and care for lung cancer patients.³

The UKLCC believes that more can be done to reduce the terrible death toll caused by lung cancer. Our vision is to meet an ambitious survival challenge: to double one year lung cancer survival by 2015 and five year survival by 2020.

The UKLCC has developed a 12 point lung cancer plan – calls for action which we believe if prioritised and acted upon would make a real difference for lung cancer patients.

Bringing standards of care across the NHS up to those in the best centres would, we believe, save many thousands of lives.

With help from our clinical partners – surgeons, oncologists, radiologists, nurses, physicians and general practitioners – working at the front line of cancer services, we have reviewed lung cancer services and put together a blue print for action. This report, *Reviewing the Lung Cancer Plan: Are we emerging from the shadow of lung cancer?*, contains ambitious calls for action across twelve key areas. It can be downloaded at <http://www.uklcc.org.uk/pdf/lungcancerreview2009.pdf>

Many of the challenges this report identifies will be familiar to you from your own work in lung cancer care, and may highlight areas where lung cancer services in your area could be improved.

| | |
|-------------------|---|
| Prevention | The UK Governments should commit to funding and implementing comprehensive national tobacco strategies with clear goals and challenging medium and long term targets, including a review of smoking cessation services to ensure they are fit for purpose and meeting users' needs. |
| Screening | The Government should monitor and support the National Institute for Health Research's feasibility study, enabling a swift decision to be made on the viability of a lung cancer screening programme. |

| | |
|--------------------------------|--|
| Awareness | National and local initiatives should be put in place to raise awareness of the signs and symptoms of lung cancer among the general public and healthcare professionals, and to improve knowledge of the treatment options for lung cancer in order to address the fatalism and stigma still associated with the disease. |
| Primary care | Incentives should be included in the Quality and Outcomes Framework to encourage GPs to refer at-risk patients for a chest x-ray, particularly patients newly diagnosed or with developing COPD symptoms. |
| Information and support | Government must ensure that lung cancer patients are offered high quality information at key points in their cancer journey, tailored to their individual needs and supported by face-to-face contact with a healthcare professional. All lung cancer patients should have access to a specialist lung cancer nurse, and receive regular holistic needs assessments and updated care plans at key points in their cancer journey, including at diagnosis, end of treatment, and end of life. |
| Diagnosis and staging | Investment should be made in radiology to assist more accurate diagnosis and staging. Every Trust should be achieving proven diagnosis rates of at least 75%. |
| Treatment | Every hospital trust should examine its levels of active treatment and strive to bring them closer to the 70% achieved in some parts of the country. Relevant clinical guidance should be updated to reflect new therapeutic and technological options, and tools developed to support commissioners in commissioning effective lung cancer services. |
| End of life care | The UK Governments must implement 24/7 coordinated community nursing across the country, as quickly and efficiently as possible, in line with the End of Life Care Strategy in England. |
| Managing care | Every lung cancer patient's case should be considered by a fully representative MDT comprising specialists, with a prime interest in lung cancer, from all the relevant disciplines. |
| Workforce capacity | Shortages in the lung cancer workforce must be addressed, and every Trust and Cancer Network should review workforce capacity as a matter of urgency, to ensure parity with services for patients with breast cancer. |
| Research | The UK Governments should invest in, and provide a supportive environment for, lung cancer research to include funding into early detection and diagnosis, basic research, treatment and clinical trials. All patients should be offered the opportunity to participate in trials if eligible. |
| Data collection | Compliance with national comparative audits should be a core part of Quality Accounts and every Trust should be striving to complete and submit datasets for all lung cancer patients. |

Lung cancer in Humber and Yorkshire Coast Cancer Network

The following table of data below has been sourced from the National Lung Cancer Audit⁴ and the National Cancer Intelligence Network (NCIN)⁵. It outlines how your cancer network is performing nationally on key lung cancer measures.

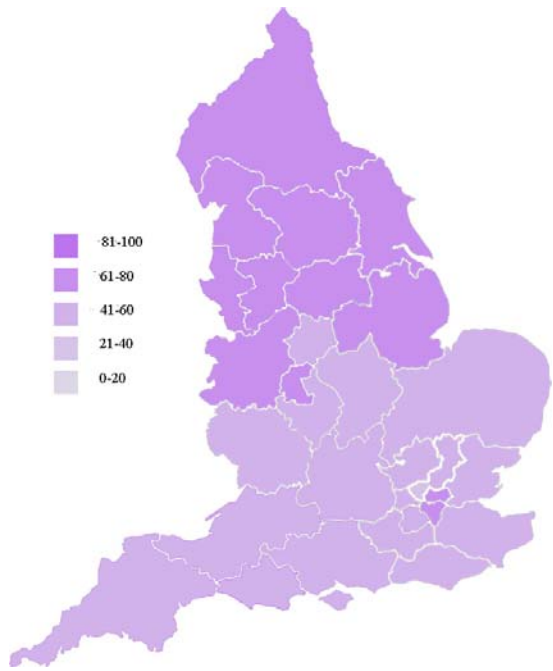
| | Humber and Yorkshire Coast Cancer Network | England Network Average |
|---|---|-------------------------|
| Lung cancer incidence (rate per 100,000 people) * | 66.8 | 59.7 |
| Lung cancer mortality (rate per 100,000 people) * | 46.2 | 39.4 |
| Lung cancer 1 year survival rate (%) * | 25.0 | 27.0 |
| Lung cancer 5 year survival rate (%) * | 7.9 | 7.9 |
| Discussed at MDT (%) ** | 96.3 | 88.6 |
| Patients seen by nurse specialist (%) ** | 45.5 | 50.5 |
| Nurse specialist present at diagnosis (%) ** | 26.6 | 28.7 |
| Patients receiving active treatment (%)** | 57.0 | 53.5 |
| Patients with histological diagnosis (%) ** | 62.8 | 73.9 |
| Receiving surgery all cases (%) ** | 11.9 | 11.5 |
| Receiving radiotherapy (%) ** | 21.0 | 24.0 |
| Small cell receiving chemotherapy (%) ** | 83.9 | 62.5 |

* *Cancer e-Atlas*, National Cancer Intelligence Network - data covers 2003-2005

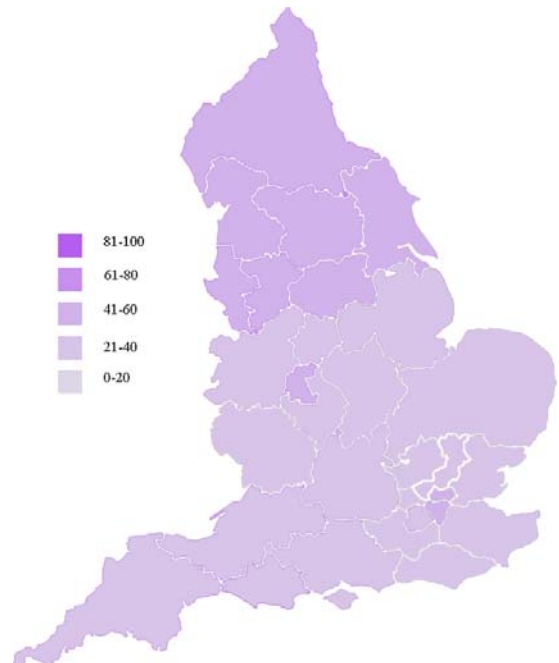
** *National Lung Cancer Audit 2009*, NHS Information Centre- data covers 2008

The following maps show how Humber and Yorkshire Coast Cancer Network compares to other areas of the country on key measures for lung cancer.

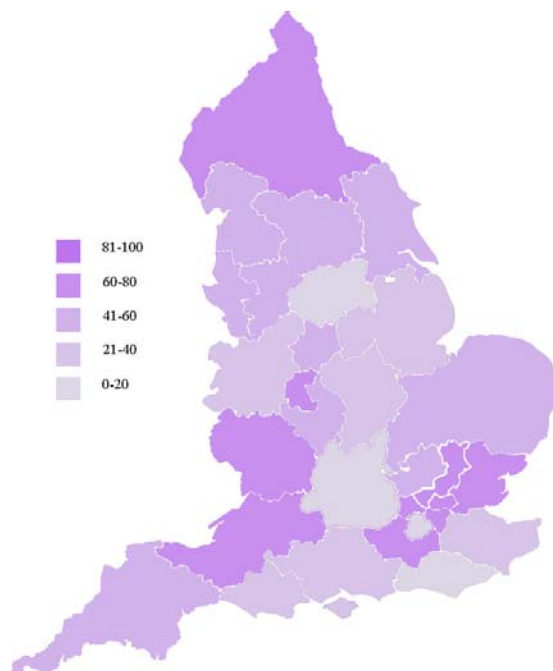
Lung cancer incidence rate per 100,000 people



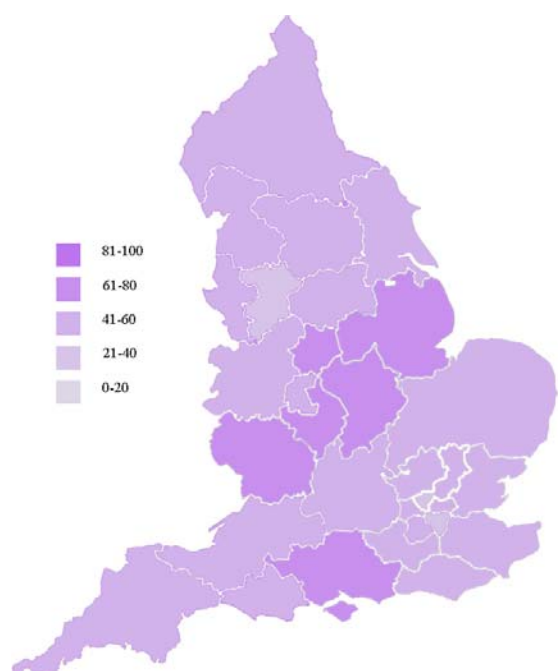
Lung cancer mortality rate per 100,000 people



Patients seen by a nurse specialist (%)



Patients receiving active treatment (%)



Your local commissioner

Below you will be able to find out the name of the commissioner at your Primary Care Trust (PCT) who is responsible for lung cancer services, and an e-mail address at which you can contact them.

| | | | |
|-------------------------------------|-----------------|---|--|
| East Riding of Yorkshire PCT | Gary Lusty | Assistant Director of Strategy and Market Development | gary.lusty@erypct.nhs.uk |
| Hull Teaching PCT | Karen Mazingham | Commissioning & Service Improvement | karen.mazingham@hullpct.nhs.uk |
| North East Lincolnshire PCT | Jo Gander | Cancer Commissioning Lead | Joanne.Gander@nelctp.nhs.uk |
| North Lincolnshire PCT | Caroline Briggs | Lead Commissioner | caroline.briggs@nlpct.nhs.uk |
| North Yorkshire and York PCT | John Hancock | Lead Commissioner | john.hancock@nyypct.nhs.uk |

Template email

We have created a template email below as a guide should you wish to contact your local commissioner to arrange a meeting to discuss improving lung cancer services in your area.

Dear [insert contact name]

I am a [insert job title] at [insert workplace] and I am writing about the commissioning of lung cancer services in our area.

The seriousness of this disease and the variable level of care that lung cancer sufferers receive is documented in the recent publication of the *National Lung Cancer Audit 2009*. This report showed that despite some recent improvements in service provision, there are still wide variations in standards across the country, including diagnosis, treatment and care for lung cancer patients.

In [insert region], while we do well on [insert aspect of care which your region does well on], I believe we could do better on [insert aspect of care your region could improve].

I would be keen to contribute my expertise to support the stronger commissioning of lung cancer services. I am therefore contacting you to see if it would be possible to arrange a [meeting/telephone call] to discuss how our region is presently faring in the delivery of lung cancer services and how this situation could be improved

I can be reached on [contact details] and look forward to hearing from you soon.

Yours sincerely,

[Insert Name]

Engaging with your local commissioner

Commissioners are assessed by the Department of Health on a number of competencies which include “*effective engagement with clinicians to shape services*”. This means that they should welcome the chance to hear your thoughts. However, NHS commissioners are pulled in many directions by the need to stretch tight budgets across many services and disease areas. We have therefore compiled a number of hints and tips to help you make your case for improvements in lung cancer services as persuasive as possible.

General tips

- It will be important when engaging with your local commissioner to put yourself in their shoes in order to understand their motivations and how to best make the case for the changes you are proposing.
- The commissioner you will be speaking to will be responsible for commissioning a wide range of services, not just those for lung and other cancers. They will therefore need to consider how investment in lung cancer services will affect funding for other areas, and which changes will provide the greatest overall benefits to the population.
- As you will be aware, all NHS commissioners are operating within very tight spending constraints and budgets are likely to get tighter. Therefore, it will be helpful when suggesting new services or requesting extra funding to highlight the ultimate cost savings or efficiencies that these could lead to.
- Remember that there is a long lead time for commissioning decisions. For new funding to be made available for a service in the 2011/2012 financial year, commissioners will need to begin scoping options in summer 2010. Therefore the earlier you engage with your commissioner the greater chance of success you have.
- You should prepare your case as thoroughly as possible in advance of speaking to your local commissioner. Commissioners have to submit a business case for each of their proposals, so the more of this thinking that you can do for them in advance the better.
- The data from this toolkit on how your area is performing on lung cancer services will help you to highlight to your local commissioner where the area could go further.

What motivates commissioners?

In order to understand what motivates your local commissioner it is useful to consider the wide range of targets they are required to meet and Government initiatives that they are being asked to undertake. Below are just some of these. Aligning your messages with these targets will help to give weight to your requests.

- **Vital Signs** – Vital Signs are set within the NHS Operating Framework and are used by the Department of Health to measure the performance of NHS Trusts. Some vital signs measures are national requirements, such as cancer wait targets. Some are national priorities for which PCTs must have plans in place: this includes the need to take action to improve smoking quit rates.
- **World Class Commissioning assurance process** – As part of the World Class Commissioning initiative being led by the Department of Health, PCTs were asked to select up to eight outcomes to be measured against which reflect the health priorities of their local area. Over two thirds of PCTs chose to select the “smoking quitters” indicator. Cancer services were the fourth most prioritised disease or service area. Commissioners should be looking for ways in which they can improve their performance on these indicators.
- **Quality, Innovation, Productivity, Prevention (QIPP) or the Quality and Productivity Challenge (QPC)** – David Nicholson, the NHS Chief Executive set all NHS trusts the challenge of improving quality, innovation, productivity and

- prevention. This is also known as the “Quality and Productivity Challenge”. These factors will need to be considered in all commissioning decisions.
- **Cancer waiting time targets** – The Department of Health has set much publicised targets for NHS trusts to ensure that patients wait no longer than two weeks for referral from their GP to an outpatient appointment, no longer than 31 days for treatment after diagnosis and no longer than 62 days from referral for suspected cancer to first treatment. The Government are also financing a new guarantee that patients with suspected cancer should wait no longer than one week from seeing their GP for the results of their diagnostic test.
 - **Improving Outcomes Guidance** – Commissioners will need to ensure that Trusts are implementing improving outcomes guidance from the National Institute for Health and Clinical Excellence (NICE) on the diagnosis and treatment of lung cancer. This can be found here <http://www.nice.org.uk/nicemedia/pdf/cq024fullguideline.pdf>

Things to consider when you are making your case

- How would your proposal better meet the needs of the local population? Would it fill a previously unmet need, improve access for patients, or provide patients with care in the location where they want it?
- What benefits would your proposal bring to healthcare providers? These could include improved quality, reduced costs, fewer unplanned admissions, increased capacity, reduced risk and improved patient outcomes.
- Would your proposal help to achieve a reduction in waiting times?
- Would your proposal help to reduce health inequalities?
- Could your proposal help to realise efficiency savings or reduce costs in other areas?
- Would your proposal require disinvestment from another service?
- What barriers currently exist to implementing your proposal?
- Is a new service required or alternatively could existing services be configured to work more effectively and efficiently?
- Does the service need to be provided by the NHS or could these needs be met by the voluntary sector?

Things to ask your commissioner

- What are their top commissioning priorities at the moment?
- Does the PCT recognise the aspects of lung cancer services where it may be falling behind and could make improvements?
- How much funding is there currently for lung cancer services? Is this set to continue?
- What would help them to commission more effective lung cancer services?

Contacting us

You can find out more about the UK Lung Cancer Coalition at www.uklcc.org.uk

We would be delighted to receive feedback on the experiences you have in engaging with your local commissioners of lung cancer services. Please send these to uklcc@blf-uk.org

Other sources of information

For further information about lung cancer services and commissioning, you may find the following websites of use:



British Lung Foundation
www.lunguk.org



National Lung Cancer Forum for Nurses
www.nlcn.org.uk



Cancer Black Care
www.cancerblackcare.org.uk



Cancer Research UK
www.cancerresearchuk.org



PCRS UK
www.pcrs-uk.org



Macmillan Cancer Support
www.macmillan.org.uk



Marie Curie Cancer Care
www.mariecurie.org.uk



The Roy Castle Lung Cancer Foundation
www.roycastle.org



Tenovus
www.tenovus.org.uk



National Cancer Intelligence Network (NCIN)
www.ncin.org.uk



Cancer Reform Strategy
www.dh.gov.uk/en/Healthcare/Cancer/ReformStrategy



Cancer Commissioning Toolkit
www.dh.gov.uk/en/Healthcare/Cancer/Commissioning



National Lung Cancer Audit
www.ic.nhs.uk/services/national-clinical-audit-support-programme-ncasp/cancer/lung

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- ¹ Cancer Research UK available at <http://info.cancerresearchuk.org/cancerstats/types/lung>
- ² Cancer Research UK available at <http://info.cancerresearchuk.org/cancerstats/types/lung>
- ³ Cancer Research UK available at <http://info.cancerresearchuk.org/cancerstats/types/lung>
- ⁴ *National Lung Cancer Audit 2009*, NHS Information Centre, 2 December 2009
- ⁵ *Cancer e-Atlas*, National Cancer Intelligence Network available at <http://www.ncin.org.uk/analysis/eatlas.shtml>