

State of the Nation: An overview of the impact and priorities for lung cancer in Northern Ireland

Introduction

Lung cancer is Northern Ireland's biggest cancer killer. It causes more than one in five of all cancer-related deaths and more than twice as many deaths as the next ranked cancer¹. This briefing sets out the latest evidence on the burden of the disease in Northern Ireland and what steps need to be taken to help improve outcomes for lung cancer patients, as well as a series of suggested actions you may wish to consider taking forward to help raise the profile of these important issues.

Summary

- Lung cancer is Northern Ireland's biggest cancer killer, accounting for one in five of all cancer-related deaths – more than twice as many as the next ranked cancer
- In 2012, there were around 1,150 new cases diagnosed and almost 1,000 deaths caused by lung cancer
- There are approximately 2,000 people living with lung cancer in Northern Ireland
- Unlike the majority of cancers, improvements in relative survival for lung cancer have been modest in recent years – outcomes in Northern Ireland and the rest of the UK remain poor when compared with other countries
- Just 11% of lung cancer patients live for up to five years after the point at which they are diagnosed, below the European average (13%)
- Earlier diagnosis is a key challenge in Northern Ireland as patients diagnosed at a later stage are more likely to have advanced disease and a poorer prognosis
- You can play a key role in helping to raise the profile of lung cancer and supporting the drive to improve patient outcomes and the quality of services

What actions can you take to improve the quality of services for lung cancer patients?

- Call for the Public Health Agency (PHA) to include specific messages on the signs and symptoms of lung cancer as part of its planned national cancer awareness campaign
- Table written questions and secure a debate in the Northern Ireland Assembly to scrutinise action taken by the Department of Health, Social Services and Public Safety (DHSSPS) to improve lung cancer survival rates
- Contact the Northern Ireland Cancer Network (NICaN) Lung Group regarding the participation of hospitals in Northern Ireland in the *National Lung Cancer Audit*
- Write to the Guidelines and Audit Implementation Network (GAIN) to request an update on plans on measuring progress against the recommendations from *Monitoring care of Lung cancer patients in Northern Ireland*
- Contact your local health and social care trust and local commissioning group to identify what plans they have in place to improve the experience of care for lung cancer patients

What is the burden of lung cancer in Northern Ireland?

Incidence data, which captures the number of new lung cancer cases identified in a specific area or time period, shows that the number of people being diagnosed with lung cancer in Northern Ireland has increased over the last 20 years. In 2012, there were around 1,150 new cases recorded – approximately 13% of all new cancer diagnoses².

Figure 1 – Number of new cases and age-standardised incidence rate for lung cancer in Northern Ireland (1993-2012)³

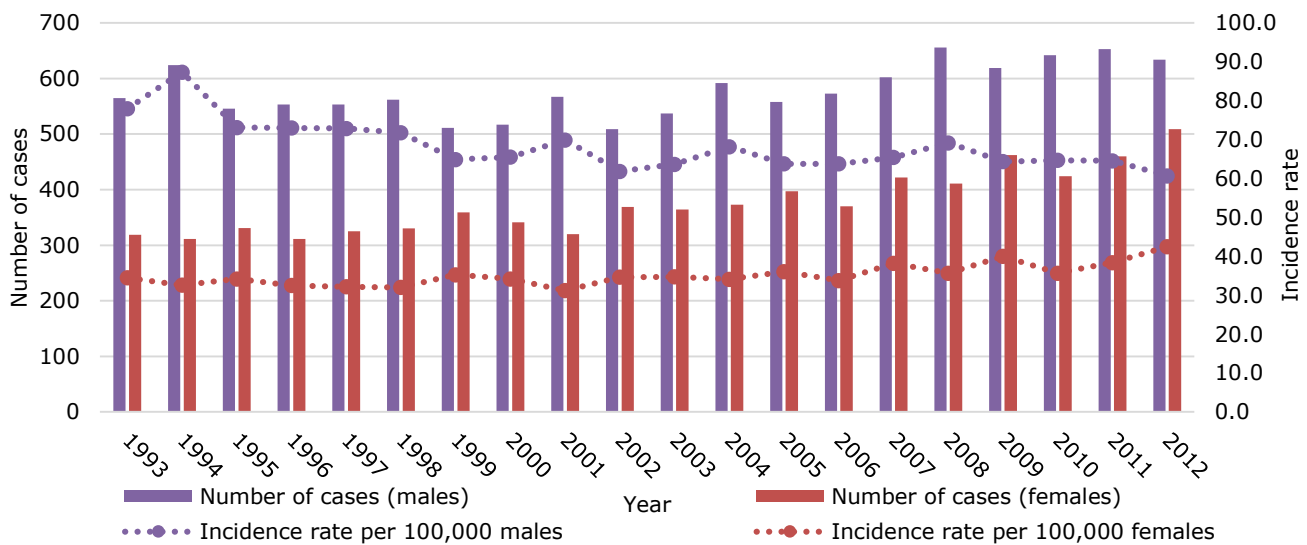
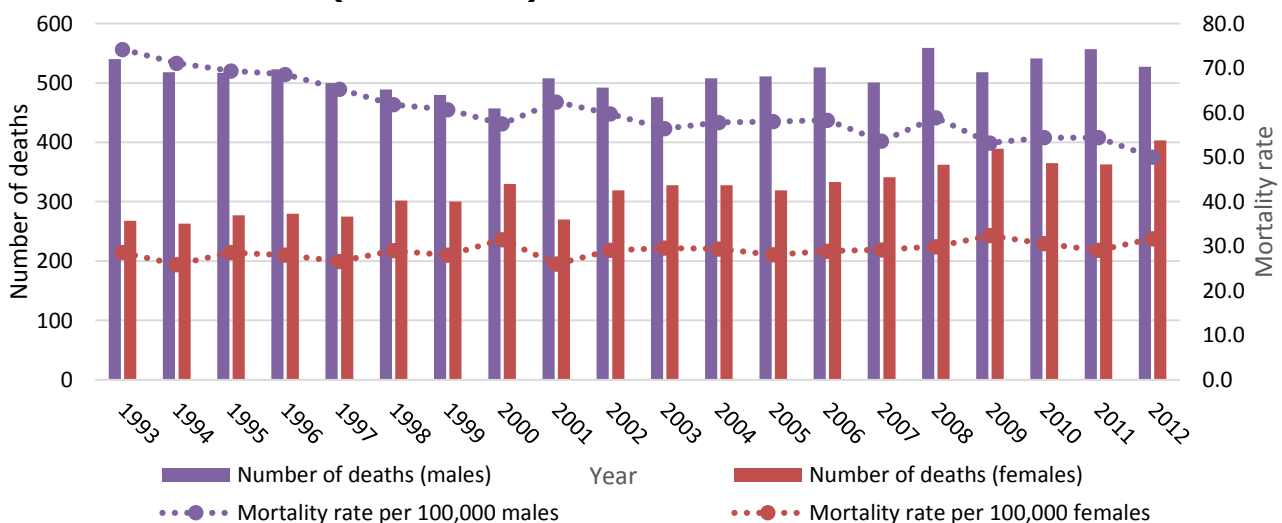


Figure 1 demonstrates that the rate of new lung cancer cases has been consistently higher among men, although the gender gap has narrowed steadily in recent years. This pattern has been attributed to contrasting trends in smoking prevalence among men and women⁴. It has been estimated that there are approximately 2,000 people living with lung cancer in Northern Ireland⁵.

As well as diagnosing more cases earlier, improving tobacco controls, greater awareness of the dangers of smoking and better access to smoking cessation services have been identified as key priorities for tackling the burden of lung cancer by the DHSSPS⁶.

The latest mortality statistics (Figure 2), which measure the number of deaths caused by lung cancer in a specific area or time period, show there has been a steady decline in the number of deaths caused by lung cancer in Northern Ireland over the past 20 years⁷.

Figure 2 – Number of deaths and age-standardised mortality rate for lung cancer in Northern Ireland (1993-2012)⁸



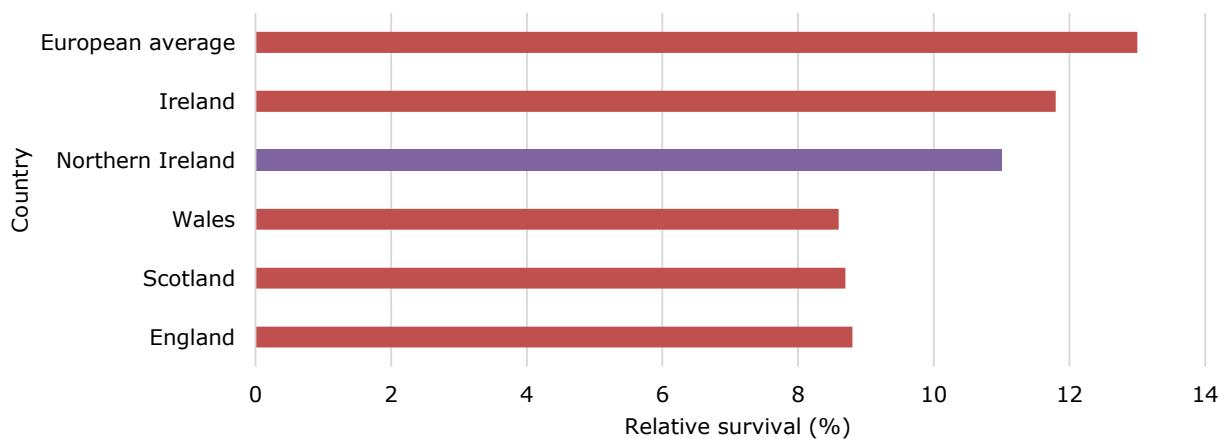
In 2012, almost 1,000 people were killed by lung cancer – approximately a quarter (23%) of all cancer-related deaths⁹. Lung cancer related mortality in the most deprived areas is

five and a half times that in the least deprived. There is also regional variation in lung cancer mortality rates with a higher proportion of deaths recorded in Belfast (58 deaths per 100,000 people), compared to the national average (40 deaths per 100,000 population)¹⁰.

Survival data refers to the percentage of patients who live for a specified period after being diagnosed. Trends in survival provide key insights into the overall effectiveness of the health system in managing a specific cancer. There have been steady improvements in one- and five-year lung cancer survival in Northern Ireland in recent years¹¹, however, a recent European study across 29 different countries shows five-year survival is poorer in Northern Ireland, and across the UK, than the rest of Europe¹².

More research is needed to investigate the potential causes for this trend, specifically focusing on the impact of late diagnosis and restrictions in access to the latest treatments¹³.

Figure 3 – Five-year age-standardised relative lung cancer survival for adult patients with cancer, diagnosed 2000–07¹⁴



How are lung cancer services organised and delivered in Northern Ireland?

The Service Framework for Cancer Prevention, Treatment and Care¹⁵ sets standards in relation to prevention, diagnosis, treatment, care, rehabilitation and palliative care aimed at ensuring all cancer services are safe, effective and accessible.

This framework is used to support those organisations involved in health and social care to plan, provide and monitor care, including:

- **Health and Social Care Board (HSCB) and Local Commissioning Groups (LCGs):** Responsible for planning services based on the needs of the population
- **Health and Social Care Trusts:** Responsible for delivering health and social care to people. Cancer units are based in each of the Trusts, with the cancer centre located in the Belfast HSC Trust
- **Regional Quality Improvement Authority (RQIA):** Responsible for regulating the quality of health and social services through a programme of monitoring and inspections and driving improvements across the health and social care service

The health and social care system in Northern Ireland is currently undergoing significant reform. The *Transforming Your Care* programme sets out a series of changes aimed at delivering more patient-centred care¹⁶. It specifically identifies the need to expand

regional radiotherapy services, establish Acute Oncology Services in all Trusts and offer more comprehensive follow-up services to cancer survivors¹⁷.

What do we know about the quality of lung cancer services in Northern Ireland?

Measuring the performance of services is crucial to supporting effective decision-making and driving improvements in the quality of services to patients. *Monitoring care of lung cancer patients in Northern Ireland*, undertaken by the Northern Ireland Cancer Registry in 2007, benchmarked data on lung cancer services to assess whether they were being delivered in line with the recommended clinical guidelines on investigation and treatment¹⁸.

The review identified significant progress in a number of areas, as well as clear priorities for improvement. The authors of the report called for lung cancer services in Northern Ireland to be re-audited in 2014¹⁹.

Figure 4 – Key findings on the quality of lung cancer services²⁰

Measured improvements	Priorities for action
<ul style="list-style-type: none"> • More patients are presenting earlier • Reduced waiting times for investigation and treatments • Wider use of complex imaging techniques to support more effective diagnosis • Better access to specialist multi-disciplinary teams (MDTs) • Increased uptake of chemotherapy treatments • Positive impact of surgery on survival rates • More equity in service provision across the country 	<ul style="list-style-type: none"> • Promote earlier diagnosis to reduce high proportion of patients being identified at an advanced stage • Better recording of stage of disease at diagnosis • Increasing surgical, radiotherapy or chemotherapy treatment rates where clinically appropriate • Better communication between teams and staff responsible for managing an individual's care and treatment

Early diagnosis: Diagnosing lung cancer earlier is key to improving patient outcomes. 45% of lung cancer cases are identified when a patient attends hospital as an emergency at a more advanced stage of the disease when the outlook for patients is significantly poorer²¹. It is important that the Public Health Agency (PHA) delivers on its commitment to launch a public awareness campaign on cancer in 2014/15 and includes specific messages on lung cancer. The UK Lung Cancer Coalition (UKLCC) is calling for the PHA to publish more details on the timelines for the campaign launch and arrangements for managing the likely increase in those presenting with suspected symptoms.

Driving clinical practices: The *National Lung Cancer Audit* looks at the care delivered during referral, diagnosis, treatment and outcomes for people diagnosed with lung cancer and mesothelioma. There had been plans for data from hospitals in Northern Ireland to be included in the 2013 *Audit*, however, data returns were not submitted in time for inclusion and were due to be published online at a later date. By contrast, every trust or health board in England, Wales and Scotland have participated in the audit²². In addition, all trusts are also expected to ensure that cancer lung cancer multi-disciplinary teams (MDTs) undertake the Northern Ireland Cancer Network (NICaN) peer review process and develop action improvement plans which will be shared with HSCB.

Improving patient experience: Research indicates that there is a correlation between patient experience and clinical outcomes²³. The *Service Framework for Cancer Prevention, Treatment and Care*²⁴ includes a series of overarching standards aimed at improving the experience of care through tailored support based on the needs and preferences of the individual. Monitoring the experiences of patients is key to driving better standards of care by helping to identify those aspects of care which matter most to them and those areas where improvement and investment should be prioritised. Plans for undertaking a survey of cancer patients in Northern Ireland to gather information on their experiences has been delayed.

About the UKLCC

Established in November 2005, the UK Lung Cancer Coalition (UKLCC) is a coalition of the UK's leading lung cancer experts, senior NHS professionals, charities and healthcare companies. Through our campaigning activity we aim to:

- Raise political awareness of lung cancer
- Raise the general public's awareness of lung cancer – and especially encourage earlier presentation and symptom recognition
- Empower patients to take an active part in their care
- Improve lung cancer services in the UK

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