

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

Introduction

Lung cancer is Scotland's biggest cancer killer. It causes approximately one quarter of all cancer-related deaths – more than twice as many deaths as any other cancer¹. This briefing sets out the latest evidence on the burden of the disease in Scotland and what steps have been, and can 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 Scotland's biggest cancer killer, accounting for approximately one quarter of all cancer-related deaths in 2012 – more than twice as many as any other cancer
- In 2010, an estimated 6,000 people were living with lung cancer in Scotland
- There were over 5,000 new cases and 4,000 deaths caused by lung cancer in 2012 alone
- The five year survival rate for lung cancer patients in Scotland after the point at which they are diagnosed (8.7%) is lower than the rest of Europe (13%)
- Tackling the reasons for this gap through increasing awareness of the dangers of smoking, maintaining effective smoking cessation services, ensuring early testing and diagnosis, and measuring patient experience to which service improvements can be gauged against, should be a number of the priorities for health and social care services in Scotland
- You can play a key role in helping to raise the profile of lung cancer and scrutinise lung cancer services in Scotland

What actions can you take to help raise the profile of lung cancer and scrutinise lung cancer services

- Table parliamentary questions asking when the first national report on lung cancer Quality Performance Indicators (QPIs) can be expected for publication
- Table parliamentary questions or initiate a debate asking for an evaluation of the impact of the *Detect Cancer Early* campaign and what plans are in place for future activities, including targeting hard-to-reach communities
- Write to your regional NHS Board to find out what processes are in place to deliver greater awareness of the dangers of smoking and better access to smoking cessation services
- Write to NHS Scotland on plans to develop and roll-out a national cancer patient experience survey
- Write to NHS Scotland querying how the Scottish Referral Guidelines for Suspected Cancer are being communicated and implemented to ensure prompt testing and diagnosis for lung cancer patients

What is the burden of lung cancer in Scotland?

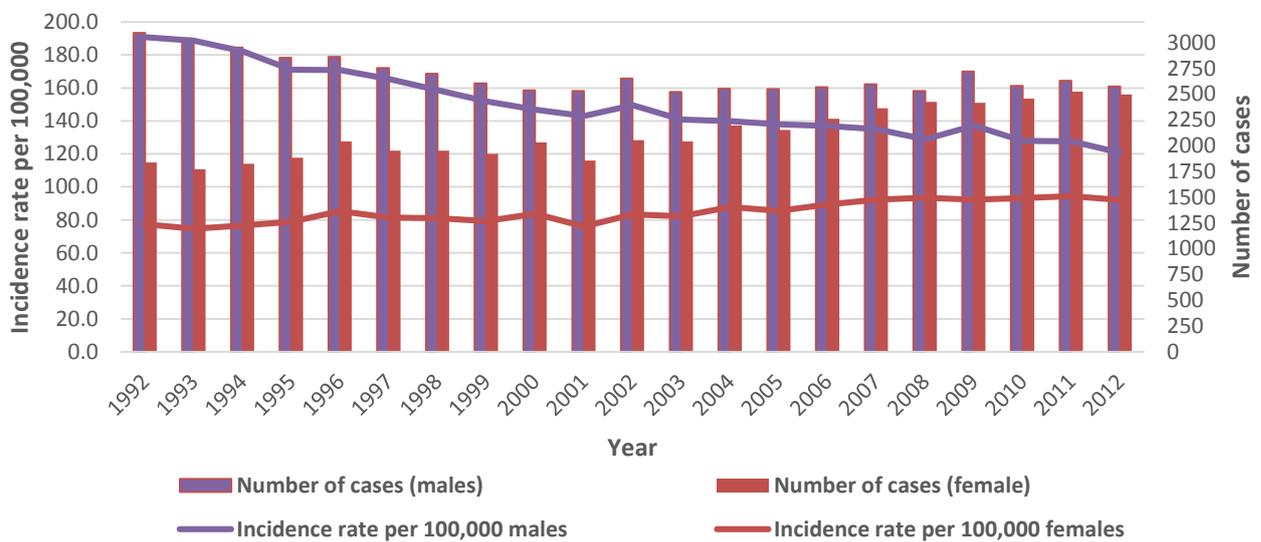
Incidence data, which capture the number of new lung cancer cases identified in a specific area or time period, show that despite improvements over recent years Scotland has among one of the highest incidence rates in the world – 106 cases per

100,000 population in 2012². This equates to just over 5,000 new cases diagnosed each year.

Whilst the incidence rate for lung cancer has broadly decreased in recent years, rates within Scotland’s female population have increased since 1992 from 77 cases per 100,000 of the population to 92. By contrast, during the same period, male lung cancer incidence rates have fallen from 191 per 100,000 to 121² (see Figure 1).

Lung cancer incidence rates are closely linked to past trends in cigarette smoking prevalence, with smoking rates peaking earlier in males than in females, allowing more time for the rate to decrease. In 1975 the male-to-female ratio for lung cancer cases was approximately 39:10. This fell to 12:10 in 2011³.

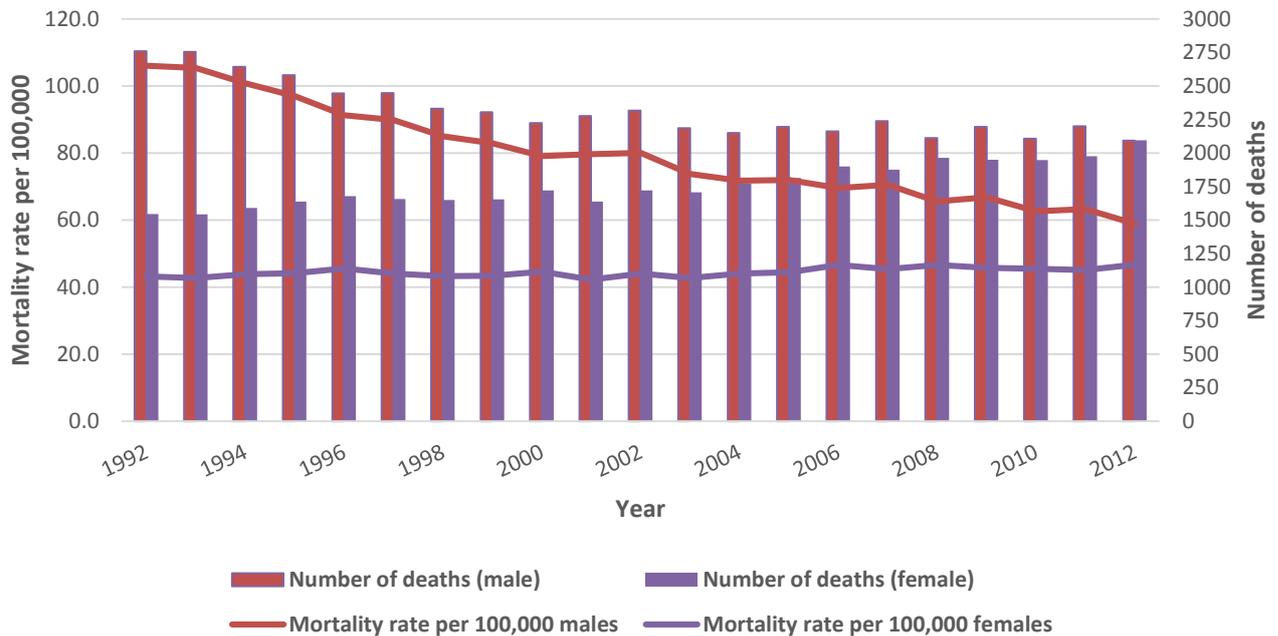
Figure 1: Number of new cases and age-standardised incidence rate for lung cancer in Scotland (1992-2012)²



Scotland remains the only UK nation where lung cancer is the most common cancer³, with 6,000 people estimated to be living with the disease in 2010⁴. This is broadly reflective of the country’s historically high smoking prevalence (in 2012 it was estimated that one in four adults in Scotland was a smoker⁵) and the cultural association with the nation’s male-dominated industrial workforce in the last century³.

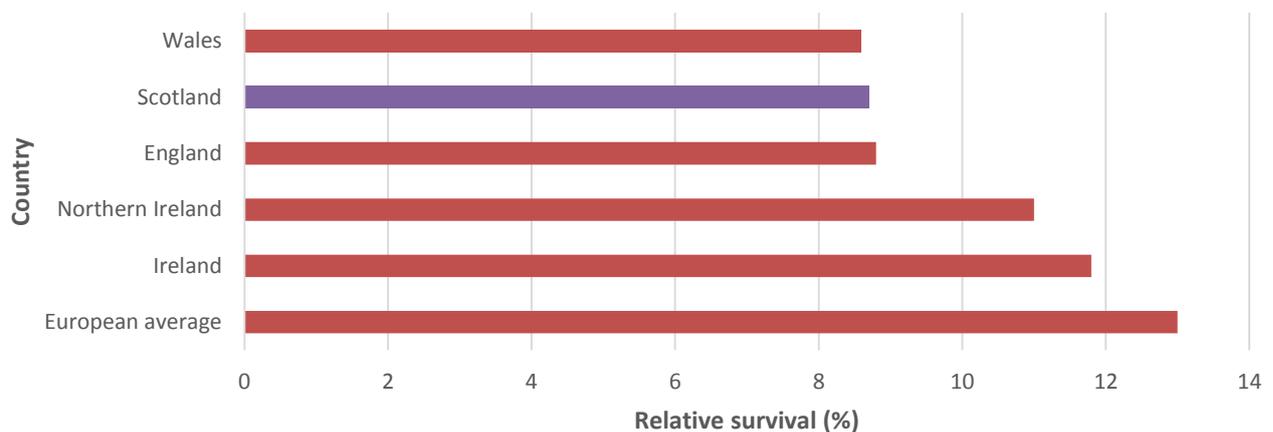
With a significant rate of incidence and prevalence throughout the country, in 2012 alone around 4,200 people died as a consequence of lung cancer, representing 53 deaths per 100,000 of the population⁶. Although lung cancer mortality has declined in recent years, this still represents over a quarter of cancer-related deaths among men (26.4%) and women (26.7%)⁷. Recent trends in male and female mortality can be found in Figure 2 below.

Figure 2: Number of deaths and age standardised mortality rate for lung cancer in Scotland (1992-2012)⁶



Lung cancer outcomes in Scotland are amongst the worst in Europe. A recent pan-European study on cancer survival rates found that out of 29 countries studied, Scotland has the third lowest 5-year survival rate for adult patients at 8.7%⁸. Five-year survival rates across the UK can be found in Figure 3 below.

Figure 3: Five-year age standardised relative lung cancer survival for adult patients with cancer, diagnosed 2000-07⁹



How are lung cancer services organised and delivered in Scotland?

Each of NHS Scotland's 14 regional NHS Boards, responsible for the protection and improvement of their population's health and for the delivery of frontline healthcare services, are closely associated with one of three Regional Cancer Networks (RCNs). RCNs broadly support partnership working across organisational boundaries, involving patients in planning cancer services, and serve to promote high standards of cancer care and equity of access to cancer services.

Respiratory services more broadly are supported by Managed Clinical Networks (MCNs) in NHS Board areas, with the Respiratory National Advisory Group (RNAG) acting as the umbrella group for MCNs, sharing examples of best practice and service innovation.

The Scottish Government has identified cancer as a national priority¹⁰. *Better Cancer Care: An Action Plan*, published in October 2008¹¹, recognised the challenges of the growing burden of cancer in Scotland and set out a series of actions and priorities designed to improve cancer services and care. Building upon *Better Cancer Care*, the Scottish Government and NHS Scotland have rolled out two major programmes.

Firstly, the *Detect Cancer Early* programme, which was developed in February 2012 with the overall aim of improving five-year survival rates for people diagnosed with cancer in Scotland¹². The main aims of the programme include strengthening data collection, performance reporting and raising public awareness of national cancer screening programmes. This was supported with the launch of the dedicated *Detect Lung Cancer Early* campaign in November 2013, which promoted awareness and early diagnosis of lung cancer specifically.

Secondly, launched in June 2013, the *Transforming Care After Treatment (TCAT)* programme is a partnership to support redesign of care following active treatment for cancer¹³. Supporting and enabling cancer survivors to live as healthy a life as possible, the programme develops services tailored to the needs and preferences of patients, improving integration between different service providers. Eight projects were approved by the Programmes Board for the TCAT's first phase and, whilst a lung cancer specific project was not approved, it remains a positive development and opportunity with second phase projects to be announced in the autumn of 2014.

Further supporting the drive to improve the quality of lung cancer care and services are the following:

- **Scottish Intercollegiate Guidelines Network (SIGN):** Developing evidence based clinical practice guidelines for the National Health Service in Scotland, SIGN has developed a dedicated guideline for the management of lung cancer, setting out the appropriate diagnostic and treatment processes for clinicians to follow¹⁴
- **Lung Cancer and Cancer Patient Experience Quality Performance Indicators^{15,16} (QPIs):** Responsive to changes in clinical practice and emerging evidence, QPIs set out distinct care indicators to drive continuous quality improvements in cancer care and ensure activity is focussed on areas most important to improving survival, reducing variation and ensuring safe, effective and person-centred cancer care. NHS Boards are mandated to report against QPIs as part of the national cancer quality programme
- **Scottish Referral Guidelines for Suspected Cancer¹⁷:** Published in March 2009, the referral guidelines include a dedicated lung cancer guideline indicating the appropriate clinical pathway to ensure speedy testing and diagnosis for lung cancer patients

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

Building on the wide range of guidance and initiatives already in place, the UK Lung Cancer Coalition (UKLCC) has identified and welcomed a number of priorities to help achieve better outcomes for lung cancer patients across Scotland.

Screening: At present, there is no national lung cancer screening programme anywhere in the UK. First recommending the development of feasibility studies in lung cancer screening services in *Better Cancer Care*¹², assessment of cost effective technologies has continued with the roll out of a dedicated lung cancer screening programme trial in 2012, the first results from which are expected later in 2014.

Patient experience: Recognising the importance of measuring patient experience in a cancer treatment pathway, the Scottish Government had developed the now defunct *Better Together Programme* in April 2009 to support NHS boards, frontline staff and patients in driving forward service improvements. At present, however, Scotland is the only UK nation that does not, or has no plans to, gather evidence of people's experience of cancer as a means of monitoring and improving services.

Access to appropriate treatments: The Scottish Government has taken steps to change the process for determining access to the latest treatments for advanced lung cancer. For example, from May 2014, Patient and Clinical Engagement (PACE) committee meetings will give patients and clinicians earlier input into discussions about unmet need and clinical benefit of these new drugs¹⁸.

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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