

TEN YEARS ON IN LUNG CANCER:
THE CHANGING LANDSCAPE OF THE
UK'S BIGGEST CANCER KILLER

TEN YEARS ON

OCTOBER 2015



UNITED KINGDOM
LUNG CANCER COALITION

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The CAG is supported by leading patient and charity group members, including:

- British Lung Foundation
- Cancer Research UK
- Macmillan Cancer Support
- Roy Castle Lung Cancer Foundation
- Tenovus Cancer Care

It is also supported by the following industry organisations:

- AstraZeneca
- Boehringer-Ingelheim
- Eli Lilly and Company
- Novartis
- Pfizer Ltd
- Roche

ABOUT THE UKLCC

Established in November 2005, the United Kingdom 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

CONTACT DETAILS

The UKLCC is keen to work with all interested organisations and bodies to improve the quality and outcomes of lung cancer treatment and care. For more information about our work and our partners, please visit www.uklcc.org.uk or contact our secretariat:

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INTRODUCTION

The United Kingdom Lung Cancer Coalition (UKLCC) was established in November 2005 to help bring lung cancer out of the political, clinical and media shadow, and help support efforts to improve the one and five-year survival rates for lung cancer patients across the UK.

Campaigning hard to achieve this ambition, the UKLCC has sought to raise public awareness of some of the most important issues facing the lung cancer community today, and support clinicians in delivering high-quality lung cancer care and services.

Marking the ten year anniversary of the UKLCC's formation, *Ten Years On* builds further upon this body of work and assesses the progress made in lung cancer services and outcomes across the UK as a whole, and in each of the four nations individually over the past decade.

Underpinned by the latest data and information sources available at the point of publication, what we find across the UK is a varied and complex picture:

- Lung cancer is by far the UK's biggest cancer killer¹, causing more than one in five (22 per cent) of all cancer deaths in males and females; more than breast and bowel cancer combined²
- Despite this, 89 per cent of lung cancer cases in the UK are in fact preventable³
- A pan-European study on cancer survival rates between 2004 and 2007 found that out of 29 countries studied, the UK nations had some of the lowest 5-year survival rates for adult patients⁴

- Over the last decade (between 2001-2003 and 2010-2012), European age-standardised incidence rates in the UK have decreased by 11 per cent in males, but increased by 17 per cent in females⁵
- On average, UK lung cancer incidence rates are estimated to be 7th lowest in males in Europe⁵

As a coalition of the UK's leading lung cancer experts and professionals, we are only too aware of the competing priorities and stresses facing the health and social care system today: a rapidly ageing patient population; increasing patient co-morbidities; and the greatest financial pressures health services across the UK have faced in generations, or indeed their history.

Despite these difficulties, however, continued aspiration is crucial to bringing to life the key issues facing the lung cancer community today. *Ten Years On* sets out the UKLCC's vision for the future direction of lung cancer services, and what steps are needed to get there.

We hope this report will play a significant role in identifying and driving forward improvements in lung cancer services across the UK, and we look forward to the UKLCC's next ten years, working to help secure the best possible outcomes for lung cancer patients across the UK.

LUNG CANCER IN THE UK

35,300 DEATHS

OVER 35,300 DEATHS FROM LUNG CANCER IN 2012³



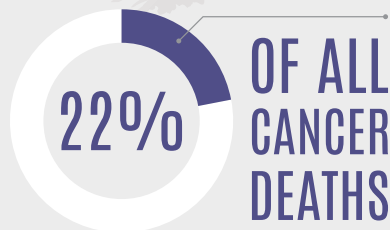
OVER THE LAST DECADE (BETWEEN 2001-2003 AND 2010-2012), EUROPEAN AGE-STANDARDISED INCIDENCE RATES IN THE UK HAVE DECREASED BY 11 PER CENT IN MALES, BUT INCREASED BY 17 PER CENT IN FEMALES⁵



SMOKING, POOR DIET AND PHYSICAL INACTIVITY ARE MODIFIABLE FACTORS THAT CAN CONTRIBUTE TO AN INCREASED RISK OF CANCER⁶

LUNG CANCER UK'S BIGGEST CANCER KILLER

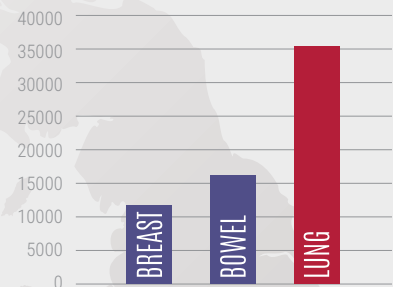
LUNG CANCER IS BY FAR THE UK'S BIGGEST CANCER KILLER¹



LUNG CANCER ACCOUNTS FOR MORE THAN ONE IN FIVE (22 PER CENT) OF ALL CANCER DEATHS IN MALES AND FEMALES; MORE THAN BREAST AND BOWEL CANCER COMBINED²



THERE ARE ABOUT 10 MILLION ADULTS WHO SMOKE CIGARETTES IN GREAT BRITAIN, WHICH REPRESENTS ABOUT A SIXTH OF THE TOTAL POPULATION⁷



NUMBER OF DEATHS IN THE MOST COMMON CANCERS IN 2012 IN THE UK²



89 PER CENT OF LUNG CANCER CASES IN THE UK ARE PREVENTABLE³



IN 1979, THE MALE:FEMALE RATIO FOR LUNG CANCER CASES WAS AROUND 33:10, BUT HAS SINCE FALLEN SHARPLY (12:10 IN 2012)⁵

44,500 NEW CASES

ALMOST 44,500 NEW CASES OF LUNG CANCER IN 2012⁵

LUNG CANCER IN ENGLAND

1 YEAR SURVIVAL RATES HAVE IMPROVED

SINCE THE UKLCC'S INCEPTION, ONE-YEAR SURVIVAL RATES HAVE IMPROVED. 29 PER CENT OF MEN AND 33 PER CENT OF WOMEN WERE ALIVE ONE-YEAR AFTER DIAGNOSIS IN 2010, COMPARED TO ONLY 17 PER CENT OF ALL PATIENTS IN 1990¹³

720,000 DIAGNOSED



720,000 PEOPLE WERE DIAGNOSED WITH LUNG CANCER IN ENGLAND BETWEEN 1990 AND 2011⁹

MDT REVIEWS HAVE INCREASED

SINCE THE UKLCC'S INCEPTION, THE NUMBER OF PATIENTS REVIEWED BY MDTs HAS INCREASED FROM 86% IN 2007¹⁰ TO 95% IN 2013¹¹

NURSE SPECIALISTS HAVE INCREASED

SINCE THE UKLCC'S INCEPTION, THERE HAS BEEN AN INCREASE IN THE NUMBER OF PATIENTS ASSIGNED TO A LUNG CANCER CLINICAL NURSE SPECIALIST, RISING TO 84% IN 2013¹¹, UP FROM 35% IN 2007¹⁰



15,700 MALE DEATHS

IN 2011 ALONE, AROUND 15,700 MEN AND AROUND 12,500 WOMEN DIED OF LUNG CANCER IN ENGLAND⁸

12,500 FEMALE DEATHS



DIAGNOSIS VARIES BETWEEN TRUSTS

PATIENTS DIAGNOSED WITH STAGE IIIB OR IV LUNG CANCER VARIES FROM 11% TO 76% BETWEEN TRUSTS¹²



THE PERCENTAGE OF ALL PATIENTS RECEIVING ACTIVE TREATMENT* UNDER THE AGE OF 65 WAS 76.9% IN 2013; HOWEVER, THIS WAS ONLY 28.1% FOR THOSE OVER THE AGE OF 80¹¹

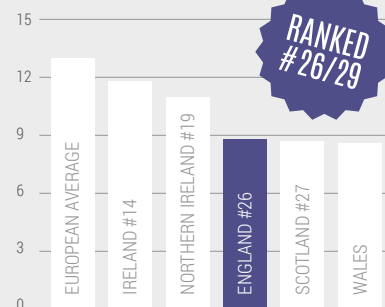


ACTIVE TREATMENT AGE

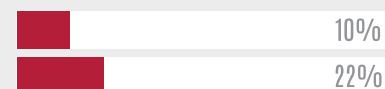


BIGGEST CANCER KILLER ENGLAND

LUNG CANCER IS THE SECOND MOST COMMON CANCER IN ENGLAND AND IS THE BIGGEST KILLER⁸



A PAN-EUROPEAN STUDY ON CANCER SURVIVAL SHOWED ENGLAND PERFORMED POORLY COMPARED TO THE REST OF EUROPE IN TERMS OF FIVE-YEAR SURVIVAL RATES. JUST 8.8% OF LUNG CANCER PATIENTS LIVED FOR UP TO FIVE YEARS AFTER THE POINT AT WHICH THEY ARE DIAGNOSED IN 2011⁴, BUT A MORE RECENT STUDY PREDICTS THAT OF PATIENTS DIAGNOSED IN 2013, 16 PER CENT WILL BE ALIVE AFTER 5 YEARS¹⁴



SURGICAL RESECTIONS FOR NSCLC PATIENTS HAS INCREASED FROM 10% IN 2007 TO 22% IN 2012¹⁵

SMOKING RESPONSIBLE FOR ALMOST 85% OF LUNG CANCER CASES⁶



*EXCEPT CASES WITH SCLC OR MESOTHELIOMA

THE UKLCC'S TEN YEAR VISION FOR ENGLAND

1

As lung cancer is the second most common cancer in England, and the biggest cancer killer, the Department of Health, NHS England and other national bodies should ensure that it is appropriately prioritised within the implementation of the five year cancer strategy and the cancer taskforce report

2

With 85 per cent of lung cancer diagnoses attributable to smoking⁶—a modifiable risk factor—it is essential that Public Health England and local authorities continue to drive efforts to reduce smoking rates and maintain funding for smoking cessation services

3

In order to improve GP referral rates, GP contracts should prioritise cancer diagnosis to help improve early diagnosis rates and lung cancer survival

4

Given the clear benefit it brings in helping to raise awareness of the signs and symptoms of lung cancer, the Be Clear on Cancer cough campaign should be continued by the Department of Health and Public Health England to improve early diagnosis

5

Following the results of the NELSON trial, the UK National Screening Committee should urgently re-assess the benefits of introducing a screening programme for lung cancer in England

6

NHS England should work with commissioners to ensure that all patients receive access to the full range of molecular diagnostic tests for lung cancer and as such can receive the best personalised treatments available

7

Evidence from the most recent National Lung Cancer Audit presents serious issues with regards to equitable access to services and treatments. The Department of Health and NHS England should introduce specific measures to tackle unacceptable variations in cancer services

8

Positive developments with regards to data access should be maintained and organisations should to broaden the scope and scale of data collection so that it can continue to be used to improve lung cancer services

9

Numbers of lung cancer clinical nurse specialists (CNSs) should be increased to a level where no trust has less than two CNSs and the case load is no more than 100 new patients per year, in order to ensure patients' care is fully integrated and that they are supported throughout their care pathway

10

Efforts need to be made to ensure there is equitable recruitment for lung cancer clinical trials, with multi-disciplinary teams (MDTs) supported to ensure that entry can be offered to all suitable patients

INTRODUCTION

Lung cancer is the second most common cancer for both men and women in England and is the biggest cancer killer overall⁸. In 2011 alone it accounted for 13 per cent of all newly diagnosed cases on average⁸. However, studies suggest that 1,300 deaths from lung cancer could be avoided each year if survival rates in England matched the best survival rates in Europe¹⁶.

This chapter of the UKLCC's ten-year on report examines the last ten years of policy for lung cancer in England to determine how services have progressed, and to provide recommendations on how services can continue to develop in order to improve patient outcomes.

CANCER AS A PRIORITY: LEVERS AND DELIVERY

The UKLCC has welcomed the efforts made with regards to cancer services over the past ten years, which has culminated in several pieces of national guidance and levers designed to improve the delivery of care:

The NHS Cancer Plan 2000¹⁷

Although before the UKLCCs formation, the *NHS Cancer Plan* was a key milestone in cementing cancer as a high Government priority and presented the strategy for investment and reform for cancer services across the NHS. The plan also set out the Government's national programme to reduce death rates, improve survival and quality of life through prevention, and promote early detection and effective screening practices.

Cancer Reform Strategy 2007¹⁸

Following the *NHS Cancer Plan*, the *Cancer Reform Strategy* set out an ambitious five year cancer programme and highlighted the Government's commitment to devolve power and authority to local NHS bodies in order to improve services.

Improving Outcomes: A Strategy for Cancer 2011¹⁹

The 2011 *Strategy for Cancer* set out how services would put patients, service users and members of the public at the heart of cancer care; would be oriented towards delivering the improvements in outcomes which people themselves wanted; and how local organisations and frontline professionals would be empowered to deliver them. Fundamentally, the plan aimed to save an additional 5,000 lives by 2014/15 and deliver outcomes which were comparable with the best performing countries in Europe, supported by a £750 million investment fund designed to support improvements in cancer services.

The strategy also called for work to be undertaken to evaluate the impact of multi-professional and palliative care input throughout the lung cancer pathway, for those with active and advanced disease.

Four subsequent reports have been published, demonstrating annual progress alongside the original strategy, holding services to account and identifying future areas for improvement.

NHS Five Year Forward View²⁰

At the end of 2014, Simon Stevens, Chief Executive of NHS England, presented his vision for the NHS over the next five years in the *Five Year Forward View (5YFV)*. Despite the vast improvements there have been in cancer outcomes, there was emphasis within the plan on the need for tailored and improved treatment as well as more comprehensive diagnoses.

Achieving World-Class Cancer Outcomes: A Strategy for England 2015-2020²¹

To support the implementation of the vision for cancer set out in the 5YFV, NHS England announced the establishment of an independent taskforce to develop a five year strategy for cancer services in January 2015. The new strategy, *Achieving World-Class Cancer Outcomes: a strategy for England 2015-2020*, was published in July 2015 and sets six strategic priorities for the improvement of cancer care in England, including:

1. Spearheading a radical upgrade in prevention and public health
2. Driving a national ambition to achieve earlier diagnosis
3. Establishing patient experience as being on a par with clinical effectiveness and safety
4. Transforming our approach to support people living with and beyond cancer
5. Making the necessary investments required to deliver a modern high-quality service
6. Overhauling processes for commissioning, accountability and provision

As well as these priorities, the strategy sets out a further 96 recommendations, four of which specifically refer to lung cancer, as summarised below:

Recommendation 13: The National Screening Committee should examine the evidence for lung and ovarian cancer screening and Public Health England should be ready to pilot lung or ovarian screening within 12 months following evidence of significant positive mortality outcomes and cost-effectiveness from studies currently underway, together with a plan for subsequent national roll-out

Recommendation 15: Public Health England should continue to invest in Be Clear on Cancer campaigns to raise awareness of possible symptoms of cancer and encourage earlier presentation to health services. Campaigns should include lung, breast over 70s, and other cancer types where pilots prove effective

Recommendation 37: NHS England should nationally commission access to molecular diagnostic tests to guide treatment, starting with the following cancer types in 2016: melanoma, lung, colorectal, breast and all paediatric cancers

Recommendation 82: NHS England should commission a rolling programme of national clinical audits for critical cancer services, including annually for lung cancer, and oversee an annual audit of cancer diagnosis

Following the publication of the strategy in July 2015, the cancer taskforce is currently working with NHS England to develop a plan for the strategy's implementation. *Achieving World-Class Cancer Outcomes* has made significant steps in providing national guidance for how lung cancer care needs to be delivered to improve outcomes. It is essential that such recommendations are encapsulated within the final implementation plan for this strategy.

HOW ARE LUNG CANCER SERVICES ORGANISED AND DELIVERED IN ENGLAND?

NHS England

Following the enactment of the Health and Social Care Act 2012, which aimed to put clinicians at the centre of service commissioning²², lung cancer care (including pleural mesothelioma) has been delivered by the 211 clinical commissioning groups (CCGs) within England who commission services for the most common cancers. Services for radiotherapy, chemotherapy and specialist interventions are, however, commissioned directly by NHS England as a specialised service. NHS England has recently established a Lung Cancer Clinical Reference Group to develop a Service Specification for lung cancer to support the optimal commission of lung cancer services.

Other organisations also involved in helping to shape and deliver lung cancer services include:

Department of Health

Provides national direction and leadership in how cancer services should be delivered. Until 2013, the Department was supported by a National Cancer Action Team who helped to coordinate improvements in cancer services locally.

National Clinical Director for Cancer

Provides expert insight and leadership in the delivery of cancer services.

Public Health England (PHE)

Works with health and wellbeing boards and has core roles in the collection of data through the National Cancer Registration Service, plus the analysis and publication of information and indicators to support commissioning via its National Cancer Intelligence Network (NCIN)²³. PHE also plays a key role in developing and implementing preventative measures to support a reduction in cancer incidence through modifiable risk factors, such as smoking. In addition, PHE is responsible for the Be Clear on Cancer programme of public awareness campaigns.

Local authorities

Undertake assessments of local needs and demands in order to inform and guide the planning and commissioning of health, wellbeing and social services, particularly informing health and wellbeing boards joint health and wellbeing assessments (JSNAs). Such assessments look at local need and demand on lung cancers, informed by local prevalence data; the quality of existing services; and the challenges faced by the service. As well as this, they also support work through public health measures to help reduce the risk factors associated with cancer.

NCIN Lung Site-Specific Clinical Reference Group

One of NCIN's 12 clinical reference groups which ensure that data are available to improve clinical care, as well as to advise on what data needs to be collected and what analyses conducted²⁴. The standards are central to supporting the vision for an NHS focused on delivering the best possible outcomes for patients, emphasised in the previous Government's NHS White Paper *Equity and Excellence – Liberating the NHS*²⁵.

The National Institute for Health and Care Excellence (NICE), has also produced 13 quality standards for cancer, including a dedicated standard for lung cancer, which sets prioritised statements designed to drive measurable quality improvements. Quality standards are aimed at a variety of different audiences, with the lung cancer standard targeted towards the public, health and social care professionals, commissioners and service providers in order to define what is considered high quality lung cancer care.

The UKLCC welcomed the standard for lung cancer and fed in suggestions towards the content during its development. It includes 15 quality statements which include emphasis on several aspects of lung cancer care across the patient pathway, such as:

- Public awareness campaigns on the signs and symptoms of lung cancer
- Referral for cases of suspected lung cancer
- Guidelines for the involvement of a multi-disciplinary team within care, including lung cancer nurse specialists
- Holistic needs
- Information at diagnosis
- Choice of treatment
- Treatment plans

England has made significant steps since the UKLCC's inception to prioritise cancer, but outcomes for patients in England continue to lag behind other countries in Europe⁴. Given that it is one of the most common cancers within England, it is important that lung cancer is appropriately prioritised alongside other cancer types. Indeed, it was highlighted within the cancer taskforce's statement of intent that survival for lung cancer, amongst others, remains stubbornly low in comparison to other cancers and efforts should be made in order to drive improvements in this area²⁶.

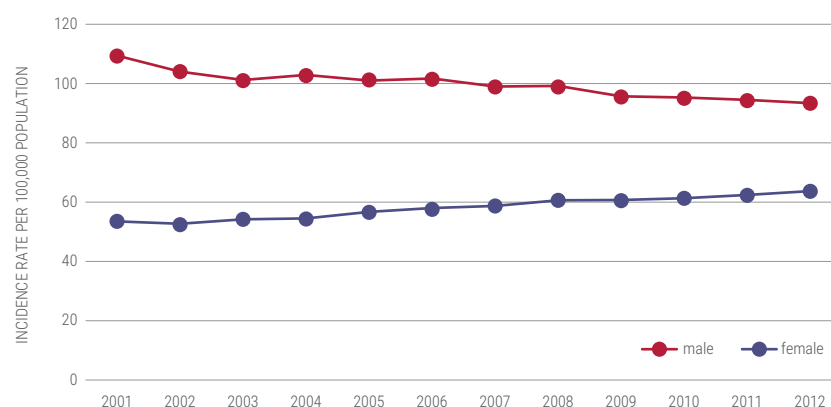
The section below examines how services for lung cancer have improved over the last ten years and what future steps are needed to assure that all patients diagnosed achieve the best outcomes possible. This progress is mapped against the patient pathway and is also measured specifically against the priorities which have been set over the past decade through key national guidance and strategies.

PREVENTION

Almost 720,000 people were diagnosed with lung cancer in England between 1990 and 2011⁹. While incidence rates have improved over the last ten years overall, it is notable that though male lung cancer diagnoses have declined dramatically, female diagnoses have increased⁹.

Figure 1

Directly age-standardised rates per 100,000 population of newly diagnosed cases of malignant neoplasm of trachea, bronchus and lung (2001-2011)²⁷



The decrease in male incidences of lung cancer over the past 20 years is partly attributable to the significant decline in smoking prevalence among men. Similarly the rise in female incidences reflects the increased number of women who were found to take up smoking after the Second World War⁹.

Smoking is the biggest risk factor for lung cancer and is responsible for almost 85 per cent of all cases⁶. Given its clear correlation with incidences of the disease, there have been multiple national initiatives over the past 10 years to reduce smoking rates, including:

Smokefree legislation: The Health Act 2006²⁸

As part of the Health Act 2006, smoking was prohibited in July 2007 by law in most enclosed or substantially enclosed work and public places within the UK to reduce the risks of 'second-hand' smoke.

Legal age raised for people buying tobacco²⁹

Since October 2007 it has been against the law for anyone under the age of 18 in England and Wales to buy or be sold tobacco products, where previously the legal age was 16.

Stoptober³⁰

Stoptober is a Public Health England campaign and is the nation's biggest quit smoking initiative undertaken each year during the month of October. In 2014, the campaign had more than 250,000 participants.

Legislation for standardised cigarette packaging³¹

In March 2015, Parliament voted in favour of introducing standardised cigarette packaging. The new legislation, which comes into effect in May 2016, will mean that all cigarette packing will have to be uniform in size, shape and design; with the hope that this will reduce the appeal of cigarettes.

Tobacco Display Ban³²

Since April 2015, there has been a ban on displaying tobacco products at the point of sale in shops across the UK.

Positive momentum on campaigns undertaken thus far needs to be maintained, while also investing in future programmes to reduce smoking rates and therein reduce the incidences of lung cancer. It is also essential that funding is maintained for smoking cessation services, which act as a key preventative measure, and it should be ensured that local authorities, with impending cuts to their budget, do not de-commission such services.

Prevention is one of the key principles within the 5YFV, and smoking remains one of the largest modifiable risk factors for cancer, responsible for more than 50,000 new cases in England per year²⁶. As such, it is encouraging that the *Cancer Strategy* aims to reduce adult smoking prevalence to less than 13 per cent by 2020 and less than 5 per cent by 2035 as one of its six strategic priorities²¹.

SCREENING AND DIAGNOSIS

Identifying suspected lung cancer at the earliest opportunity is key to achieving better outcomes for patients, and is proven to improve the rate of survival³³. However, there is still significant variation in the rate of diagnosis across England, with the number of patients being diagnosed with lung cancer with stage IIIB or IV lung cancer varying from 11 to 76 per cent¹².

Screening

Effective screening is one of the key ways to improve early detection rates for cancer, however the UK National Screening Committee currently does not recommend a national screening programme for lung cancer, despite the fact that it is proven to improve the rate of survival³³. For example, one major US trial showed a 20 per cent reduction in lung cancer specific mortality using low dose spiral CT as the screening tool¹⁹. As well as this, other studies such as the NELSON trial³⁴ are also exploring the benefit of lung cancer screening, the results are due to be published in 2016.

Following these results, the UK National Screening Committee should urgently re-assess the benefits of introducing a screening programme for lung cancer to improve the rate of early diagnosis; as recommended within the latest Cancer Taskforce Report²⁹.

Raising awareness

Despite the importance of screening, population-based screening only detects around 5 per cent of all cancer cases, with the vast majority detected following symptomatic presentation by patients²⁶. As such, awareness of symptoms is crucial in ensuring early diagnosis and is emphasised in NICE's quality standard for lung cancer, which states:

"People are made aware of the symptoms and signs of lung cancer through local coordinated public awareness campaigns that result in early presentation"³⁵

The *Doncaster Cough Campaign* evidenced an increase in the number of people seeing their GP and an increase in patients diagnosed at an earlier stage of lung cancer, from 11 to 19 per cent¹⁹. Following this, the Government invested £10.7 million into local and national 'signs and symptoms' campaigns for breast, bowel and lung cancer to help improve the rate of diagnosis¹⁹, including the *Be Clear on Cancer* cough campaign.

Evidence from the national cough campaign demonstrated a positive impact on the number of cancers identified and saw an increase in the number of urgent referrals for suspected lung cancer by 30 per cent during the months of the campaign, compared with the previous year³⁶. Professor Kevin Fenton, Director of Health and Wellbeing at Public Health England, commented on the campaign in December 2013 saying that:

"Our Be Clear on Cancer Campaign led to around 700 extra patients being diagnosed with lung cancer—many at an early stage— and resulted in around 300 more patients getting surgery which gives them the best chance of prolonged survival...we must do more and work with NHS England to work towards earlier diagnosis and better outcomes"³⁷

In July 2015, the UKLCC wrote an open letter to the Secretary of State for Health to urge the Department of Health to re-institute this campaign, to continue to improve outcomes and save lives.

While the Department of Health stated that the campaign had not been shelved³⁸, clarity on its' future is still yet to be announced. In order to improve public awareness of the signs and symptoms of lung cancer, this campaign's momentum should be built upon in line with the recommendation in the Cancer Strategy to continue the investment²¹.

Access to diagnostic tests

Once patients present with symptoms, it is essential that they have equitable and funded access to the full range of molecular diagnostic tests for lung cancer, to ensure that all patients receive the best available treatment for their very specific type of cancer. It is also identified as a key priority within the Cancer Strategy for NHS England to nationally commission to molecular diagnostic tests for lung cancer by 2016²⁹.

As well as making sure that patients have access to the full range of tests, commissioners must also ensure that there is adequate diagnostic capacity. This can be done partly by ensuring that GPs have direct access to tests such as chest x-rays and CT scans, but also that other specialities, such as radiologists, are properly sourced and supported in a time where there are increasing demands for services.

For example, a number of the core elements of current cancer services are under significant strain, in particular radiology and medical oncology, with the total number of CT scans having more than doubled in the past 10 years³⁹.

REFERRAL

Raising awareness of symptoms is crucial to ensure timely and effective referral, with a 2014 study suggesting that the peak performance of the urgent cancer (two week wait) referral coincided with local and national awareness campaigns for lung cancer⁴⁰.

One in four of all cancers are detected through emergency presentation¹⁹, however for lung cancer these figures are much worse, with as many as 38 per cent of cases being diagnosed in this way⁴¹. As well as this, 32 per cent of lung cancer patients have to see their GP three times or more before being referred to hospital⁴².

It is essential that those who present with symptoms receive a swift diagnosis, with figures suggesting that those who are diagnosed through GP referral are almost four times more likely to survive than those diagnosed following an emergency admission⁴¹.

Given this, there have been several efforts on a national level to ensure that there is increased use of the urgent referral pathway to deliver earlier diagnosis with emphasis placed towards the importance of referral in recent national strategies and guidance. More recently, NICE updated their guidelines for *Suspected cancer: recognition and referral*⁴³, to focus on more effectively recognising the symptoms of different cancer types which a patient may experience, to ensure timely referral and diagnosis. Whilst the guidelines are a useful resource to aid effective referral, they contain no statement on the correct procedure if a person with suspected cancer presents with symptoms, but has a normal X-ray.

As well as this NICE guidance, NHS England, with Cancer Research UK and Macmillan, also initiated the ACE programme in June 2014, which aims to 'Accelerate, Coordinate, and Evaluate' learning to achieve early diagnosis of cancer. The programme contains a specific pilot to optimise the lung cancer pathway, which explores the most effective and efficient pathway from referral to diagnosis⁴⁴.

The UKLCC recognises the difficulty GPs face in identifying the symptoms of lung cancer in patients, and that increasing support is needed for earlier diagnosis within primary care. This situation is further compounded by a lack of timely access to GPs and continued reluctance by some individuals to visit their GP²⁶.

Prioritising cancer diagnoses within GP contracts and setting out clear statements which cover all possible scenarios within NICE referral guidance would help improve early diagnosis and overall lung cancer survival. It is also important to continue to invest in programmes such as ACE to further support these efforts. However, as mentioned above, it is also important that individuals themselves have increased awareness of the early symptoms of the disease, so that they are further encouraged to see their GP when these present.

TREATMENT

Having access to the right type of treatment, be it radiotherapy, chemotherapy or surgery, was outlined as one of the critical elements in improving cancer outcomes within the 2011 *Cancer Strategy*. Access to treatments have notably improved following the establishment of the Cancer Drugs Fund (CDF) and improved access to, and the establishment of, local and specialist MDTs. However, despite this, significant variations in access to treatments and experiences of care still persist.

Access to treatment

Variations in access due to locality is evident in a large proportion of the core treatments for lung cancer:

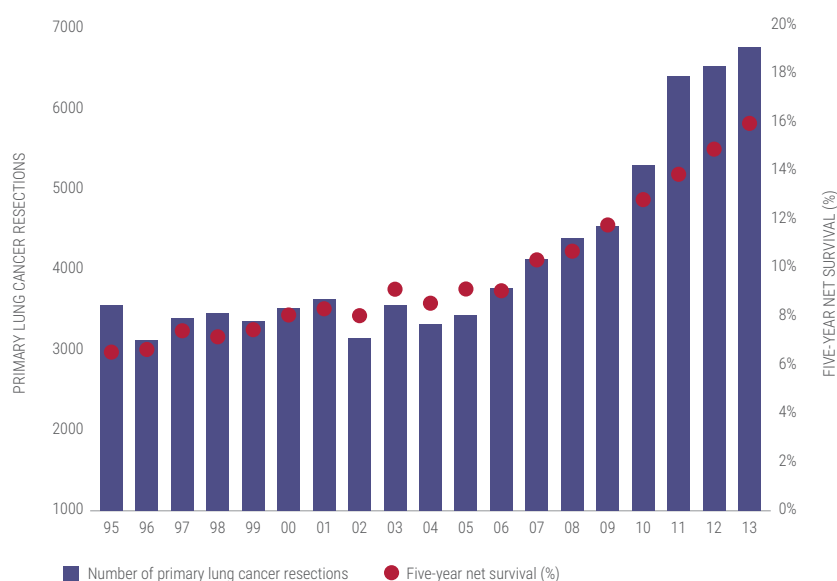
- The proportion of patients with early stage lung cancer who received surgery varies from 33 to 63 per cent at strategic clinical network (SCN) level in England and Wales¹¹. Since surgery can represent the best chance of treating lung cancer, these figures suggest a significant number of patients are not receiving the treatment that gives them the best chance of surviving
- Rates for chemotherapy, which can extend life expectancy and improve quality of life, vary from 46 to 63 per cent across strategic clinical SCNs in England and Wales¹¹
- Access to specialised treatments is also incredibly variable. Unique radiotherapy techniques for example, such as Stereotactic Ablative Radiotherapy (SABR), is not available to all patients, despite the fact that it has been proven to improve lung cancer mortality rates⁴⁵

Not only does variation exist due to a patient's locality, but equitability in access to services can be variable as a result of age. For lung cancer, recent statistics show that the percentage of all patients receiving active treatment (except cases with SCLC or mesothelioma) under the age of 65 was 77 per cent in 2013; however, for the same year, this was only 28 per cent for those over the age of 80¹¹.

A patient's place of residence, or indeed their age, should not affect their ability to access treatments. The UKLCC therefore welcomed the Cancer Taskforce's emphasis on the need to tackle these unacceptable levels of variation within the five year strategy for cancer²¹.

Positively, however, although variations exist for surgical resections for NSCLC patients, on average the proportion of patients undergoing this type of treatment has increased from 10 per cent in 2007¹⁰ to 22 per cent in 2012¹⁵. Even more positively, the Society of Cardiothoracic Surgeons audit has recorded a doubling of the actual number of surgical resections for lung cancer from an average of 3,220 up to 2005 to 6,713 in 2013⁴⁶, and there is a very strong correlation between this increase in the rate of resection and the time-trend of major improvements in one- and five-year lung cancer survival rates in England¹⁴.

Figure 2
Five-year net survival (%) from lung cancer versus number of primary lung cancer resections, 1995-2013^{14,46}



Patient experience and personalised care

Patient experience and patient needs should be given the upmost priority at each stage of a lung cancer patient's pathway. Cancer support functions and appropriate staffing levels are fundamental to realising this and personalised care.

A key way to ensure this is universal access to multi-disciplinary teams (MDTs), which were established to support the move away from generalist care, siloed working practices and poor communication between healthcare professionals and patients. In November 2012, the UKLCC's *The Dream MDT*⁴⁷ report set out an aspirational vision for how these teams should be organised and operated, going beyond the existing clinical guidance for lung cancer.

Since the UKLCC's formation and its 2012 report, there have been significant improvements in the structure of, and access to, MDTs. Encouragingly the number of patients reviewed by MDTs has increased in England from 86 per cent in 2007¹⁰ to 95 per cent in 2013¹¹, and a large majority of trusts have secured full membership of their specialist teams⁴⁷.

There have also notably been an increasing number of patients assigned lung cancer clinical nurse specialists (CNSs) in England and Wales, rising to 84 per cent in 2013¹¹ – up from 35 per cent in 2007¹⁰. The increase in lung cancer CNSs is encouraging, particularly as they play a vital role in the care of patients as part of the wider lung cancer MDT. However, there is still significant variation in the percentage of patients seen by a nurse specialist, varying from 36 to 100 per cent within England in 2013¹¹.

In order to continue to improve patient experience and personalised care, the number of lung cancer CNSs should be increased to a level where no trust has less than two lung cancer CNSs, and the case load is no more than 100 new patients per year, in order to ensure patients' care is fully integrated and that they are supported throughout their care pathway.

Clinical trials and research

Information about, and access to, research and clinical trials is important for patients and MDTs in order for all treatment options to be explored and to ensure further progress in lung cancer and other respiratory conditions.

According to recent figures in the 2014 *National Cancer Patient Experience* survey however, only 30 per cent of lung cancer patients were asked whether they would like to take part in cancer research following their diagnosis. Furthermore, of those patients asked, only 58 per cent went on to participate in such research⁴⁸.

Efforts need to be made to ensure that all parts of the lung cancer pathway are involved in, and are delivering, clinical research, and that the number of patients enrolled into lung cancer clinical trials increases further.

These improvements can be supported, for example, by promoting greater support for local recruitment into clinical trials in lung cancer. As well as this, resources should be provided to allow for clinical trial entry to be offered to all suitable patients in every MDT, and to ensure that access to such trials is equitable across the country⁴⁸.

Data

A significant area of improvement is in the collection and reporting of data for lung cancer outcomes over the past 10 years, particularly the *National Lung Cancer Audit* (NCLA). The Audit covers approximately 98 per cent of expected new lung cases within the UK and includes data for almost all cases of lung cancer presenting to secondary care in the UK¹¹.

Since the first report was published in 2005, the lung cancer clinical community has made great progress in improving the quality of services and, through higher rates of treatment, has positively impacted on survival and mortality. Much of this success is attributable to the NCLA in helping to drive improvements in service delivery, inform the commissioning of services and driving change towards more specialisation within the culture of clinical professionals¹¹. This was clearly evidenced in the independent report by Roy Castle Lung Cancer Foundation, which found that the NCLA has been instrumental in informing national policy and guidance, with NICE, referencing the NLCA 36 times within relevant documentation⁴⁹.

The findings from the NCLA have multiple uses across the lung cancer community and have also been used by the Roy Castle Lung Cancer Foundation to develop interactive maps to provide information on lung cancer locally⁴⁹. This highlights one of the most important factors of the NCLA, which is that it is a data source that not only helps to inform and improve services, but given that it has been open to the public from the outset, it allows patients themselves to be informed about their own local services.

As well as the NCLA, the NHS Outcomes Framework also includes specific indicators on cancer survival, including one-year and five-year survival for lung cancer⁵⁰ and lung cancer service profiles have been produced by the NCIN on MDTs, which bring together data on a wide range of routinely collected quality and service indicators. The National Cancer Registration Service and National Cancer Intelligence Network within PHE now also collect a wide range of data along the whole patient pathway for all cancers and there will be an increasing number of routine indicators available to providers, commissioners and the public on lung cancer from this source.

The UKLCC has welcomed the vast improvements that have been made in data collection for lung cancer services and outcomes over the past 10 years, which act as essential benchmarks for improving services. In addition there have been significant steps made in providing data on patient experience. The Cancer Reform Strategy 2007 first made the commitment to establish a new NHS Cancer Patient Experience Survey Programme, which would monitor national progress and drive improvements locally¹⁸. Since 2010, there have been annual publications of the survey covering all 153 acute and specialist NHS trusts in England that provide adult and acute cancer services⁴⁸.

England has made significant steps in investing in the collection of lung cancer data and utilising it as a key marker to improve lung cancer care. However, it is essential that more is done to broaden the scope and scale of data collection in order for data to continue to be used to improve outcomes.

LUNG CANCER IN ENGLAND: OUTCOMES

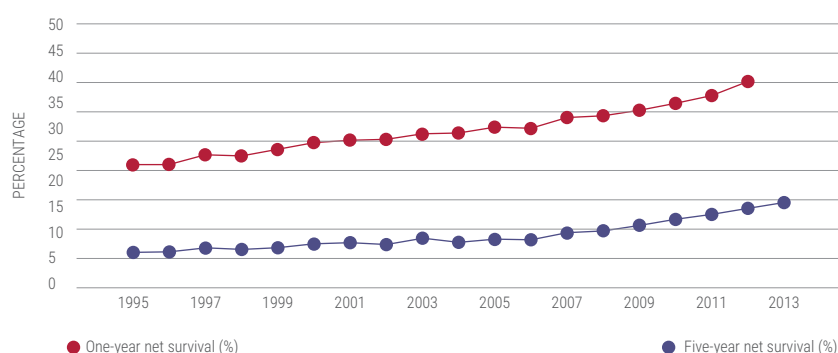
Lung cancer outcomes have certainly improved for patients since the UKLCC's formation 10 years ago, with five-year survival rates in particular having almost doubled from 2004 (9 per cent) to 2013 (16 per cent predicted)¹⁴ and trebled since 1991-93 (5 per cent)⁵¹. In addition, absolute one-year survival rates have increased by almost 10 per cent during the same period with 39 per cent of individuals surviving one-year after diagnosis in 2012; this represents 30 per cent relative increase in one-year survival rate over that period¹⁴.

While there have been significant improvements in the outcomes for lung cancer patients in England, probably largely due to increased treatment rates such as surgical resection for NSCLC patients; overall survival rates are poor and there is still a great more to do to ensure that those diagnosed have the best possible chance of survival. Still in 2011 alone, around 15,700 men and around 12,500 women died of lung cancer in England⁸.

Although it has improved, previous estimates of five-year age-standardised lung cancer survival rate demonstrates that England is falling behind the best performing countries in Europe. For example, in the Eurocare study it was reported that 8.8 per cent of lung cancer patients in England survived five years after diagnosis, below the average across Europe⁴. Estimates also show that 1,300 deaths from lung cancer could be avoided each year if UK survival rates matched the European average¹⁶. If, however, the recent estimates of a five-year survival rate of 16 per cent for patients diagnosed in 2013¹⁴ are shown to be accurate, then it would appear that this 'survival gap' between England and its European counterparts, may have been significantly narrowed.

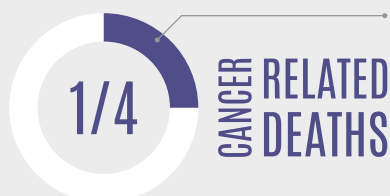
Figure 3

Trends in one- and five-year net survival from lung cancer in England by year of diagnosis¹⁴



It is important to acknowledge that while survival rates have improved across England, there is still significant variation across the country in survival rates with a two-fold variation between trusts in the percentage of patients who survive after one-year of diagnosis¹². In order for England to meet its ambition to match the best countries across Europe, certain cancer types, such as lung, need to be appropriately prioritised in order to improve overall outcomes.

LUNG CANCER IN SCOTLAND



LUNG CANCER CAUSED APPROXIMATELY ONE QUARTER OF ALL CANCER-RELATED DEATHS IN 2013. MORE THAN TWICE AS MANY AS ANY OTHER CANCER⁵³

5,000 NEW DIAGNOSES A YEAR

SCOTLAND HAS ONE OF THE HIGHEST LUNG CANCER INCIDENCE RATES IN THE WORLD – 106 CASES PER 100,000 OF THE POPULATION IN 2013. THIS EQUATES TO OVER 5,000 NEW DIAGNOSES A YEAR⁵⁴

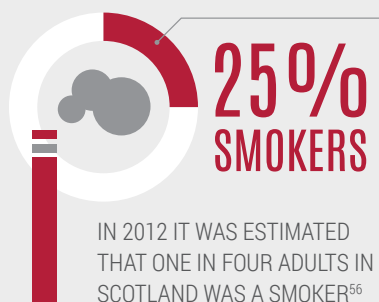
INCIDENCE HAS DECREASED



SINCE THE UKLCC'S INCEPTION, LUNG CANCER INCIDENCE HAS DECREASED FROM 112 DIAGNOSES PER 100,000 OF THE POPULATION, TO 106 IN 2013⁵⁴



IN 2013 ALONE 4,120 PEOPLE DIED AS A CONSEQUENCE OF LUNG CANCER⁵⁵



IN 2012 IT WAS ESTIMATED THAT ONE IN FOUR ADULTS IN SCOTLAND WAS A SMOKER⁵⁶



JUST 8.7% OF LUNG CANCER PATIENTS LIVED FOR UP TO FIVE YEARS AFTER THE POINT AT WHICH THEY ARE DIAGNOSED IN 2011⁴

MORTALITY RATES HAVE DECLINED



SINCE THE UKLCC'S INCEPTION IN 2005, LUNG CANCER MORTALITY RATES HAVE DECLINED FROM 96 PER 100,000 OF THE POPULATION, TO 87⁵⁵. A PAN-EUROPEAN STUDY ON CANCER SURVIVAL RATES IN 2011, HOWEVER, FOUND THAT OUT OF 29 COUNTRIES STUDIED, SCOTLAND HAD THE THIRD LOWEST FIVE-YEAR SURVIVAL RATE FOR ADULT PATIENTS⁴



FROM 2002-2006, ONE-YEAR RELATIVE LUNG CANCER SURVIVAL HAS INCREASED FROM 30 PER CENT TO 33 PER CENT FOR 2007-2011⁵⁵

LUNG CANCER SCOTLAND'S BIGGEST CANCER KILLER



THE UKLCC'S TEN YEAR VISION FOR SCOTLAND

1

In advance of the 2016 Scottish election, lung cancer should continue to be prioritised at a national level by the Scottish Government and NHS Scotland, underpinned by a publically consulted refresh of *Better Cancer Care*

2

The Scottish Government should undertake and publish an assessment of the *Detect Cancer Early* campaign in increasing the proportion of people who are diagnosed in the early stages of lung cancer by 25 per cent by the end of 2015, and commit to the programme's continuation in future years

3

A proactive impact assessment of the Scottish government's efforts to drive greater awareness of the dangers of smoking, and better access to smoking cessation services should be undertaken, underpinning the programme's continuation across the country

4

Following the October 2014 public announcements, the Scottish Government should provide a public update on the development and roll-out of the national cancer patient experience survey, providing a detailed timeline for its launch and interrogation

5

Following the UK National Screening Committee's rejection of systematic population screening in adult cigarette smokers for lung cancer in July 2006, the Scottish Government should work closely with public health partners in support of the publication of the results of the NELSON randomised lung cancer screening trial

6

The Scottish Government should commit to making the findings of the study into the effectiveness of the ECLS trial for lung cancer blood testing throughout Scotland publically available and consider its implications for the future of lung cancer diagnostics

7

Supporting an effective and timely referrals process, the Scottish Government and NHS Scotland should undertake a review of the awareness and uptake of the *Scottish Referral Guidelines for Suspected Cancer* among primary care clinicians

8

Underpinning the development of effective treatment options, the Scottish Government should undertake a review of its clinical trials processes ensuring equity of access and resource among the lung cancer community

9

A review of the Scottish Intercollegiate Guidelines Network's (SIGN) lung cancer clinical practice guideline should be implemented by NHS Scotland to assess its impact on the uptake of treatments for patients and the streamlining of the lung cancer patient pathway

10

Building on the *Transforming Care After Treatment* programme, the Scottish Government should publically review the support in place for supporting lung cancer patients following active treatment of cancer, supporting and enabling cancer survivors to live as healthy a life as possible, for as long as possible

INTRODUCTION

For both males and females combined, lung cancer remains Scotland's most common cancer, accounting for 17 per cent of all cases in 2013 alone⁵³. The disease is also the country's biggest cancer killer⁵⁷, causing approximately one quarter of all cancer-related deaths, more than twice as many as any other cancer⁵⁷.

This chapter explores how Scotland has looked to prioritise the development and delivery of cancer services and outcomes over the last decade, what levers exist to support high quality care across the patient pathway and, ultimately, how the outcomes of lung cancer patients compare in recent years.

CANCER AS A PRIORITY: LEVERS AND DELIVERY

Better Cancer Care: An Action Plan⁵⁸

Since the UKLCC's inception in 2005, the Scottish Government has reaffirmed cancer as a national priority in *Better Cancer Care: An Action Plan*. Published in October 2008 by the then Deputy First Minister and Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP, *Better Cancer Care* – currently in the process of being refreshed – outlined the future of cancer services across the patient pathway in Scotland, and set out a commitment to "strengthen [Scotland's] approach to cancer prevention and tackling inequalities in both access and outcomes."

Aspirational in its tone, the commitments outlined within *Better Cancer Care* were driven by the Scottish Cancer Taskforce (SCT), replacing the then Scottish Cancer Group. Chaired by Dr Aileen Keel, the Scottish Government's former Acting Chief Medical Officer, the SCT was established in January 2009 and included representatives from Cancer Area Networks, NHS Chief Executives' Groups, NHS Directors of Nursing Groups, the NHS Information Services Division and voluntary sector⁵⁹. As part of its role the SCT was charged with reviewing the cancer 'delivery landscape' and ensuring the network of advisory and delivery groups were streamlined and fit for purpose in delivering high quality and patient-centred care.

National Cancer Quality Steering Group

Created by the SCT, the National Cancer Quality Steering Group (NCQSG) was designed to provide more detailed strategic leadership to effectively deliver the commitments set out in *Better Cancer Care* and ensure that all quality related work streams relating to cancer were being progressed. Chaired by Dr Hilary Dobson, much like its parent SCT, the NCQSG was comprised of a number of key stakeholders, including representatives from the three regional cancer networks and Health Improvement Scotland.

Quality Performance Indicators⁶⁰

A key commitment set out within *Better Cancer Care* was the development of "a work programme which will define how we will take forward...quality indicators for cancer services." To support the attainment of such an aspiration, the NCQSG was granted responsibility for:

- The development of small sets of tumour specific national quality performance indicators (QPIs)
- Overseeing the implementation of the national governance framework that underpins the reporting of performance against these national QPIs

There are currently 13 dedicated lung cancer QPIs focusing on the lung cancer patient pathway, including multi-disciplinary team (MDT) meetings, pathological diagnosis and lymph node assessments⁶¹. The first QPIs were published by the Scottish Government and Healthcare Improvement Scotland in December 2012 and are refreshed on a regular basis; most recently in March 2015.

HOW ARE LUNG CANCER SERVICES ORGANISED AND DELIVERED IN SCOTLAND?

NHS Scotland's 14 regional NHS Boards play a key role in underpinning the Scottish Government's approach to "ensuring better, local and faster access to health care" and supporting the development and provision of lung cancer services⁶².

Responsible for the protection and improvement of their population's health and for the delivery of frontline healthcare services, Scotland's regional NHS Boards are closely associated and aligned with one of three Regional Cancer Networks (RCNs) across the country – North of Scotland (NOSCAN); South East Scotland (SCAN); and West of Scotland (WOSCAN). Regional NHS Boards have the overarching aim of ensuring that clinical activities are focused on areas most important in terms of improving survival and patient experience, while also reducing variation and ensuring safe, effective and person-centred cancer care⁶³.

Boards also have a specific requirement to report against QPIs (see above) as part of a mandatory national cancer quality programme⁶⁴, with subsequent reports published by ISD underpinned by such local data.

RCNs broadly support partnership working across organisational boundaries, involve patients in planning cancer services and 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 accordingly.

PREVENTION

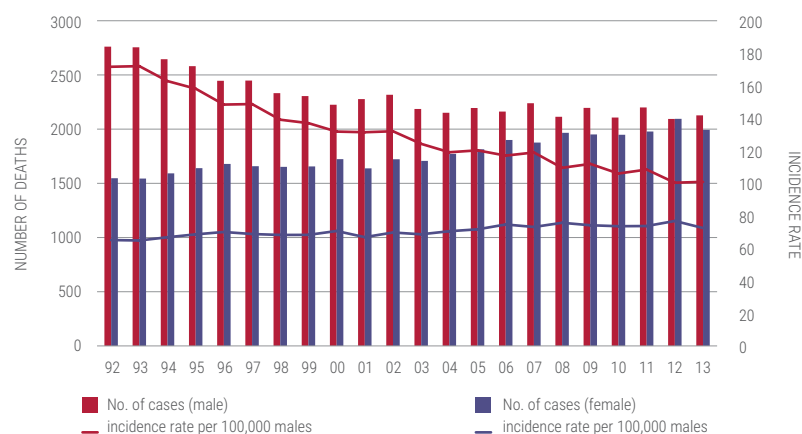
Lifestyle factors such as smoking, poor diet and physical inactivity are, broadly speaking, modifiable factors that can contribute to an increased risk of cancer⁶. For lung cancer in particular, where the lifetime risk of developing the disease among men and women is one in 12 and one in 14 respectively⁵³, smoking is a significant contributing factor, with Government efforts to address this focused on altering population habits.

A year prior to the UKLCC's formation, 91 per cent and 88 per cent of lung cancer deaths were deemed to be attributable to smoking for men and women respectively⁵⁸. Recognising such a correlation, the Scottish Government has in recent years committed to a number of initiatives:

- £42 million from 2008/09 to 2010/11 was dedicated to support the wide-ranging programme of actions arising from A Breath of Fresh Air for Scotland, including increased emphasis on preventing people from becoming smokers in the first instance⁵⁸
- Scotland's Future is *Smoke-free: A Smoking Prevention Action Plan* was developed, setting out NHS Scotland's longer-term, strategic approach to smoking prevention⁶⁵
- Published in 2013, *Creating a tobacco-free generation: A Tobacco Control Strategy for Scotland* continued to indicate the Scottish Government's prioritisation of smoking cessation and its ambition for creating "a tobacco-free generation of Scots by 2034", building on the perceived effectiveness and value of the 2006 public smoking ban⁶⁶
- The *Take it right outside* campaign was launched in March 2014, responding to the harmful effects of second-hand smoke on children, with an ambition of sparing 50,000 children from second-hand smoke by 2020⁶⁷

Figure 4

Number of new cases and age-standardised incidence rate for lung cancer in Scotland (1992-2013)⁵⁴



In line with such efforts, the incidence rate for lung cancer has encouragingly decreased in recent years.

Although, this is a top-line analysis of incidence data, which captures the number of new lung cancer cases identified in a specific area or time period, it shows that Scotland still has one of the highest incidence rates in the world – 106 cases per 100,000 population in 2013. This equates to just over 5,000 new cases diagnosed each year⁵⁴.

Indeed, whilst rates broadly are falling, within Scotland's female population they have in fact increased since 1992 from 77 cases per 100,000 of the population to 93.5. By contrast, during the same period, male lung cancer incidence rates have fallen from 191 per 100,000 to 119⁵⁴ (see Figure 4).

Interestingly, 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 2011⁶⁸.

Such high incidence rates are also broadly reflective of the country's ageing population, historically high smoking prevalence (in 2012 it was estimated that one in four adults in Scotland was a smoker) and the cultural association with the nation's male-dominated industrial workforce in the last century⁶⁹.

SCREENING AND DIAGNOSIS

Early diagnosis is a vital part of improving patient outcomes, with *Better Cancer Care* stating that “the earlier that cancer is diagnosed, the better the chance of a complete cure”⁵⁸.

Since the UKLCC's formation in 2005, the *Detect Cancer Early* initiative was launched in February 2012 by the then Cabinet Secretary, Nicola Sturgeon MSP, with an overall aim to improve five-year survival for people in Scotland. The programme identified eight objectives to underpin its ambitious aims. These included increasing the proportion of people diagnosed at stage one of the disease; raising the public's awareness of the national cancer screening programmes; and ensuring there was sufficient capacity in the screening programmes to meet the expected increase in those taking part⁶⁹.

Building on the initiative, a dedicated *Detect Lung Cancer Early* campaign was launched by the Scottish Government and NHS Scotland in November 2013, and repeated the following year with a view to increasing the proportion of people who are diagnosed in the early stages of lung cancer by 25 per cent by the end of 2015. Driven by an ad-campaign involving Sir Alex Ferguson, the initiative encouraged people who have had a cough for three weeks to visit their GP⁷⁰. Reflecting improvements in lung cancer treatments, the campaign emphasised the ever-improving outcomes for lung cancer patients and the importance of early diagnosis in supporting effective treatment options and outcomes⁷⁰.

Whilst such initiatives are a positive move within the cancer community, the UK National Screening Committee ruled in July 2006 that it did not recommend systematic population screening in adult cigarette smokers for lung cancer, with the policy set to be reviewed after the results of the NELSON randomised lung cancer screening trial are published⁷¹.

The ECLS trial for lung cancer blood tests was also announced in March 2012. Testing smokers who are deemed at the highest risk of developing lung cancer in order to improve early detection, the test monitors the levels of antibodies in the blood, which could increase when cancer develops. Patients with increased levels of antibodies will be referred for a CT scan to determine whether they have cancer, a landmark development, the results of which are yet to be made publically available⁷².

REFERRAL

The importance of timely and accurate referral cannot be understated, with *Better Cancer Care* stating in 2008 that “key components of successful cancer management include prompt referral and rapid access to investigations and treatment”⁵⁸.

A subsequent commitment was directly made within that document to develop and audit electronic referral systems within NHS Scotland, to ensure that patients are referred quickly, and appropriately, between primary, secondary and tertiary care centres⁵⁸.

Since the UKLCC's formation, strides have been taken across Scotland to support the redesign of the referral and investigations pathway for suspected lung cancer patients. Should they deem it necessary, GPs are now able to refer patients directly for a chest x-ray, and to a chest clinic to be seen by a respiratory physician for a CT scan, ensuring rapid access to further investigations, diagnosis and, ultimately, treatment⁵⁸. This was further augmented by *Better Cancer Care*'s commitment to introduce an 18-week Referral to Treatment standard throughout Scotland by 2011, with an additional 31-day target introduced for cancer patients covering the period from the decision to treat to the start of treatment⁵⁸.

Preceding such developments, in March 2009 a Quick Reference Guide to the *Scottish Referral Guidelines for Suspected Cancer* was published. Based on the full 1997 guidelines, the guide was distributed to all GP practices in Scotland to improve symptom awareness among practitioners. The guidelines were once again updated in August 2014, helping to clearly identify common lung cancer presentations in primary care and signpost when either an urgent chest x-ray should be undertaken or cancer referral made⁷³.

TREATMENT

Treatment options for lung cancer vary significantly, from surgery to radiotherapy and chemotherapy – or indeed any combination of the three as part of a coordinated care plan⁵⁸. *Better Cancer Care* first set out the Scottish Government's commitment to ensuring services to treat cancer are world-class and that NHS Scotland resources are spent in the most efficient and effective manner to meet the needs of those diagnosed with the disease.

Clinical trials and research

Clinical trials play an important role in the development and testing of new treatments, or novel uses for currently available treatments, which can ultimately be made available to patients throughout Scotland.

Better Cancer Care estimated in 2008 that the Scottish Government spent around £2.9 million on directly-funded research projects and initiatives as well as £10 million to support cancer research within NHS Scotland⁵⁸. Once cancer research financially supported by all funders was considered, the total neared £400 million in 2006 with the 2010 *Better Cancer Care: Progress Report* reporting over 28 per cent of Scottish cancer patients were involved in clinical research⁶⁵.

Access to appropriate treatments

The Scottish Government has taken steps to change the process for determining access to the latest treatments for patients with advanced lung cancer. From May 2014, Patient and Clinical Engagement (PACE) committee meetings have been held by the Scottish Medicines Consortium (SMC) – Scotland's medicine evaluation body – giving patients and clinicians earlier input into discussions about unmet need and clinical benefit of these new drugs⁷⁴.

The Scottish Intercollegiate Guidelines Network (SIGN) also develops key evidence based clinical practice guidelines for NHS Scotland. Supporting the uptake of treatments for patients, SIGN has developed a dedicated guideline for the management of lung cancer in patients, setting out the appropriate diagnostic and treatment processes, as well as pathways for clinicians to follow⁷⁵.

As an exemplar of improvements in the delivery of cancer services, the percentage of patients receiving a CT scan before bronchoscopy has increased in recent years, rising from 86 per cent of lung cancer patients in 2009 up to 95 per cent in 2013¹¹. Figures from the latest *National Lung Cancer Audit* also show that the percentage of patients discussed at a multidisciplinary team (MDT) meeting has increased from 86 per cent in 2008 up to 97 per cent as of 2013¹¹. MDTs are an essential part of high quality care for all cancer patients, providing a breadth of invaluable experience and continuity of care which only serves to help improve patient experience and outcomes.

Despite a number of improvements, certain markers of high quality lung cancer care appear to be falling short.

Anecdotal evidence suggests there is variation in access to radiotherapy services across Scotland. The latest iteration of the *National Lung Cancer Audit* – which plays a vital role in holding service providers to account throughout Scotland – also showed that the percentage of patients receiving any anti-cancer treatments decreased between 2008 and 2013, from 64 per cent to 61 per cent¹¹.

Unpacking this further, however, it is interesting to note that the percentage of patients receiving an operation, including lung resection, rose during the same time period from 11 per cent to 14 per cent¹¹.

Furthermore, as of 2013, only 81 per cent of lung cancer patients were seen by a clinical nurse specialist (CNS), falling from 84 per cent in 2010 (the earliest point at which such data is available)¹¹. Whilst any improvements in the treatment and care lung cancer patients are receiving should be lauded, it is vital that policymakers keep pushing through change until improvements are identified consistently across the board.

Assessing the effectiveness of, and developments in, lung cancer treatments is only possible with the availability of robust and accurate data. Broadly speaking, the data on lung cancer services and outcomes on Scotland is quite top line, with further efforts needed to address the availability and breadth of lung cancer data.

Transforming Care After Treatment programme

As a result of earlier detection and better treatments, more people are living longer with, and after, cancer. However, services supporting people after cancer treatment have historically not always been suitably fit for purpose. In an effort to transform care after cancer treatment, and do more to support people with the physical, emotional and financial issues they face, the *Transforming Care After Treatment (TCAT)* programme was launched by the Cabinet Secretary for Health and Wellbeing in June 2013.

A partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities to support a redesign of care following active treatment of cancer, the programme's aim was to support and enable cancer survivors to live as healthy a life as possible, for as long as possible⁷⁶.

In addition to taking steps to improve the experiences of people affected by cancer following the completion of their treatment, a central tenet of TCAT was the inclusion and integration of services, managing patient transitions from the acute sector back in to the community⁷⁶.

Supported by a £5 million grant over five years from Macmillan Cancer, models of care focused on:⁷⁶

- Enabling people affected by cancer to play a more active role in managing their own care
- Providing services which are more tailored to the needs and preferences of people affected by cancer
- Giving people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatments
- Improving integration between different service providers and providing more care locally

Leadership for the programme is provided by the *TCAT* Programme Board, consisting of key stakeholders including representatives from RCNs, primary care and the Scottish Government. The board is further supported by the establishment of a Patient/Carer Reference Group, which provides vital input and perspective underpinning service redesign and delivery.

Patient experience

Recognising the importance of measuring patient experience, the Scottish Government developed the now defunct *Better Together Programme* in April 2009 to support NHS boards, frontline staff and patients in driving forward service improvements. Whilst Scotland remains the only UK nation that does not gather evidence of people's experience of cancer as a means of monitoring and improving services, it was announced in October 2014 that the Scottish Government was intending to launch its first ever cancer patient experience survey in 2015, with support and funding from Macmillan Cancer Support⁷⁷.

LUNG CANCER IN SCOTLAND: OUTCOMES

The Scottish Government and NHS Scotland have made significant efforts to improve lung cancer services over the last decade, and in particular since the publication of *Better Cancer Care* in 2008. A number of achievements have been secured in this time, including greater public awareness of the signs and symptoms of lung cancer and improvements in the delivery of optimal clinical practice, including the role and use of MDTs and CNSs.

However, high rates of lung cancer incidence and high levels of prevalence remain throughout Scotland. In 2013 alone just over 4,120 people died as a consequence of lung cancer, representing 87 deaths per 100,000 of the population⁵⁵. Although lung cancer mortality has encouragingly declined in recent years, this still represents over a quarter of cancer-related deaths among men (26 per cent) and women (27 per cent)⁵³. Recent trends in male and female mortality based on the latest available ISD Scotland figures can be found in Figure 5 below.

Figure 5

Number of deaths and age standardised mortality rate for lung cancer in Scotland (1992-2013)⁵⁵

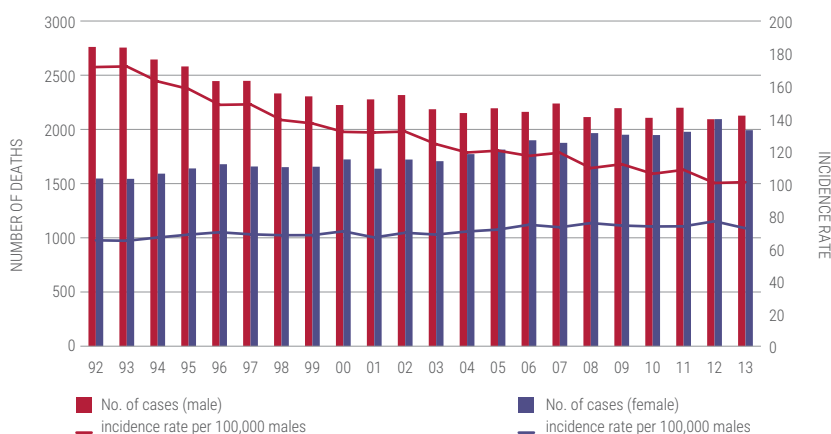
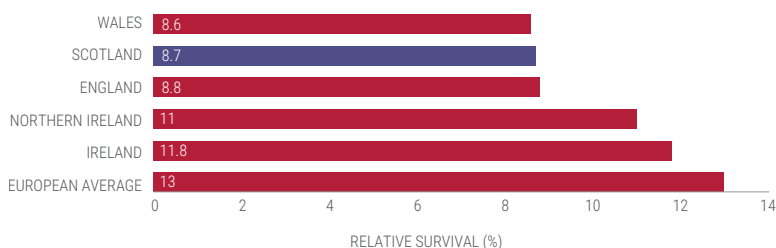


Figure 6

Five-year age standardised relative lung cancer survival for adult patients with cancer, diagnosed 2000-2007⁴



Lung cancer outcomes in Scotland remain amongst the worst in Europe. A pan-European study of cancer survival rates found that out of 29 countries studied, Scotland had the third lowest 5-year survival rate for adult patients at 8.7 per cent⁴.

Tackling cancer should be a long-term government priority and the UKLCC welcomes the commitments shown by the Scottish Government to-date. However, more can and needs to be done to help improve the delivery and effectiveness of cancer services across the country. As the UK's leading coalition of lung cancer experts, senior NHS professionals, charities and healthcare companies, the UKLCC is committed to working with government and key stakeholders throughout Scotland to drive such improvement forward.

LUNG CANCER IN WALES

**2,400
NEW CASES**

THERE WERE ALMOST 2,400 NEW CASES OF LUNG CANCER DIAGNOSED IN 2013⁷⁹

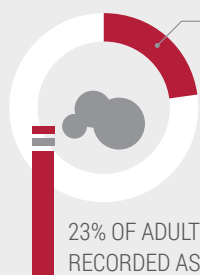
MDT REVIEWS HAVE INCREASED

SINCE THE UKLCC'S INCEPTION, THE PROPORTION OF PATIENTS REVIEWED BY MDTs HAS INCREASED FROM 92 PER CENT IN 2007¹⁰ TO ALMOST 100 PER CENT IN 2013¹¹



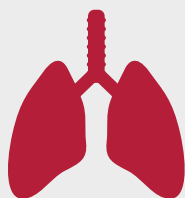
NURSE SPECIALISTS HAVE INCREASED

SINCE THE UKLCC'S INCEPTION, ACCESS TO LUNG CANCER NURSE SPECIALISTS IN ENGLAND AND WALES HAS INCREASED FROM 35 PER CENT IN 2007¹⁰ TO 84 PER CENT IN 2013¹¹



**23%
SMOKING**

23% OF ADULTS WERE RECORDED AS CURRENTLY SMOKING IN 2010⁸¹



**1,900
DEATHS**

ALMOST 1,900 PEOPLE DIE ANNUALLY BECAUSE OF LUNG CANCER, WHICH IS NOW MORE THAN BOWEL AND BREAST CANCER COMBINED⁷⁸



DIE WITHIN SIX MONTHS OF DIAGNOSIS



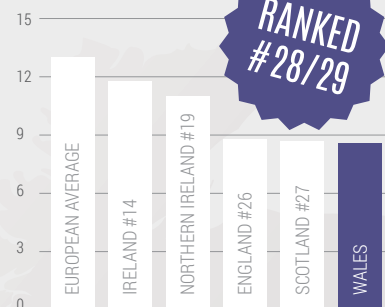
DIE WITHIN A YEAR OF DIAGNOSIS

HALF OF PEOPLE WITH LUNG CANCER WILL DIE WITHIN SIX MONTHS OF DIAGNOSIS AND ALMOST THREE QUARTERS WILL DIE WITHIN A YEAR⁸⁰

ACCESS TO NON-SMALL CELL SURGERY HAS INCREASED



SINCE THE UKLCC'S INCEPTION, VARIATION IN PROPORTION OF PATIENTS RECEIVING SURGERY HAS DECREASED FROM MORE THAN TEN-FOLD IN 2007¹⁰ TO FOUR-FOLD IN 2013¹¹



WALES STILL HAS SOME OF THE WORST SURVIVAL RATES IN EUROPE FOR LUNG CANCER, RANKING 28TH OUT OF 29 COUNTRIES WITHIN A COMPARATIVE COUNTRY STUDY ON SURVIVAL⁴. JUST 8.6 PER CENT OF LUNG CANCER PATIENTS LIVE FOR UP TO FIVE YEARS AFTER THE POINT AT WHICH THEY ARE DIAGNOSED⁴



SURVIVAL RATES IMPROVING

19.3% OF PEOPLE WERE ALIVE ONE YEAR AFTER DIAGNOSIS IN 1995-1999, INCREASING TO 29% IN 2008-2012⁸²



BIGGEST CANCER KILLER IN WALES⁷⁸

THE UKLCC'S TEN YEAR VISION FOR WALES

1

Ahead of the Welsh General Election in 2016, the Welsh Government and opposition parties should look to build on the progress made by local health boards in achieving the ambitions set out in the *Cancer Delivery Plan 2012-2016*. The UKLCC recommends that any future plans should recognise lung cancer as the biggest cancer killer, and should set clear milestones against which care for lung cancer can be improved

2

Efforts should continue to be made to ensure that the diagnostic pathway is designed by a multi-disciplinary team to encourage use of fewer, but higher value, tests, in order to increase the likelihood that diagnosis and stage of the disease is assigned as quickly and effectively as possible

3

The Welsh Government should take action to remove unfair inconsistencies in the current Individual Patient Funding Request (IPFR) process, ensuring decision making is consistent across Wales and takes account of previous decisions. This could be achieved by introducing a national IPFR panel to undertake decision making

4

The Welsh Committee for screening should work with the UK National Screening Committee to review whether there should be a lung cancer screening programme in Wales, following the results of the NELSON trial

5

The Welsh Government should conduct a review of the current National Cancer Standards for Wales, and determine whether they need to be updated following the last refresh in 2005

6

The Welsh Government should maintain the positive momentum in patient access to lung cancer nurse specialist, and should set future ambitions for every patient to have access to this service

7

In order to capture more detailed information on lung cancer which is fundamental to improving services, the Welsh Government should work with NHS Wales Informatics Service and Public Health Wales to improve data collection and analysis for lung cancer, particularly secondary episode care

8

Given how critical research is to effective care, it is important to increase the number of research programmes taking place for lung cancer and ensure that research activity is co-ordinated amongst health boards across Wales

9

There should be greater monitoring of clinical trials to ensure that patients are participating in studies. It should also be ensured that patients know at the point of diagnosis that they are entitled to participate in such trials

10

Whilst improvements have been made, genetic and molecular diagnostic tests need to be integrated within future national cancer strategies, to ensure that they are introduced in a timely manner and that all patients have access to them

INTRODUCTION

Lung cancer is the biggest cancer killer in Wales, accounting for almost 22 per cent of all cancer deaths – more than the next two ranked cancers (bowel and breast cancer) combined⁷⁸.

This chapter provides an overview of the latest evidence and policy for lung cancer in Wales to determine how the delivery of services has progressed over the past ten years, along with an overview of how outcomes for lung cancer patients have shifted over the past decade.

CANCER AS A PRIORITY: LEVERS AND DELIVERY

Cancer continues to be a priority for the Welsh Government, with around one in three people in Wales estimated to be diagnosed with cancer before the age of 75, and around four in ten expected to be diagnosed with cancer within their lifetime⁸³.

Since its formation, the UKLCC has welcomed the Welsh Government's prioritisation of cancer, which has culminated in the development of vital levers such as national guidance and initiatives designed to improve the delivery of cancer care:

National Standards for Cancer Services⁸⁴

In 2005 the Cancer Services Co-ordinating Group (CSCG) oversaw the development of revised National Standards for Cancer Services, developed to agree minimum standards for cancer services in Wales. Overall, 16 such standards were produced, one of which was dedicated to lung cancer. The standards include specific metrics across cancer services against which progress and improvement can be measured, such as evidence that the multi-disciplinary team (MDT) has considered the views of its patients or carers regarding the appropriateness of communication. High levels of compliance are seen against these standards, which have been found to help better organise and deliver effective care⁸³.

Designed to Tackle Cancer in Wales: Strategic Framework (2008-2011)⁸⁵

The dedicated Strategic Framework for Cancer (2008), Designed to Tackle Cancer in Wales, sets out the specific policy aims and outcome measures needed in order to improve services; with the goal of bringing cancer services in line with the best performing countries in Europe

Together for Health, Cancer Delivery Plan⁸³

The drive to prioritise cancer services in Wales culminated in the publication of the Cancer Delivery Plan in 2012, as well as subsequent annual reports to support the plan's implementation. The delivery plan sets out the key priorities for cancer services in the NHS up to 2016. These priorities included:

- Preventing cancer
- Detecting cancer quickly
- Delivering fast, effective treatment and care
- Meeting people's needs
- Caring at the end of life
- Improving information
- Targeting research

HOW ARE LUNG CANCER SERVICES ORGANISED AND DELIVERED IN WALES?

Underpinning priorities within the Cancer Delivery Plan is a framework for action for different organisations to adopt locally, particularly health boards and Public Health Wales, in order to improve cancer services overall. Organisations involved in delivering these actions include:

Health Boards, working with local cancer networks to plan and deliver local cancer services

Specialist Cancer Centres, providing specialist cancer services and training for cancer nurses, pharmacists and medical physicians

Public Health Wales, providing support to Health Boards for prevention and early diagnosis such as awareness campaigns, screening programmes, data collection around incidence and mortality to help inform service planning and campaigns around the associated risk factor for lung cancer

Cancer Networks, working in partnership with Health Boards, Velindre and Public Health Wales to co-ordinate the planning, organisation and delivery of cancer services within defined local areas; including how care is delivered by multi-disciplinary teams

As well as national goals to implement locally set by the *Cancer Delivery Plan*, health boards have produced annual local delivery plans since 2012 to identify tailored action needed to improve cancer outcomes in their area. Many of these have a focus on lung cancer, particularly for those where the incidence and prevalence rate is comparatively high to other health boards⁸⁶.

In the most recent iteration of the *Cancer Delivery Plan* in 2014, it was noted that there were 16,400 new cases of cancer per year⁸⁷, lung cancer being one of the most commonly diagnosed. Improving lung cancer outcomes was therefore identified as one of the five agreed national goals by the Government's Cancer Implementation Group within the action plan:

"A focus upon improving outcomes for lung cancer patients: in particular exploring an awareness campaign, improving access to curative treatments and research and stratified medicine initiatives."⁸⁷

As part of this national focus the implementation group agreed to endorse a nationally coordinated programme of activity to improve lung cancer care⁸⁸. This includes work to:

- Raise awareness of the key signs and symptoms of lung cancer
- Promote positive attitudes to lung cancer
- Promote timely help for patients experiencing symptoms
- Equip health professionals with the knowledge and support to respond to patients appropriately and effectively
- Ensure minimal waiting times and access to optimal treatments

Another piece of key guidance in order to continue to deliver best practice is the *National Standard for Lung Cancer* from 2005. It sets out standards which aim to ensure that patients⁸⁴:

- Have their treatment and care plans drawn up and reviewed by a multidisciplinary team (MDT)
- Are referred as urgent suspected cancer by their GP and, if diagnosed with lung cancer, start definitive treatment within 2 months of receipt of the referral at the hospital
- Are seen by the lung cancer Clinical Nurse Specialist (CNS) when informed of a diagnosis of cancer

Wales has made important steps within the past decade to give lung cancer the prioritisation it deserves, however, more still needs to be done to improve outcomes for those in Wales in order to match some the best performing countries in Europe.

The section below examines what steps have been taken to improve services for lung cancer over the last ten years, mapping this against the patient pathway and identified priorities.

RAISING AWARENESS AND PREVENTION

Identifying suspected lung cancer at the earliest opportunity is key to achieving better outcomes for patients, and is proven to improve rates of survival⁸⁹. However, a significant proportion of men and women diagnosed with lung cancer in Wales still present at a late stage of the disease (stage III or IV)⁹⁰.

In 2008, *Designed to Tackle Cancer in Wales*⁸⁵ set out a clear strategic framework to prioritise early detection and prevention to improve survival rates. In particular, the strategic framework set out that Wales should aim to have “comparable cancer incidence rates with the best performing European quartile by 2015”⁸⁵. This would be achieved through effective national population screening programmes and increasing public awareness of symptoms⁸⁵.

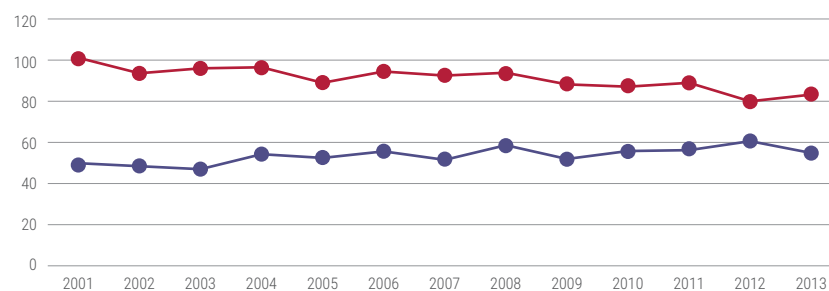
However, there has not been a huge amount of progress in taking these ambitions forward for lung cancer and, critically, Wales still has some of the worst survival rates in Europe for lung cancer, ranking 28th out of 29 countries within a comparative country study on survival⁸².

According to the European age-standardised incidence rate for lung cancer, the overall prevalence of lung cancer in Wales has decreased over the past ten years⁸². Though, despite some improvements, lung cancer is still one of the most common cancers in Wales, with almost 2,400 new cases diagnosed in 2013⁷⁹.

The annual number of deaths from lung cancer (1,894) is now more than bowel and breast cancer combined (1,506)⁷⁸ and mortality rates for lung cancer over the past 15 years follow similar trends in incidence rates, with a steady decline in male mortality rates and a slow increase in the mortality rate among the female population⁷⁹.

Figure 7

European age-standardised incidence rate for lung cancer in Wales (2001-2013)⁷⁹



Raising awareness

As part of the *Cancer Delivery Plan*, health boards were tasked with raising public and GP awareness of cancer symptoms to promote prompt referrals in line with national guidance, local pathways and waiting time standards. However, within the delivery of local cancer services, and where prevalence is particularly high, health boards don't have any dedicated plans or collaborative initiatives with Public Health Wales to raise the awareness of the signs and symptoms of lung cancer.

Similarly, in 2014 the Welsh Government identified awareness campaigns in the *Cancer Delivery Plan* as one of the key areas to improve in order to assure better outcomes for those with lung cancer overall. It was also identified in the *National Standard for Lung Cancer* a decade earlier as one of the key ways to improve diagnosis and survival rates⁸³.

Historically, national public awareness campaigns have been largely based around the associated risk factors of lung cancer, such as *Stop Smoking Wales*⁹¹, as opposed to signs and symptoms awareness campaigns. However, the Cancer Implementation Group has confirmed that they will be funding a public awareness campaign for lung cancer in Wales in May 2016, based on the *Be Clear on Cancer* initiative launched in England.

Screening

Effective screening is one of the main ways in which cancer can be detected in a timely and accurate manner. Currently, NHS Wales provides three cancer screening programmes for breast, cervical and bowel cancer which are managed in line with guidance from the UK National Screening Committee and Wales Screening Committee. There is, however, no national programme for lung cancer screening in Wales⁹².

Following the results of the NELSON trial, which assesses the benefit of lung cancer screening, such prioritisations towards this may be set to change⁷¹. It goes without saying that the introduction of a lung cancer screening programme, which is shown to improve rates of survival⁸⁹, should be prioritised.

REFERRAL

As well as through increased awareness of the signs and symptoms of lung cancer, early diagnosis can also be assured through improved pathways for referral, although evidence has demonstrated that some patients may be waiting too long between their diagnosis and a decision to treat in Wales.

Whilst initial efforts ten years ago were directed to ensure that patients referred urgently with suspected cancer were offered an appointment with a member of a Multi-Disciplinary Team (MDT) within ten working days, ambitions were subsequently broadened to ensure that patients were also given timely diagnostic investigations⁸⁴. As such, in the latest Wales *Cancer Delivery Plan*, it is made clear that in order to improve diagnostic testing, particularly ultrasound and CT scans, such tests should be made available to primary care practitioners wherever this will reduce the time to diagnose⁹¹.

There are several initiatives currently taking place in order to take this ambition forward by The Welsh Government, including a pilot single lung cancer pathway in Betsi Cadwaladr University Health Board which aims to ensure that patients regardless of their referral route will be put on to the two month suspected cancer pathway as soon as a clinician suspects cancer. Such an approach ensures consistency in practice reflective of a single MDT and single organisation⁹³. Further to this, all GPs were required to complete a significant event audit for each patient diagnosed with lung cancer in 2014, in order to promote earlier diagnosis and increase the number of lung cancer patients diagnosed on an urgent suspected cancer referral pathway⁹⁴.

Such efforts are essential to ensure that patients with suspected lung cancer are assessed at a dedicated rapid access clinic at the earliest opportunity, as this can be critical in improving their rate of survival.

TREATMENT

Key to personalised and high-quality treatment and care is ensuring equitable access to services, which are also co-ordinated through the utilisation of MDTs.

Diagnosis

Once a patient is referred, access to the additional diagnostic tests to ensure that patients have access to the correct treatment, which is tailored for their specific cancer type, is a crucial part of high-quality care. Positively, genetic testing for those already diagnosed increasingly occurs within some services in order to aid decisions around cancer treatments. For example, Epidermal Growth Factor Receptor (EGFR) testing occurs within services in Cardiff, and helps to predict a patient's sensitivity to treatments for non-small cell lung cancer⁹⁵.

Whilst improvements have been made, genetic and molecular diagnostic tests need to be integrated within future national cancer strategies, to ensure that they are introduced in a timely manner and that all patients have access to them.

Access to treatment

According to the 2014 NCLA there is more than a four-fold variation in the percentage of patients in Wales receiving surgery for non-small cell lung cancer (5 per cent – 22 per cent)¹¹. Whilst this has dramatically improved since 2007¹⁰, variation in access to treatments tends to be the case across the UK, however clear actions to tackle this are not addressed within Wales' *National Strategy for Cancer*, apart from within broader references to improve access to curative treatments within the *Cancer Delivery Plan*.

There lies an issue with ensuring that all patients have access to effective and innovative therapies. The Welsh Government aims to take an evidence based approach to making decisions on which medicines could be available, with a view to ensuring that all medicines approved by NICE and/or the All Wales Medicines Strategy Group (AWMSG) are routinely available⁹⁶.

To ensure that patients have access to the most innovative and cost-effective medicines there are Individual Patient Funding Requests (IPFR) for treatments which fall outside the routinely funded range of services. The process of IPFR is structured around the all-Wales IPFR policy and is adopted by all health boards. However, the Health and Social Care Committee found that with regards to cancer patients there was inconsistency in the implementation of the IPFR process, particularly with regards to the use of 'exceptionality'⁹⁷.

The Government should consider the Committee's recommendation of a national programme board to oversee IPFR to ensure consistency and to prevent were patients live acting as a barrier to innovative treatments⁹⁷.

Patient experience and personalised care

Wales has made progress in the monitoring and evaluation of patient experience through the Welsh *Cancer Patient Experience Survey*, published in 2013. However, areas of improvement were identified for lung cancer patients, where only 57 per cent of patients were given written easy to understand written information about lung cancer⁹⁸.

A key part to ensuring that patients have a more positive experience of care, and have care which is more personalised, is ensuring that patients are engaged with, and reviewed by, MDTs. Existing UK clinical guidelines make it clear that patients with a diagnosis of lung cancer should have their treatment discussed at a lung cancer MDT meeting, and patients who are actively managed by a specialist MDT are more likely to receive higher quality, well-coordinated care, and report a better experience overall.

Wales has made significant strides in improving the quality of MDTs since the UKLCC's formation. In particular, the number of patients reviewed by MDTs has increased from 91 per cent¹⁰ in 2007 to almost 100 per cent in 2013¹¹ and all MDTs are now chaired by a chest physician that has a special interest in lung cancer. However, it is notable that following a peer review in 2012, many smaller MDTs in West Wales have now merged, reducing the number of MDT teams from 16 to 11.

Access to lung cancer nurse specialists (LCNs) in England and Wales, which play a key part in having an effective MDT has improved substantially, rising to 84 per cent in 2013¹¹ – up from 35 per cent in 2007¹⁰.

Lastly, there have been steps made towards improvements in assessing the quality of the service MDTs deliver⁹⁹. Almost all health boards in Wales clearly set out within their local cancer delivery plans that they are participating in the peer review programme for lung cancer. These combine self-assessment with independent expert review, to ensure that effective MDTs are in place for lung cancer. These not only aim to ensure that the most effective care is delivered for patients, but also that clinical teams are working together effectively.

Clinical trials and research

The *Cancer Delivery Plan* set out that the Welsh NHS must continue to promote its research base and ensure access to clinical trials as these are well established to lead to better patient outcomes. It also set the target that 10 per cent of new cancer patients should participate in clinical trials each year⁸³.

Despite these ambitions, it has been found that research activity is not always integrated into the work of health boards and that there is no clear translation of the outcomes of research into service development and improvement.

In order to achieve the 10 per cent participation target, there needs to be greater monitoring of clinical trials to ensure that patients are in fact participating in these studies, and participation is not precluded by availability of current standards of care. It should also be ensured that patients know at the point of diagnosis that they are entitled to such participation. For example, the *Wales Cancer Patient Experience*

Survey showed that taking part in research was discussed with only 31 per cent of lung cancer patients⁹⁸.

Something which will also increasingly need to be given consideration is the use of stratified medicines, which involves targeting treatments based on genetics and the molecular characteristics of tumours in order to achieve better outcomes with fewer side effects. As such, the *Cancer Delivery Plan* sets out that health boards and NHS trusts should be working with universities and research organisations to ensure that Wales is involved in the development of such medicines. However, there are concerns that the availability of the new diagnostic systems and molecular tests which would be required to support the use of stratified medicines is not covered within the Plan⁹⁷.

Positive steps, however, have been taken by the Government who are, through the National Institute for Social Care and Health Research, funding a number of initiatives including the expansion of the genomics facility at the Wales Gene Park. Whilst the Government have clearly recognised the importance of the uptake and diffusion of new innovations in genetics and stratified medicine, and support the exploration of this through the £25 million Health Technology Fund, more needs to be done to ensure access to such treatments⁹⁸.

In line with recommendations from the Health and Social Care Committee, the Government should develop an integrated stakeholder approach to stratified medicine, setting out clear actions which will be taken and looking ahead to see how services can be developed in order to deliver this important treatment.

Data

The *Cancer Delivery Plan* also commits to improve access to information across the NHS in Wales as well as improve processes and data analysis⁸³. The NCLA demonstrated that Wales has certainly improved in this respect, with every hospital entering data for the audit in 2013¹¹. The Cancer Network Information Centre (CaNISC) is also particularly strong in regards to collecting data at primary diagnosis.

Not only this, but positive steps have also been made in using data to improve outcomes, such as through Wales's active membership of the International Cancer Benchmarking Partnership (ICBP), which allows all partners to share insights and best practice examples to help improve cancer outcomes¹⁰⁰.

There are, however, limitations in data collection, particularly with regards to data programmes which can detect wider outcomes such as the number of patients with metastatic disease.

More work needs to be done in collaboration with the NHS Wales Informatics Service and Public Health Wales in order to capture more detailed information on secondary episodes of care, which can therein be used for research purposes, along with an assessment of whether CaNISC needs to be amended in order to fulfil these data ambitions.

LUNG CANCER IN WALES: OUTCOMES

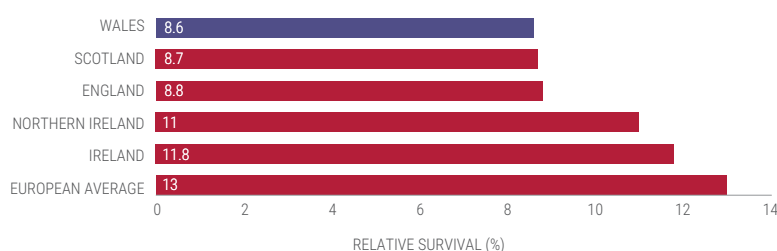
The Welsh Government's ambition within previous frameworks was to have a comparable one- and five-year survival rate to the quartile of best performing countries in Europe by 2015.

Despite improvements in survival overall, with one year survival rates for example increasing from 19% to 29%, from 1995-1999 to 2008-2012⁸², survival rates after five years for the four most common cancers in Wales vary. Just 6 per cent of lung cancer patients survive five years after diagnosis (male and female) compared to 86 per cent of breast cancer patients (female) from 2004-2008⁷⁹.

Survival for lung cancer is still poor compared to most other common cancers and survival in Wales is almost the lowest in Europe, 28th out of 29 countries when included within a comparative study on survival⁴. Estimates suggest that around half of people with lung cancer will die within six months of diagnosis and almost three-quarters will die within a year⁸².

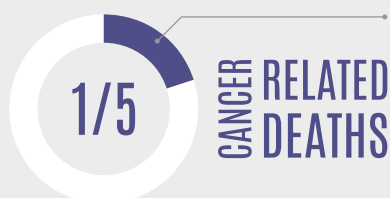
Figure 8

Five-year age standardised relative lung cancer survival for adult patients with cancer, diagnosed 2000-2007⁴



Whilst it is clear that Wales has made significant strides in prioritising lung cancer over the past ten years, there are still improvements that can be made to services in order to improve survival rates and the quality of life for those diagnosed.

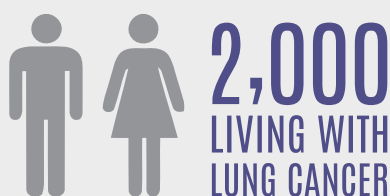
LUNG CANCER IN NORTHERN IRELAND



LUNG CANCER CAUSES MORE THAN ONE IN FIVE OF ALL CANCER-RELATED DEATHS AND MORE THAN TWICE AS MANY DEATHS AS THE NEXT RANKED CANCER¹⁰²

1,212 NEW CASES DIAGNOSED

IN 2013, 1,212 NEW LUNG CANCER CASES WERE DIAGNOSED IN NORTHERN IRELAND, ACCOUNTING FOR OVER 14 PER CENT OF ALL CANCER DIAGNOSES¹⁰³



IT IS ESTIMATED THAT THERE ARE APPROXIMATELY 2,000 PEOPLE LIVING WITH LUNG CANCER IN NORTHERN IRELAND¹⁰⁴

MORTALITY RATES HAVE DECLINED



SINCE THE UKLCC'S INCEPTION, THE LUNG CANCER MORTALITY RATE HAS DECLINED FROM 70 PER 100,000 OF THE POPULATION, TO 67¹⁰²



AROUND 940 PEOPLE DIE EVERY YEAR ACROSS NORTHERN IRELAND FROM LUNG CANCER¹⁰²

INCIDENCE
65 **CASES**
PER 100K POPULATION

LUNG CANCER INCIDENCE ACROSS NORTHERN IRELAND IS AROUND 65 CASES PER 100,000 OF THE POPULATION¹⁰²



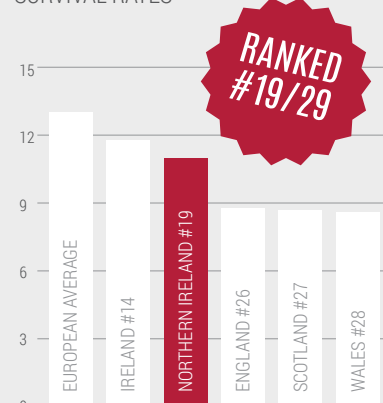
RISK FACTORS, SUCH AS SMOKING, REMAIN PREVALENT IN NORTHERN IRELAND: AROUND 340,000 PEOPLE AGED 16 AND OVER SMOKE IN NORTHERN IRELAND WITH 2,400 PEOPLE ESTIMATED TO DIE EACH YEAR DUE TO THE HABIT¹⁰⁵

2,400 **ESTIMATED DEATHS**

LUNG CANCER **BIGGEST**
NORTHERN IRELAND'S **CANCER KILLER**

SURVIVAL RATES

A PAN-EUROPEAN STUDY ON CANCER SURVIVAL SHOWED NORTHERN IRELAND PERFORMED POORLY COMPARED TO THE REST OF EUROPE IN TERMS OF FIVE-YEAR SURVIVAL RATES⁴



SINCE THE UKLCC'S INCEPTION, ONE-YEAR LUNG CANCER SURVIVAL RATES HAVE INCREASED IN NORTHERN IRELAND FROM 30 PER CENT TO 35 PER CENT FOR PATIENTS DIAGNOSED BETWEEN 2004-2008 AND 2009-2013¹⁰³



11% LIVE FOR UP TO FIVE YEARS

JUST 11% OF LUNG CANCER PATIENTS LIVE FOR UP TO FIVE YEARS AFTER THE POINT AT WHICH THEY ARE DIAGNOSED⁴



THE UKLCC'S TEN YEAR VISION FOR NORTHERN IRELAND

1

In advance of the 2016 Northern Ireland Assembly election, lung cancer should continue to be prioritised at a national level by politicians and the Department of Health, Social Services and Public Safety

2

The Department of Health, Social Services and Public Safety should continue to commit to assessing the content and attainment of the *Service Framework for Cancer Prevention, Treatment and Care*

3

The Department of Health, Social Services and Public Safety should commit to assessing adherence to the 2011 *Transforming Your Care: A Review of Health and Social Care in Northern Ireland* recommendations, and their impact on the quality of cancer services throughout Northern Ireland

4

A proactive assessment of the government's efforts to drive greater awareness of the dangers of smoking and better access to smoking cessation services should be undertaken, underpinning the programme's continuation across the country

5

The Northern Ireland Cancer Registry should commit to publishing an updated iteration of the *Monitoring care of lung cancer patients in Northern Ireland* report to assess the quality and types of care being received by lung cancer patients across Northern Ireland

6

Investment should be continued to support the roll-out, implementation and assessment of the 2015 iteration of the lung cancer *Be Cancer Aware* programme

7

The Northern Ireland Assembly and Department of Health, Social Services and Public Safety should work together to ensure Northern Ireland is accurately and appropriately represented in the 2015 iteration of the National Lung Cancer Audit and, in the absence of existing data, support the development and availability of patients' individual health record data to support targeted improvements in lung cancer services

8

Underpinning the development of effective treatment options, the Northern Ireland Assembly should undertake a review of its clinical trials processes, ensuring equity of access and resource among the lung cancer community, and support the development of a strategic framework for the introduction and availability of molecular diagnostic and genetic testing to ensure the targeted and effective use of such treatments

9

Northern Ireland's Public Health Agency should publically commit to a timeline for the publication of the 2015 Cancer Patient Experience Survey

10

Continuous assessment of the feasibility and effectiveness of lung cancer screening programmes should be undertaken across Northern Ireland, with appropriate resource committed to supporting its development and delivery

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 cancer in 2013¹⁰².

This chapter explores how Northern Ireland has looked to prioritise the development and delivery of cancer services and outcomes over the last decade, what levers exist to support high quality care across the patient pathway and, ultimately, how the outcomes of lung cancer patients compare in recent years.

CANCER AS A PRIORITY: LEVERS AND DELIVERY

Cancer services in Northern Ireland have evolved markedly in recent years. The first cancer incidence data for Northern Ireland were published in 1999 covering the period from 1993 to 1996. This was followed five years later by the establishment of the Northern Ireland Cancer Network (NiCAN) in 2004, supporting health professionals, patients and charities to work together in a co-ordinated manner, ensuring good communication and the sharing of best cancer practice¹⁰⁶.

Since the UKLCC's inception in 2005 however, two documents in particular have helped bring attention to the disease area and drive improvements in cancer care:

Service Framework for Cancer Prevention, Treatment and Care¹⁰⁷

Cancer was first explicitly identified as a priority in Northern Ireland through the publication of the *Service Framework for Cancer Prevention, Treatment and Care* in 2011 by the then Minister for Health, Social Services and Public Safety, Michael McGimpsey MLA, and Director of Public Health, Dr Carolyn Harper.

The publication acted as a series of individual service frameworks setting out explicit standards for health and social care to be used by patients, clients, carers and their wider families, to help them understand the standards of care they can expect to receive. Each standard is then supported by performance level targets, set to be achieved over three years and subject to regular review and refinement in the light of new evidence.

The standards themselves detail aspects of care across the entire patient pathway, including prevention, awareness and early detection through to palliative and end of life care.

Making Life Better: A Whole System Strategic Framework for Public Health¹⁰⁸

Further affirming Northern Ireland's commitment to cancer services, *Making Life Better: A Whole System Strategic Framework for Public Health* was published in June 2014.

Underpinned by *The Making Life Better Charter* which set out the Northern Ireland Executive's objective to create "the conditions for individuals, families and communities to take greater control over their lives and be enabled and supported to lead healthy lives", *Making Life Better* was Northern Ireland's ten-year public health strategic framework building on the previous iteration, *Investing for health*.

Looking broadly at the range of social, economic and environmental factors which influence health and wellbeing, the framework brings together actions at government level and provides direction for implementation regionally and locally.

Pertaining explicitly to cancer, *Making Life Better* recognises that cancer, along with coronary heart disease and respiratory disease, remains the main cause of death for both males and females across Northern Ireland. There is also recognition that these diseases are "potentially preventable, since smoking, unhealthy diet, raised blood pressure, diabetes and physical inactivity are major contributions to a large proportion of these conditions" – and provides a valuable contribution to the cancer prevention and awareness agenda.

HOW ARE LUNG CANCER SERVICES ORGANISED AND DELIVERED IN NORTHERN IRELAND?

The Department of Health, Social Services and Public Safety is one of 12 Northern Ireland Department's created in 1999 as part of the Northern Ireland Executive by the Northern Ireland Act 1998 and the Departments (Northern Ireland) Order 1999¹⁰⁹.

The Department itself has three main responsibilities:

Health and Social Care (HSC)

Includes policy and legislation for hospitals, family practitioner services and community health and personal social services

Public Health

Covers policy, legislation and administrative action to promote and protect the health and well-being of the population

Public Safety

Covers policy and legislation for fire and rescue services

The three responsibilities also contribute to the Department's clear mission to "improve the health and social well-being of the people of Northern Ireland", underpinned by two principles¹⁰⁹:

- Leading a major programme of cross-government action to improve the health and well-being of the population and reduce health inequalities, including interventions involving health promotion and education to encourage people to adopt activities, behaviours and attitudes which lead to better health and wellbeing
- Ensuring the provision of appropriate health and social care services, both in clinical settings such as hospitals and GP's surgeries, and in the community through nursing, social work and other professional services

Looking at cancer services specifically, the *Service Framework for Cancer Prevention, Treatment and Care* supports 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 local population
- **Health and Social Care (HSC) 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

Transforming Your Care: A Review of Health and Social Care in Northern Ireland

In June 2011 the Minister for Health, Social Services and Public Safety announced *Transforming Your Care: A Review of Health and Social Care in Northern Ireland*. Setting out an overarching road map for change in the provision of health and social care services in Northern Ireland, *Transforming Your Care* focused on reshaping how services are structured and delivered in order to make best use of resources and ensure services are safe, resilient and sustainable into the future.

The panel commissioned to lead the review was led by the then Chief Executive of the Health and Social Care Board, John Compton, and engaged widely with the public, and clinical and professional leadership.

Reporting in December 2011, the review panel made 99 proposals for change across the full range of health and social care services¹¹⁰, including:

- Consideration by the Northern Ireland Executive of the wider role of the state in taking decisions impacting on health outcomes, including further controls on tobacco usage
- The development of admission protocols between secondary care specialist staff and those in the community
- Full rollout of the Electronic Care Record programme

Monitoring care of lung cancer patients in Northern Ireland diagnosed 2006 (with comparisons 1996 and 2001)¹¹¹

Published in 2009 by the Northern Ireland Cancer Registry, *Monitoring care of lung cancer patients* described the characteristics of patients with lung cancer and their care in 2006, making comparisons with the care received by lung cancer patients in 1996 and 2001. In a review of how care was received across the lung cancer pathway, the report positively found that:

- Patients were presenting earlier, with reduced waiting times for investigations and treatments
- There was better recording of patient performance status and staging
- Use of complex imaging (such as CT and PET Scan) was enhanced
- There was an increased equity of service provision by geographical area
- There was increased referral to respiratory physicians and palliative care

However, the report also found additional areas for improvement, most notably:

- Survival on the whole, for lung cancer patients, was very poor
- Patients continued to present with serious symptoms, including cough, pain and breathlessness
- More efforts were needed to ensure early diagnosis
- More efforts were needed to reduce smoking habits among certain age demographics

PREVENTION

Around 340,000 people aged 16 and over smoke in Northern Ireland with 2,400 people estimated to die each year due to the habit¹⁰⁵. Reducing smoking is a high priority within public health across the region and it is now against the law to smoke in almost every enclosed public space across the country, including cafes and restaurants, shopping centres and railway stations¹¹².

Awareness

With lung cancer being one of the most common cancers in Northern Ireland, the Public Health Agency recognises the role of early detection in improving outcomes for people with the disease.

Indeed, the *Service Framework for Cancer Prevention, Treatment and Care* recognised smoking as a significant risk factor for the disease, with approximately 90 per cent of lung cancer patients having had a history of the habit, with 'Standard 5' of the Framework setting out how:

"Health and social care should work in co-operation with voluntary, education, youth and community organisations to prevent the recruitment of young people to smoking"¹⁰⁷

As part of a further effort to improve early detection, in May 2015 the Public Health Agency launched the next phase of its *Be Cancer Aware* campaign, focusing specifically on lung cancer¹¹³.

Launched to coincide with the All Ireland Cancer Consortium Conference, the *Be Cancer Aware* campaign was supported by an updated website providing information about cancer signs and symptoms, helping people understand what they should do if they have suspected symptoms, and signposting to recommended sources of support or further information.

SCREENING AND DIAGNOSIS

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. During the UKLCC's inception in 2005 just over 950 new cases of the disease were recorded. Looking back on 2013, however, this has increased to approximately 1,200 new cases – around 14 per cent of all new cancer diagnoses¹⁰³.

Figure 9

Number of cases and incidence rates by sex and year of diagnosis (Lung, Bronchus and Trachea) in Northern Ireland (1993-2013)¹⁰³

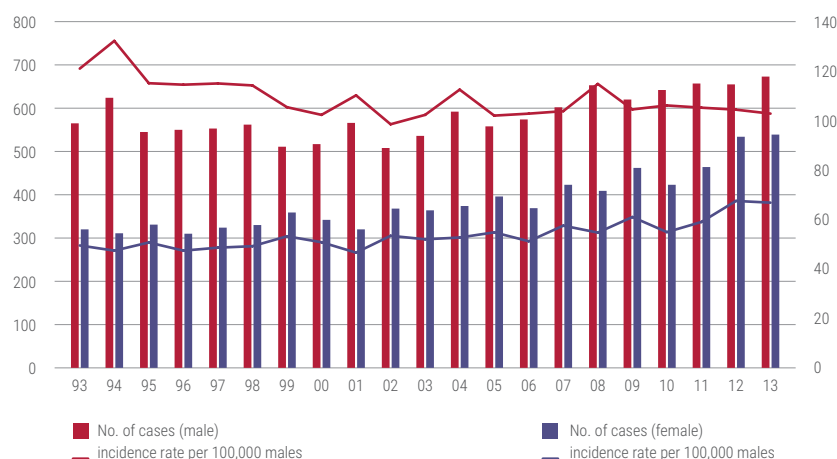


Figure 9 demonstrates that the rate of new lung cancer cases has been consistently higher among men since the records were first made available in 1993, although the gender gap has narrowed steadily in recent years. This pattern has been attributed to contrasting trends in smoking prevalence among men and women¹³. Overall, it is now estimated that there are approximately 2,000 people living with lung cancer in Northern Ireland¹⁰⁴.

Early diagnosis is undoubtedly vital to improving patient outcomes, with the *Service Framework for Cancer Prevention, Treatment and Care* recognising that 45 per cent of lung cancer cases are only found when a patient attends accident and emergency¹⁰⁷. As such, in an effort to drive early and accurate lung cancer diagnoses, 'Standard 12' notes that:

"The public should be made aware of the early signs and symptoms of cancer so they know when they need to go to their doctor for advice"

It is interesting to note that at present, breast, cervical and bowel screening programmes are in place across Northern Ireland¹¹⁴. However, it would appear there are no plans currently for the introduction of similar screening programmes for lung cancer.

REFERRAL

Timely referral to an appropriate specialist is vital in helping support high quality patient outcomes. Indeed, recognising the importance of the referral pathway, the *Service Framework for Cancer Prevention, Treatment and Care* states¹⁰⁷:

"All people with signs and symptoms that might suggest cancer should be appropriately assessed by their GP and referred promptly to hospital for further tests if needed"

For lung cancer patients, 'Standard 41' recommends that:

"All patients suspected of having lung cancer and who have an abnormal chest should have a CT Scan of their chest and abdomen before having any invasive procedures such as a bronchoscopy"

With the absence of Lung Cancer Audit data for Northern Ireland, it can be difficult to assess the quality of lung cancer care across the patient pathway. It is encouraging to note, however, that in the 13-year period between 1996 and 2009, the proportion of suspected lung cancer patients referred within 32 days has increased from 93 per cent to 97 per cent and also that the number of patients referred after 64 days has increased from 97 per cent to 99 per cent¹¹⁵.

TREATMENT

Access to appropriate treatments

Transforming Your Care noted that “treatment for cancer has been revolutionised over the past decade with survival rates improving across a range of cancers”¹¹⁰. MDTs are an important part of this revolution and are recognised within the service framework as being a vital component of high quality patient care with MDTs more likely to ensure the delivery of co-ordinated and expert care:

“All patients who have high clinical suspicion or have a diagnosis of cancer should have their care managed by an appropriately constituted and effective multidisciplinary team (MDT) which meets weekly or fortnightly (in accordance with the manual of Cancer Services Standards)”

¹¹⁰

CNSs in particular play a key role in the make-up of MDTs and in providing expert and tailored care, with ‘Standard 21’ recognising that:

“All patients should be assessed by a clinical nurse specialist (CNS) at the time of diagnosis, at the end of each treatment episode and as required throughout their cancer journey”

Accurate and timely treatments are vital for all cancer patients. As such, it is encouraging to see that the proportion of patients accessing treatments for lung cancer 64 days from the point of referral increased from 57 per cent to 65 per cent between 1996 and 2009¹¹⁵.

However, whilst patients across Northern Ireland are accessing treatments in an increasingly timely manner, access to new medicines is often perceived to be poor among specialists in the field, with funding uncertainties resulting in slow uptake and ultimately impacting on the outcomes of lung cancer patients across Northern Ireland.

Patient experience and data

Measuring the performance of services is crucial to supporting effective decision-making and driving improvements in the quality of services for patients. *Monitoring care of lung cancer patients in Northern Ireland*, undertaken by the Northern Ireland Cancer Registry in 2009, benchmarked data on lung cancer services to assess whether they were being delivered in line with the recommended clinical guidelines on investigation and treatment¹¹¹.

The review identified significant progress in a number of areas, as well as clear priorities for improvement with the authors of the report calling for lung cancer services in Northern Ireland to be re-audited in 2014¹¹¹.

Recognising the value of ensuring high quality patient experience, the first standard within the *Service Framework for Cancer Prevention, Treatment and Care* states that:

“All patients, clients and carers should expect effective communication...as an essential part of the planning and delivery of health and social care”¹⁰⁷

To further support effective use of data and service improvement the NiCAN published *Lung Cancer and Mesothelioma Patient Information Pathway(s)* in 2011; which acts as a valuable resource for individuals who provide support to lung cancer patients, containing links to information sources across the entire patient pathway¹¹⁶.

Understanding patient experience is vital in driving improvements in cancer care. It was announced, following the success of the Cancer Patient Experience Surveys in England and Wales, that Northern Ireland's Public Health Agency, with support from Macmillan Cancer Support, would undertake a similar survey at the end of 2013. With a view to enabling the service to “identify and build on progress that has already been made and target efforts to continue to improve patients' experience of NHS cancer care”, the survey covered approximately 4,000 adult cancer patients in Northern Ireland aged 16 years and over¹¹⁷.

Whilst timelines were pushed back for the dissemination of the survey, it was confirmed in February 2015 that health and social care trusts had begun posting out the surveys to the estimated 5,500 adults diagnosed with cancer and discharged from hospitals between December 2013 and May 2014.

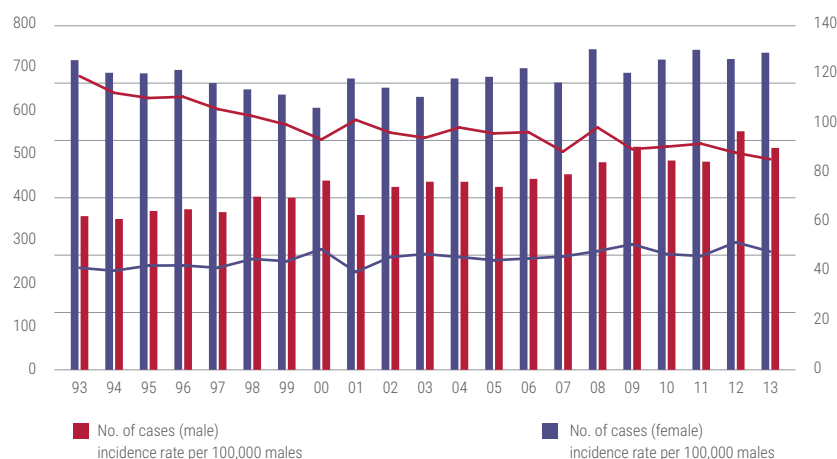
The NCLA¹¹ provides an additional annual assessment of the quality of lung cancer services across England, Wales and Scotland. Unfortunately, the data for Northern Ireland was not available at the time of the 2014 publication and has not been included in the latest iteration.

LUNG CANCER IN NORTHERN IRELAND: OUTCOMES

The latest mortality statistics (Figure 10), 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 rate of deaths caused by lung cancer in Northern Ireland over the past 20 years¹⁰².

Figure 10

Number of deaths and mortality rates by sex and year of diagnosis (Lung, Bronchus and Trachea) in Northern Ireland (1993-2013)¹⁰²



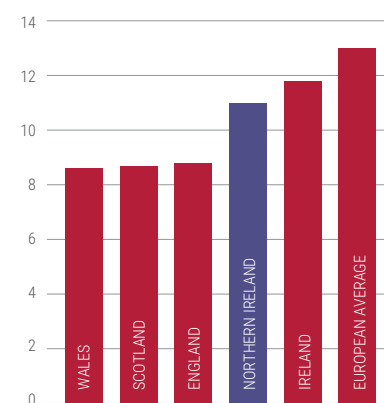
In 2005, over 800 people died as a result of lung cancer. As of 2013, the figure stood at 940—almost a quarter of all cancer-related deaths. Interestingly, the mortality rate per 100,000 of the population has decreased for males since 1993, from 120 to 86 in 2013, whilst increasing for females from 42 to 48¹⁰².

Survival data refer to the percentage of patients who live for a specified period after being diagnosed. Trends in survival rates provide key insights into the overall effectiveness of the health system in managing a specific cancer. Indeed, there have been steady improvements in one- and five-year lung cancer survival rates in Northern Ireland in recent years¹⁰². However, a European study across 29 different countries showed five-year survival rates were poorer in Northern Ireland, and across the UK, than the rest of Europe⁴.

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 treatments.

Figure 11

Five-year age-standardised relative lung cancer survival for adult patients with cancer, diagnosed 2000–2007⁴



Tackling cancer should be a long-term priority of any government in Northern Ireland, and the UKLCC welcomes the commitments shown by the Northern Ireland Assembly to date.

However, more can and needs to be done to help improve the delivery and effectiveness of cancer services across the country. As the UK's leading coalition of lung cancer experts, senior NHS professionals, charities and healthcare companies, the UKLCC is committed to working with government and key stakeholders throughout Northern Ireland to drive such improvement forward.

CONCLUSION

A decade on from the UKLCC's formation, *Ten Years On* forms an important contribution in understanding how far lung cancer services and outcomes have come, and where improvements must be targeted in the future.

Significant strides have of course been made and should be recognised and applauded. The publication of NHS England's *Achieving World-Class Cancer Outcomes: A Strategy for England 2015*; Northern Ireland's *Service Framework for Cancer Prevention, Treatment and Care*; Scotland's efforts to eradicate smoking, including the 2013 publication of *Creating a Tobacco-Free Generation*; and the Welsh Government's *Together for Health, Cancer Delivery Plan* setting out the priorities for cancer services in the Welsh NHS up until 2016, are all welcomed and all represent invaluable steps towards helping to contribute to a general decline in overall lung cancer incidence across the UK since 2005.

However, the stark fact remains that across the UK, lung cancer is the biggest cancer killer, with over 35,000 deaths attributable to the disease in 2012 alone³, and five-year survival rates across the UK continue to lag behind our European counterparts⁴.

Effectively implementing technological advances is one area which will be vital in driving improvements moving forward. The concept of stratified medicine in particular will be key, with Cancer Research UK recently launching the first part of its Stratified Medicine Programme. Aiming to establish a network for nationwide molecular testing, the programme will be crucial for accommodating potential new targeted treatments in the future and should receive full support from all parties involved.

At the same time, however, a broad brush approach across the UK will not suffice. By setting out ten recommendations for each nation across the UK we have provided what the UKLCC feels to be necessary, yet reasonable and attainable, steps for national governments and decision makers to take to help drive improvements in lung cancer services and outcomes.

The UKLCC acknowledges the stark challenges health services are currently facing, with a rapidly ageing patient population; increasing patient co-morbidities; and the greatest financial pressures faced in generations.

However, through working in partnership significant steps can be taken to overcome these challenges and improve outcomes for lung cancer patients across the UK.

In order to achieve this, the UKLCC will continue to work tirelessly to bring key stakeholders together, hold decision-makers to account, raise public awareness of the signs and symptoms of lung cancer and support clinicians in delivering high-quality lung cancer care.

We look forward to the next ten years where we will again look to see how far we have come.

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