

25 BY 25

A TEN-YEAR STRATEGY TO IMPROVE
LUNG CANCER SURVIVAL RATES



UNITED KINGDOM
LUNG CANCER COALITION

OCTOBER 2016

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- British Lung Foundation
- Macmillan Cancer Support
- Roy Castle Lung Cancer Foundation
- Tenovus Cancer Care
- British Thoracic Society
- National Lung Cancer Forum for Nurses
- The Primary Care Respiratory Society

ABOUT THE UKLCC

The United Kingdom Lung Cancer Coalition (UKLCC) – the country's largest multi-interest group in lung cancer – 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 our website or contact our secretariat.

www.uklcc.org.uk

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INTRODUCTION

For the last ten years, lung cancer has consistently been the UK's biggest cancer killer^{1,2}. In 2014 alone, it was the cause of almost 35,900 deaths³, which is more than breast⁴ and bowel cancers combined⁵. The UKLCC was set up in 2005 with the founding ambition to tackle poor lung cancer survival outcomes and, specifically, to double five-year survival by 2015.

In response to the growing need to address cancer as a whole, nations across the UK have undertaken efforts over recent years to help support improvements in long-term survival. Following this, estimates now suggest that the UKLCC's founding ambition to double five-year survival has effectively been met in England⁶, with improvements also seen in Scotland⁷, Wales⁸ and Northern Ireland⁹. However, whilst significant improvements have been made, there is still an urgent need for more to be done. Lung cancer is not prioritised as it should be compared with other common cancer types, quality of patient outcomes highly varies¹⁰ and whilst long-term survival across the UK has significantly improved, rates still fall behind in comparison with other developed countries¹¹.

We know more needs to be done, and we know we need to aim higher to secure better outcomes for patients.

25 BY 25

THE 25 BY 25 AMBITION

The UKLCC is calling for a drastic improvement in care for those with lung cancer across the UK in order to raise five-year survival rates to 25% by 2025

To determine how to meet this ambition, the UKLCC sought to explore not just the existing evidence but also the opinions of those who face up to lung cancer every day, launching a number of surveys across the UK within the lung cancer community.

Based on this insight, this report contains a series of UK-wide principles to improve five-year survival rates and meet *The 25 by 25 ambition*. These principles, aimed across the patient pathway, are set out in three key phases up to 2025. Subsequent chapters of this report then set out tailored recommendations for each UK nation for immediate delivery, laying paths to success unique to each individual health service.

It is time for the community to redouble efforts to do the very best for people affected by lung cancer.

The NHS is facing massive financial pressures and resource strain, but there are also unprecedented opportunities offered by new national structures, local and regional autonomy and a drive for effective 'whole person' care.

A lung cancer diagnosis should not be a death sentence and we hope that those across UK Governments and health services can support the UKLCC's *25 by 25 ambition* and see its key recommendations implemented across the UK.

HOW TO MEET A NEW UK SURVIVAL AMBITION: SURVEYING THE LUNG CANCER CLINICAL AND PATIENT COMMUNITY

In order to achieve its five-year survival ambition, the UKLCC launched a series of UK-wide surveys to assess attitudes on long-term survival from across the lung cancer community.

This included a survey of 148 healthcare professionals (HCPs)* from across the composition of a multi-disciplinary team (MDT) – specialist nurses, pathologists, radiologists, oncologists, surgeons and respiratory physicians – trained in treating lung cancer. Alongside this, we surveyed 102 patients and carers from across the UK on their experiences of care and attitudes towards survival.

We also conducted a poll of over 1,000 GPs working in primary care at the forefront of detecting and referring suspected cases, and canvassed their views on what improvements need to be made to tackle poor survival.

Our aim was that, by listening to the views of the lung cancer community and utilising the latest evidence and data across the UK, we could begin to identify the necessary steps to combat the country's biggest cancer killer – steps which will stand the test of time.

This chapter summarises the key results from the surveys undertaken. These have then been used in parallel with the most recent evidence to identify the overarching principles which need to be taken across the UK to improve survival both now and in the future.

*All mentions of HCPs refer to secondary and tertiary care clinicians so as to distinguish those polled in the HCP survey from the GP poll, which exclusively surveyed primary care clinicians.



50% OF PATIENTS AND CARERS CONSIDER SURVIVING LUNG CANCER FOR MORE THAN FIVE YEARS TO BE ACHIEVABLE



ONLY 27% OF PATIENTS SAW THEIR DOCTOR BECAUSE THEY RECOGNISED THAT THEY WERE EXPERIENCING SIGNS AND SYMPTOMS OF LUNG CANCER



65% OF HCPs BELIEVE EARLY-STAGE DIAGNOSIS TO BE THE MOST IMPORTANT FACTOR FOR IMPROVING FIVE-YEAR SURVIVAL RATES



43% OF PATIENTS WAITED OVER ONE MONTH FOR INITIATION OF TREATMENT AFTER A DIAGNOSIS WAS CONFIRMED BY THEIR CLINICIAN

A UK SNAPSHOT: TACKLING BARRIERS TO SURVIVAL

CURRENT VIEWS ON FIVE YEAR SURVIVAL: PATIENTS MORE OPTIMISTIC THAN DOCTORS?



50% OF PATIENTS AND CARERS NOW CONSIDER SURVIVING LUNG CANCER FOR MORE THAN FIVE YEARS TO BE ACHIEVABLE



ON A SCALE OF HOW ACHIEVABLE FIVE-YEAR SURVIVAL IS, 65% OF HCPs CONSIDERED FIVE-YEAR SURVIVAL DIFFICULT TO ACHIEVE AND 15% COMPLETELY UNACHIEVABLE

There is an urgent need to meet the expectations of those affected by lung cancer. Of those polled, nearly half of patients and carers described surviving lung cancer for more than five years as "achievable". Such optimism, when current five-year survival rates are estimated at only 16% at their highest in the UK⁶, shows that patients have the determination and belief to fight lung cancer for longer. This also reflects the value of recent public awareness and patient group campaigns in demonstrating that lung cancer is survivable if caught early and treated effectively. However, in sharp contrast, the majority of HCPs described surviving for over five years as "difficult to achieve" and some as "completely unachievable". These views may be formed partly by recent cuts to funding for key services related to lung cancer such as smoking cessation¹², increasing strains on diagnostic capacity and ill-resourced MDTs – demonstrating that more needs to be done to support services to meet ambitions for long-term survival.

PREVENTION: BEHAVIOURAL RISK FACTORS STILL NEED TO BE SIGNIFICANTLY ADDRESSED



HCPs BELIEVE THAT A REDUCTION IN SMOKING RATES IS THE SECOND MOST IMPORTANT FACTOR, AFTER EARLY DIAGNOSIS, FOR IMPROVING FIVE-YEAR SURVIVAL RATES IN LUNG CANCER



GPs BELIEVE THAT IMPROVED ACCESS TO SMOKING CESSATION SERVICES WOULD HAVE THE SECOND BIGGEST IMPACT, AFTER PUBLIC AWARENESS CAMPAIGNS, ON IMPROVING LUNG CANCER SURVIVAL RATES

Tobacco use is the most important preventable cause of lung cancer in the UK. While we know there are a proportion of patients who have never smoked who have developed lung cancer, the majority of cases are preventable, with 86% of cases caused by smoking alone¹⁴. However, whilst also reducing the number of cases, the risk of total mortality and rate of recurrence of lung cancer is also substantially lower in smokers who manage to quit smoking following diagnosis of early stage lung cancer or small cell lung cancer¹⁵.

Whilst rates of smoking-related lung cancers reflect historical smoking trends, more needs to be done to support local services, such as those for smoking cessation, to reduce future incidence and to improve the survival of patients who are newly diagnosed¹⁴.

NATIONAL SCREENING: COULD SCREENING MAKE THE DIFFERENCE?



52% OF HCPS BELIEVE THAT A NATIONAL SCREENING PROGRAMME FOR LUNG CANCER SHOULD BE INTRODUCED

We know from international examples that screening is an effective way to increase early identification. For example, a study in the US showed a 20% reduction in lung cancer specific mortality using low spiral CT screening tools¹⁶. Positive steps are also being taken in the UK, with local initiatives such as UKLS¹⁷ and ECLS¹⁸, which assess screening techniques and the benefits of introducing screening across the country. It is therefore encouraging that our findings show that clinicians agree with the growing evidence base that screening is an effective way to enable early diagnosis and have the desire to see such an initiative implemented as a means of improving survival. However, a decision is unlikely to be made until the UK national screening committee makes a recommendation based on the results of the NELSON trial.

There is a need now for these local initiatives to make further efforts to share their findings in a way that works towards a nationally funded programme, whilst the results of the NELSON trial are still pending.

AWARENESS: LACK OF AWARENESS AMONGST PATIENTS OF THE SIGNS AND SYMPTOMS OF LUNG CANCER, AND WHEN TO SEE THEIR DOCTOR, IS STILL A CORE ISSUE

Lack of awareness amongst patients of the signs and symptoms of lung cancer, and when to see their doctor, is still a core issue



51% OF GPs BELIEVE THAT PATIENTS NOT KNOWING WHEN TO VISIT THEIR DOCTOR IS THE GREATEST CHALLENGE TO ENSURE A TIMELY REFERRAL AND AN EARLY DIAGNOSIS



ONLY 27% OF PATIENTS SAW THEIR DOCTOR BECAUSE THEY RECOGNISED THAT THEY WERE EXPERIENCING SIGNS AND SYMPTOMS OF LUNG CANCER



32% OF GPs AND 35% OF HCPS IDENTIFIED PUBLIC AWARENESS CAMPAIGNS AS THE MOST IMPORTANT FACTOR FOR IMPROVING EARLY-STAGE DIAGNOSIS



ONLY 50% OF PATIENTS AND CARERS HAD HEARD OF PUBLIC AWARENESS CAMPAIGNS FOR LUNG CANCER



40% OF PATIENTS DID NOT KNOW THAT CHEST PAIN, WEIGHT LOSS AND TIREDNESS ARE POSSIBLE SYMPTOMS OF LUNG CANCER

Both patients and clinicians need to be aware of the signs and symptoms of lung cancer to ensure patients are diagnosed as early as possible. Polling GPs, as well as HCPS, allowed us to ask those working with patients early on in the pathway what the greatest barriers in achieving this are, and how they can be overcome. However, our findings suggest that a lack of awareness from patients on the symptoms themselves, and when to see their doctor, still act as major barriers to early presentation.

Similarly, whilst it is positive that half of patients with lung cancer are aware of public awareness campaigns, one of the main channels to raise awareness, we need to invest more in these campaigns to ensure that they reach more patients, at the right time.

REFERRAL AND DIAGNOSIS: MORE NEEDS TO BE DONE TO IMPROVE PROMPT REFERRAL AND EARLY DIAGNOSIS TO ENSURE TREATMENT IS DELIVERED AS QUICKLY AS POSSIBLE



65% OF HCPS BELIEVE EARLY-STAGE DIAGNOSIS TO BE THE MOST IMPORTANT FACTOR FOR IMPROVING FIVE-YEAR SURVIVAL RATES



PROMPT ACCESS TO INVESTIGATIVE TESTING AND QUICK REFERRAL OF SUSPECTED CASES WERE IDENTIFIED AS THE GREATEST BARRIERS TO RAPID DIAGNOSIS



36% OF PATIENTS SURVEYED WAITED OVER ONE MONTH FOR A DEFINITIVE DIAGNOSIS AFTER AN INITIAL SUSPICION OF LUNG CANCER WAS MADE BY THEIR DOCTOR AND 17% WAITED OVER TWO MONTHS



43% OF PATIENTS WAITED OVER ONE MONTH FOR INITIATION OF TREATMENT AFTER A DIAGNOSIS WAS CONFIRMED BY THEIR CLINICIAN

Detecting cancer early and initiating treatment as quickly as possible following a diagnosis of lung cancer are imperative for improving survival rates. The NHS in England has set a waiting time standard of two weeks between urgent referral and hospital appointment to test for lung cancer and has also committed to the standard that treatment starts no more than 31 days after a treatment plan is agreed¹⁹ – with similar standards set across the UK. However, as the results of our survey show, lung cancer patients are still waiting a significant period of time before receiving a clear diagnosis and starting treatment. We also know from the latest statistics that across the UK, cancer waiting times vary and the targets which are set by nations are often missed^{20,21,22,23}.

TREATMENT AND VARIATION: REGIONAL INEQUALITIES IN CARE AND UNDER-PRIORITISATION OF MDTs MUST BECOME CENTRAL AREAS OF FOCUS FOR IMPROVEMENT



52% OF HCPS BELIEVE THAT A LACK OF CAPACITY AND RESOURCE PRESENTS ONE OF THE GREATEST CHALLENGES TO THEIR MDT FOR IMPROVING LUNG CANCER SURVIVAL RATES



84% OF HCPS BELIEVE REGIONAL INEQUALITIES IN HEALTH AND CARE SERVICES HAVE A MAJOR-MODERATE IMPACT ON LUNG CANCER SURVIVAL RATES



61% OF HCPS BELIEVE A STANDARDISED LUNG CANCER PATHWAY FOR THEIR NATION WOULD IMPROVE LUNG CANCER SURVIVAL RATES

More needs to be done to ensure that there is quick and equitable access to diagnosis and treatment across the UK and to ensure that MDTs, which are a crucial part of delivering this, have sufficient capacity and resource in order to do so. A standardised lung cancer pathway within each UK nation was identified by HCPS as a way to improve survival rates and this may further assist in combatting local variation rates. If HCPS believe they can do better for all patients by implementing new standards of care such as these, the benefits of doing so must be assessed and implemented by policymakers and health service leaders. Alongside this, such investments must be supported by increased investment in prevention and awareness, particularly in areas where incidence rates are at their highest, to reduce the risk of further perpetuating regional inequalities in care and outcomes.

PRINCIPLES TO ACHIEVE BY 2025: IMPLEMENTING LASTING CHANGE

Using the insights from these surveys, the UKLCC has developed a comprehensive set of UK-wide principles which are phased for immediate, medium, and long term delivery towards 2025. These principles address key areas of improvement across the patient pathway, and are aimed to transform the way lung cancer services are delivered in order to drastically improve survival and meet the UKLCC's 2025 survival ambition.

The following chapters of this report draw on the below principles marked for immediate delivery over 2016-18 and set tailored recommendations for England, Scotland, Wales and Northern Ireland that are necessary for achieving the UKLCC's survival ambition.

PHASE 1: 2016-2018

Fundamental steps to meeting a new ambition

PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE
1	2	3	4	5
Governments across the UK to prioritise the improvement of lung cancer survival in any future plans or strategies relevant to the delivery of broader health, respiratory and/or cancer services	UK governments to prioritise public health initiatives and prevention services, both locally and nationally with an aim to reduce and combat the number of lung cancer cases	Public health bodies across the UK to commit to the adoption of annual public awareness campaigns, funded nationally, which are focused on raising awareness of the signs and symptoms of lung cancer	UK governments should invest in local screening pilots, and continue to build an evidence base in anticipation of the NELSON trial results	Health organisations and UK governments to commission national clinical audits or performance measures of referral services, which include the assessment of effectiveness of referral guidelines for suspected cancer, with target recommendations of how these can be improved

PHASE 2: 2019-2022

Maximising improvements to continue to improve survival

PRINCIPLE	PRINCIPLE	PRINCIPLE
11	12	13
UK-wide taskforce set-up involving those across the lung cancer community, and led by the UKLCC, to set out renewed nation-specific recommendations for improving five-year survival based on learnings from existing European working groups (such as Cancer Benchmarking Partnership and the European Lung Foundation) and in line with European best practice and standards. UK governments to commit to taskforce recommendations for achievement by 2025	Ring-fence budgets for smoking cessation services and improve public health initiatives/programmes and prevention services, which focus on reduction in smoking rates, aligning with current national guidance and initiatives	Each nation to introduce a national screening programme for lung cancer for at risk groups, following the results of local initiatives and the NELSON trial

PHASE 3: 2023-2025

Securing the 25 by 25 ambition

PRINCIPLE	PRINCIPLE
17	18
UK-wide working group to be established by UK public health bodies to work with the European Public Health Alliance. This group to examine and learn from best practice public health initiatives across Europe with the aim of lowering smoking rates in line with tobacco free ambition of 5% by 2035	Official standard set for 60% of those in at-risk groups being screened as part of national screening programme for lung cancer



PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE
6	7	8	9	10
Invest in existing bodies, including NHS England's Lung Cancer Clinical Reference Group (CRG) and Public Health England's Lung Cancer Site-Specific Clinical Reference Group (SSCRG), and initiatives to improve and optimise referral, diagnostic and treatment pathways 3	The National Cancer Institute to offer research funding towards projects aimed at developing cost-benefit assessments of diagnostic tools for lung cancer, with the objective of creating targeted recommendations to improve rapid diagnosis from point of initial suspicion	National Institute for Health Research to work with UK nations to launch a pilot data programme to assess and address local variation for lung cancer treatment, with the aim of every part of the UK having sufficient resource and quality treatment to deliver above the European survival average by 2025	All MDTs should be responsible for designing their own diagnosis pathway following initial referral. They should also ensure that suspected cases are dealt with by a respiratory physician with a special interest in lung cancer and are assessed at a dedicated rapid access clinic	Upon diagnosis all MDTs should ensure patients have access to a lung cancer clinical nurse involved in all aspects of a patient's care, and have a dedicated chest physician and a thoracic surgeon present as core members for all meetings

PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE	PRINCIPLE
14	15	16	19	20
Annually renew public awareness campaigns, focused on raising awareness of the signs and symptoms of lung cancer at a two-month minimum, setting a minimum target to increase the number of those diagnosed at the earliest stage to 40%	Pilot the use of national lung cancer pathways in each devolved nation, aimed at improving survival outcomes and overall experiences of care	Commit to ensuring that data collection, analysis and application matches the best in Europe as a means of improving lung cancer outcomes and experience of care	Target cancer waiting times across individual nations in the UK being consistently met by over 90% of patients	All UK governments commit to having five-year survival rates for lung cancer among the top 15 performing countries in Europe

ENGLAND: MEETING THE 25 BY 25 SURVIVAL AMBITION

Lung cancer is the second most common cancer in England and is by far the biggest cancer killer overall, causing over 28,000 deaths in 2011 alone²⁴.

With one of the lowest survival outcomes of any cancer type, the UKLCC has welcomed efforts to date to improve long-term survival. In the five-year cancer strategy published by the Independent Cancer Taskforce, it was noted that survival for lung cancer remains low, with 9,900 lung cancer avoidable deaths each year due to health inequalities²⁵. The strategy sets out a number of recommendations in the report, four specific to lung cancer, focusing on screening, awareness campaigns, access to molecular diagnostics and national clinical audits for critical cancer services.

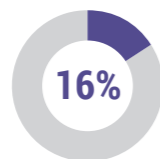
Encouragingly since the strategy's publication in 2015, several efforts have been made to deliver against its recommendations and improve long-term survival for lung cancer:

- Public Health England introduced a chest symptoms awareness campaign in 2016, which included lung cancer and ran for four months (July - October)²⁶

- Whilst the UK National Screening Committee are yet to make a decision on lung cancer until the results from the NELSON trial are published, local screening initiatives, such as the United Kingdom Lung Cancer Screening (UKLS) trial, have been commissioned by the Department of Health's Technology Assessment Programme, showing positive results in 2016 to support the case for a national programme¹⁷

- Over 93% of patients are discussed at an MDT level, a key way to ensure patients receive the highest quality treatment and have a good experience of care¹⁰

As a result of such improvements in care, long-term survival for lung cancer in England has significantly improved with recent estimates even now suggesting that five-year survival may have increased to 16%, and would appear to be directly correlated with the increase in surgical resection rates⁶.



FIVE YEAR SURVIVAL
(2013 predicted)⁶



ONE YEAR SURVIVAL
(2013)²⁹



ACTIVE TREATMENT FOR LUNG CANCER HAS FALLEN FROM 60.2% TO 57.6%¹⁰



24,000 PEOPLE A YEAR IN ENGLAND RECEIVE A LUNG CANCER DIAGNOSIS AT A LATE STAGE³



ACCESS TO A LUNG CANCER NURSE SPECIALIST VARIED FROM 33.7% TO 100% ACROSS ENGLAND IN 2014¹⁰



FIVE-YEAR SURVIVAL ESTIMATED TO HAVE INCREASED TO 16%⁶



THE PERCENTAGE OF LUNG CANCER PATIENTS RECEIVING ANTICANCER TREATMENT VARIED BY HOSPITAL TRUST FROM 32% TO 83% IN 2014¹⁰



LUNG CANCER IS THE BIGGEST CANCER KILLER IN ENGLAND²⁴

However, despite this, we know that overall outcomes are still poor in comparison to other cancer types, and the UKLCC is concerned that such positive momentum to tackle this may be under threat. For example, in only a year, active treatment for lung cancer has fallen from 60.2% to 57.6% and there is still a high level of variation against the national average (15.4%) for NSCLC surgery¹⁰. Further, whilst reform to the original Cancer Drugs Fund (CDF) model was welcomed, there is uncertainty regarding the effectiveness of the new model proposed and the subsequent impact this will have on patient's access to critical treatment. In addition, the £23 million Radiotherapy Innovation Fund launched in 2013 demonstrated how targeted service upgrades could be undertaken in a short space of time.

As well as this, smoking cessation services, which are essential to prevent cases from occurring in the first place, and to ensure those diagnosed who smoke have the best chance of survival, are under serious threat, with 40% of local authorities in England thought to be cutting their budgets to such services¹².

Below is a series of immediate recommendations for England to improve five-year survival in line with the UKLCC's 25 by 25 ambition. These are informed by the most recent evidence and data as well as on the basis of our survey findings.

These recommendations are actions to maintain momentum around prevention and awareness, and explore additional steps which can be taken to ensure that patients present as early as possible. As well as this, they include utilising existing bodies and initiatives to optimise the diagnosis, referral and treatment pathway, as well as steps to tackle the still unacceptable levels of variation that occur in England, and throughout the UK.



PHASE 1 FUNDAMENTAL STEPS TO MEETING A NEW AMBITION: 2016-2018

RECOMMENDATIONS:

1

A national cancer implementation group was set up in 2016 to oversee the delivery of the five-year cancer strategy published in 2015²⁵. Further to this, they have recently published an implementation plan which tracks progress against the plan to date³⁰.

The Cancer Implementation Group should work with NHS England to ensure that the specific recommendations for lung cancer from the report of the Independent Cancer Taskforce are delivered as a priority within the group's programme – and also ensure that lung cancer is appropriately prioritised in delivering against the wider recommendations.

3

With almost 24,000 people a year in England receiving a lung cancer diagnosis at a late stage, it is essential to focus on efforts which support early presentation³¹. Public Health England ran a new awareness campaign in 2016²⁶ following the success of previous campaigns on the signs and symptoms of lung cancer, which saw an increase in the number of urgent referrals for suspected lung cancer of 30% during that period compared with the previous year³². However, this campaign has so far been focused on respiratory conditions as a whole rather than on lung cancer specifically.

Following the results of the most recent national awareness campaign, Public Health England should commit to introducing dedicated public awareness campaigns for lung cancer annually and set a new target to double the percentage of people diagnosed at stage I of the disease in the next five years.

5

The Department of Health uses the NICE urgent referral guidelines³⁴ as a key resource to refer patients as quickly as possible. However, currently it is difficult to measure whether the guidelines are fully adopted locally and their current effectiveness for lung cancer, and more broadly how referral pathways can best be improved. Alongside this there are, however, existing innovation programmes such as Accelerate, Coordinate, Evaluate (ACE)³⁵, which are exploring innovative approaches to achieving rapid diagnosis, including referral pathways.

The Department of Health should commission an annual national audit, structured on the findings from the ACE programme's assessment of NHS England's referral routes, to assess cancer referral in England for the most common cancer types including lung.



7

The Lung Cancer CRG publishes a multitude of resources which can aid efforts to optimise pathways, however is not formally integrated into NHS England's body of work³⁷. In particular, the group recently published the lung cancer service specification or 'whole cancer pathway' for England³⁸. Having an established pathway was supported in the results of our HCP survey, with 60% believing that a standardised pathway would improve survival rates. The work of the CRG will become increasingly important now that there is no dedicated clinical reference group for thoracic surgery³⁹.

NHS England should consider how to integrate the Lung Cancer CRG within existing frameworks and support the implementation of the CRG whole lung cancer pathway.

9

Tackling variation was identified as one of the key priorities within the report by the Independent Cancer Taskforce. Given the importance of timely, appropriate, treatment as early on in the lung cancer pathway, it is essential that efforts are taken to tackle this barrier. As our survey shows, 84% of secondary/tertiary HCPs believe regional inequalities in health and care have an impact on lung cancer survival rates. For example, in England the percentage of lung cancer patients receiving anticancer treatment varied by hospital trust from 31.6% to 83.2% in 2014¹⁰.

The Department of Health should work with the National Institute for Health Research and the National Lung Cancer Audit to launch a pilot data programme to assess and address local variation for lung cancer treatment.

PREVENTION

AWARENESS

PRESENTATION

REFERRAL

DIAGNOSIS

TREATMENT

2

As identified by the UKLCC survey, smoking cessation services are one of the key ways to improve survival, not only by preventing cases from arising in the first place, but by improving survival outcomes for those newly diagnosed who currently smoke through helping them to quit as soon as possible – however such services are threatened by cuts in local budgets¹².

The Department of Health should work with local authorities to ring-fence budgets for smoking cessation services, to ensure these do not come under threat amidst increasing budget pressures.

4

The Department of Health currently do not commission a national screening programme for lung cancer following the 2006 negative recommendation from the UK National Screening Committee³³. This, however, is due to be reviewed following the results of the NELSON trial. In the meantime, the UK Health Technology Assessment programme funded the UK Lung Cancer Screening Trial (UKLS)¹⁷. This trial screened at risk individuals from trusts participating in the programme, and successfully identified individuals at an early stage of the disease, 80% of whom were eligible for surgical interventions¹⁷.

The UK National Screening Committee should consider evidence from local initiatives already undertaken, such as UKLS and ECLS, amidst its review of the effectiveness of lung cancer screening. Alongside this, the UK Health Technology Assessment programme should continue investment in local lung cancer screening pilots to build an evidence base for a national programme.

6

As in recommendation 5, there are already existing initiatives and bodies which are looking to optimise the referral, diagnostic and treatment pathways. The ACE programme, as well as looking at referral, is examining overall lung cancer diagnostic pathways and plans to support six pilots in England to trial new one-stop diagnostic pathways³⁶.

The Department of Health should utilise the recommendations from the ACE programme to optimise the referral, diagnostic and treatment pathway for lung cancer (as recommended above).

8

Evidence shows that the number of those diagnosed at an early stage is key to improving survival rates. It is also crucial, however, that there is sufficient capacity to deal with increasing demands in order to deliver against this ambition. Cancer services are under significant strain, in particular radiology and medical oncology, with the total number of CT scans, for example, having doubled in the past 10 years^{40,41}.

The Department of Health should work with the National Cancer Institute to offer research funding towards projects aimed at developing cost-benefit assessments of diagnostic tools for lung cancer, ensuring that diagnostic services are optimised and not put under strain. In the immediate term, commissioners should take the necessary steps to ensure there is adequate diagnostic capacity to meet the demand of clinicians and patients.

10

Despite the majority of patients in England being discussed at an MDT level, only 77.5% had access to a lung cancer nurse specialist in 2014, worse still this varies from 33.7% to 100% across the country¹⁰. More needs to be done to enhance MDTs and the core roles within them, which have a significant impact on both a patient's experience of care and their overall outcomes.

The Department of Health should work with commissioners to ensure local MDT structures and processes are in line with those recommended in the Lung Cancer CRG's whole lung cancer pathway, immediately prioritising the elements highlighted in Principle 9 of this report. As well as this it should ensure that all patients have access to a lung cancer clinical nurse involved in all aspects of their care, as recommended in Principle 10.

SCOTLAND: MEETING THE 25 BY 25 AMBITION

In 2014 alone, there were 4,117 deaths caused by lung cancer, representing over a quarter of all cancer related deaths⁷ and resulting in the poorest survival outcomes of any other cancer type in Scotland.

The UKLCC has welcomed steps in Scotland to tackle inequalities, improve prevention, and ultimately improve outcomes for those diagnosed with cancer. Most recently Scotland published a new plan for cancer services, *Beating Cancer: Ambition and Action*⁴², which positively had a strong focus on improving early stage diagnosis and preventing cases from arising in the first place. However, despite being the biggest cancer killer in Scotland, there were no dedicated actions in the plan for lung cancer. Quality Performance Indicators (QPIs) were also published in 2012 to support commitments against specific tumour groups, first seen in *Better Cancer Care: An Action Plan*⁴³, and these are updated annually. Further to this, there are 13 dedicated QPIs for lung cancer, including indicators related to MDT meetings, pathological diagnosis and surgical resection in non-small cell lung cancer.

The Scottish Government has introduced a number of measures on prevention in line with a national ambition to ensure patients present as early as possible in order to have the best chance of survival:

- The Scottish Government has placed a large amount of resource on supporting a reduction in smoking rates, most recently evidenced in the publication of *Creating a tobacco-free generation* in 2013⁴⁴
- The Detect Lung Cancer Early programme was launched in 2013, aiming to improve awareness

of symptoms and therefore encourage early diagnosis. The latest statistics also show that the percentage of lung cancer patients diagnosed at the earliest stage has increased by 24.7% since its launch⁴⁵

- NHS Scotland has supported a screening study, ECLS, which is trialling a new blood test called Early CDT-Lung, to test whether small lung cancers can be detected before they cause any issues amongst those who are at risk¹⁸

With regards to treatment itself:

- The percentage of all patients seen by a lung cancer clinical nurse has increased by 80.9% in 2013⁴⁶ to 84.2% in 2014¹⁰
- The percentage of NSCLC patients receiving surgery has also increased from 15.7% in 2013⁴⁶ to 21.7% in 2014¹⁰ and NSCLC patients at stage I or II having surgery has increased from 45.5%⁴⁶ to 63.1%¹⁰ during the same period



LUNG CANCER HAS THE **POOREST SURVIVAL OUTCOMES** OF ANY OTHER CANCER TYPE IN SCOTLAND⁷



LUNG CANCER REPRESENTS OVER **25% OF ALL CANCER RELATED DEATHS**⁷



THE PERCENTAGE OF ALL PATIENTS SEEN BY A LUNG CANCER CLINICAL NURSE HAS INCREASED BY **80.9% IN 2013 TO 84.2% IN 2014**¹⁰

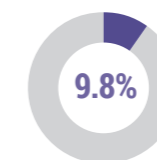


PATIENTS DISCUSSED AT MDT LEVEL DECREASED FROM 97.4% IN 2013⁴⁶ TO **93.6% IN 2014**¹⁰

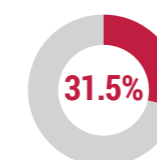


4,117 DEATHS CAUSED BY LUNG CANCER IN 2014⁷

It is clear that positive steps have been taken over the last few years to improve outcomes for patients. However, we know that momentum needs to be maintained in order to deliver substantive improvements against current survival statistics and consistently deliver a high standard of care. For example, the number of patients discussed at MDT level has slightly decreased from 97.4% in 2013⁴⁶ to 93.6% in 2014¹⁰ and long-term survival still falls behind the best performing countries in Europe.



FIVE YEAR SURVIVAL (2007-2011)⁷



ONE YEAR SURVIVAL (2007-2011)⁷

In order to make the next steps to improve five-year survival for lung cancer and meet the UKLCC's *25 by 25 ambition*, a number of recommendations for Scotland have been set out below based on the UKLCC's survey findings and the most recent data and evidence.

Overall, these focus on ensuring that lung cancer is appropriately prioritised in the future and that the Scottish government and relevant organisations continue to undertake efforts to ensure those with lung cancer are treated in a way that ensures their chances of surviving for as long as possible.



PHASE 1 FUNDAMENTAL STEPS TO MEETING A NEW AMBITION: 2016-2018

RECOMMENDATIONS:

1

The Scottish Government published the latest cancer strategy *Beating Cancer: Ambition and Action*⁴² in 2016. However, whilst the UKLCC welcomed the actions and recommendations, we were disappointed that there were no dedicated actions for lung cancer.

The Scottish Cancer Taskforce should publish annual reports to assess progress made in delivering the ambitions set out in *Beating Cancer: Ambition and Action* and set targeted recommendations accordingly.

3

Despite marginally meeting its ambition to increase diagnosis for lung cancer patients at the earliest stage (stage I) by 25% by 2015 when first launched, it is still very positive that *Detect Lung Cancer Early* increased this number to 24.7%⁴⁵.

The Scottish Government should continue to invest in the *Detect Lung Cancer Early* programme and set a new early-stage diagnosis ambition for the next five years.



5

The Scottish Government use the Scottish urgent referral guidelines⁴⁷ to facilitate appropriate referral between primary and secondary care for patients with suspected cancer. However, as with the NICE guidelines, it is difficult to measure whether the guidelines are fully adopted locally and their effectiveness in improving lung cancer care specifically. Existing innovation programmes such as ACE³⁵ aim to explore innovative approaches to achieving rapid diagnosis, including new referral pathways.

The Scottish Government should commission an annual national audit, or work with other UK bodies as part of the National Lung Cancer Audit in order to assess cancer referral in Scotland for the most common cancer types including lung, and provide targeted recommendations on how the pathway can be improved and whether the Scottish urgent referral guidelines need to be updated as a result.

7

Variation in outcomes exists in Scotland as does throughout the UK, with mortality rates varying by up to 20% across the three different regions in Scotland in 2014⁷.

The Scottish Government should work with the National Institute for Health Research to launch a pilot UK data programme to assess and address local variation for lung cancer treatment.

PREVENTION

AWARENESS

PRESENTATION

REFERRAL

DIAGNOSIS

TREATMENT

2

The Scottish Government should continue to promote smoking cessation services, following the publication of *Creating a tobacco-free generation*⁴⁴ and most recently *Beating Cancer: Ambition and Action*⁴², both to prevent future cases, and to improve survival for those who smoke and have recently been diagnosed with lung cancer.

The Scottish Government should commit to providing adequate resources in order to meet its ambition of reducing prevalence of smoking to 5% or less in Scotland by 2034, as set out in *Beating Cancer: Ambition and Action*, and also commit to reviewing progress against meeting this ambition annually.

4

Scotland has made great progress in investing in local programmes to demonstrate the value of lung cancer screening and current initiatives consider the cost-effectiveness of current screening methods versus the possible alternatives.

NHS Scotland should establish local screening initiatives, utilising the £5 million announced in *Beating Cancer: Ambition and Action*⁴² for addressing health inequalities.

6

The national standard from decision to treat until first treatment for all cancers is 31 days⁷. However the UKLCC's survey found that from the lung cancer patients surveyed, 43% waited over one month to initiate treatment after a diagnosis was confirmed. More needs to be done to optimise treatment as well as referral and diagnostic pathways in order to achieve the best outcomes possible for patients. As well as QPIs, there are other existing programmes such as ACE which consider referral and overall lung cancer diagnostic pathways that can be utilised in Scotland.

NHS Scotland should explore the possibility of introducing a pilot ACE programme in Scotland following the initial results in England. The Scottish Cancer Taskforce should also conduct an assessment of the current QPIs for lung cancer and publicly consult on a refreshed set of standards.

8

Whilst positive that the percentage of patients discussed at MDT level has increased from 86.1% to 97%⁴⁸ from 2008 to 2013, this has now decreased to 93.6% in the last year alone¹⁰. As an essential part of high quality care for all patients, the relevant organisations need to work with Trusts to ensure that MDTs are utilised to the greatest degree possible.

Healthcare Improvement Scotland should work with Trusts to ensure at a minimum that 95% of patients are discussed at MDT level in line with the standard outlined in the lung cancer quality performance indicator. The Scottish Cancer Taskforce in their review of the QPI for lung cancer should include the recommendations for MDTs outlined in Principle 9 of this report to optimise survival at the point of treatment.

WALES: MEETING THE 25 BY 25 SURVIVAL AMBITION

Over recent years, significant steps have been taken in Wales to improve outcomes for those diagnosed with lung cancer. With the worst survival outcomes in comparison to any other cancer type, accounting for almost 22% of all cancer deaths in 2013⁴⁹, the Welsh Government have identified lung cancer as one of five national cancer priority areas and in 2014 made the first necessary steps to improve survival outcomes for Wales' biggest cancer killer.

Most significantly, lung cancer was a core focus of the *Together for Health: Cancer Delivery Plan*, and has featured in the last two annual action plans which support its implementation. In the 2014 annual report, it was noted that there was a need to focus on improving outcomes for patients by exploring awareness campaigns and improving access to curative treatments, research and stratified medicine initiatives⁵⁰. In the 2015 annual report, lung cancer similarly remained one of the five national priorities for the cancer implementation group, with the report focusing on increasing access to key workers and introducing a second patient experience survey⁵¹.

The UKLCC has welcomed efforts to deliver against these ambitions to improve long-term survival. These have included focusing on early diagnosis and making positive steps to ensure that patients' quality of care and treatment is optimised and equitable across Wales:

- NHS Wales launched a new public awareness campaign, 'Be Clear on Cancer', to help raise awareness of the signs and symptoms of lung cancer running from July - August 2016⁵². Previous campaigns had only focused on the risk factors of lung cancer, such as *Stop Smoking Wales*⁵³
- The Lung Cancer initiative was launched in South Wales with the aim to increase survival for lung cancer patients, with later ambitions to introduce the initiative across the whole of Wales in 2017⁵⁴

- Welsh Government and Macmillan Cancer Support launched the second cancer patient experience survey in July 2016 to gain insight into people's experiences of cancer care, what is working and what areas need to improve, and to better understand the clinical and non-clinical needs of people with cancer in Wales⁵⁵
- Since 2014, 99.6% of patients have been discussed at MDT level, which is a key way to ensure that patients have the best possible experience and care¹⁰
- Treatment levels have also increased with the number of people with NSCLC stage IIIB/IV and PS 0-1 receiving chemotherapy increasing from 56.4% between 2011 and 2013/46 to 61.1% in 2014¹⁰
- A number of regional cancer diagnostic work programmes have been undertaken across Wales, such as the *Cwm Taf Early Stage Cancer Diagnosis Model*⁵⁶
- The 'One Wales' interim commissioning process was introduced to facilitate equitable access to treatments deemed effective for cohorts of patients which do not have a positive technology appraisal from the National Institute for Health and Care Excellence⁵⁷



**OVER 10% OF LUNG
CANCER PATIENTS
STILL DO NOT
HAVE ACCESS TO
A CLINICAL NURSE
SPECIALIST¹⁰**



**LUNG CANCER
CAUSES 22% OF ALL
CANCER DEATHS IN
WALES⁴⁹**



**WALES RANKED
28TH OUT THE
29 COUNTRIES
ASSESSED IN THE
LAST EUROPEAN
COMPARISON
STUDY⁵⁸**



**ONLY 12% OF
PATIENTS ACROSS
WALES DIAGNOSED
AT STAGE I⁴⁹**

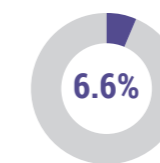


**99.6% OF PATIENTS
HAVE BEEN
DISCUSSED AT MDT
LEVEL¹⁰**

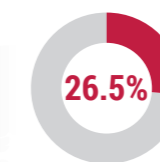


However, despite improvements, gaps still exist, leading to patients not always receiving the best care possible. For example, over 10% of lung cancer patients still do not have access to a clinical nurse specialist (88.0% in 2014) and regional variation is still high¹⁰. Most worryingly, a significant proportion of men and women diagnosed with lung cancer still present at a late stage of the disease (III or IV), with only 12% of patients across Wales diagnosed at stage I, immediately reducing their chances of long-term survival⁴⁹. Compounding this, the number of NSCLC patients receiving chemotherapy ranged from 33.3% to 87.5% across health boards in 2014¹⁰.

Whilst significant improvements have been made, more urgently needs to be done to improve long-term survival with Wales ranked 28th out of the 29 countries assessed in the last European wide comparison study⁵⁸.



**FIVE-YEAR SURVIVAL
(2002-2006)⁵⁹**



**ONE-YEAR SURVIVAL
(2006-2010)⁶⁰**

By utilising both the existing evidence, and the results from our UK-wide survey, the UKLCC have set out specific recommendations across the patient pathway for Wales, tailored from the UK principles, in order to take the necessary next steps to improve long-term survival in Wales.

This includes ensuring that lung cancer remains a focus for the Welsh Government and local health boards in the refresh of the strategic Wales Cancer Delivery Plan 2016 -2020, health board annual reports and intermediate term plans. In particular, relevant health bodies should continue to shine a spotlight on the signs and symptoms of lung cancer, which we know from our survey is essential in order to improve survival rates, and make the necessary additional steps to ensure patients present as early as possible. Crucially, whilst the Welsh Government has already made great steps early on in the patient pathway, it needs to now also increase efforts to ensure that patients are referred, diagnosed and have the best course of treatment initiated as quickly as possible. Alongside such improvements, it remains fundamental to tackle variation across Wales.

PHASE 1 FUNDAMENTAL STEPS TO MEETING A NEW AMBITION: 2016-2018

RECOMMENDATIONS:

1

Lung cancer has been a named priority in the last two annual reports of the *Together for Health: Cancer Delivery Plan*. The current plan runs until 2016, and as such will be refreshed by the Welsh Government's Cancer Implementation Group. Similarly, local health board cancer delivery plans, which were developed as part of the recommendations in *Together for Health*, also run up until 2016, and will be due to be re-assessed and updated.

In order to build on the momentum already made, it is essential that lung cancer remains a priority in the new iteration of the national and local cancer delivery plans. The Welsh Government and local health boards should also commit to publish annual reports and action plans against the new plan/(s) which tracks progress of delivery.

3

Wales currently has national screening programmes for breast, bowel and cervical cancers⁶¹. However, despite causing more deaths than breast and bowel combined⁴⁹, there is no screening initiative available for lung cancer. The Welsh Government will consider the introduction of such a programme following advice from the UK National Screening Committee and the Welsh Screening Committee, both of which are awaiting for evidence from the NELSON trial. The Welsh Government stated that it will consider new evidence as soon as it becomes available⁶². In the meantime, the results from existing local screening trials should be evaluated and new local programmes in the immediate term should be introduced.

Health and Care Research Wales should fund a local screening initiative to build the evidence base for lung cancer screening programmes, utilising evidence from the results of existing local lung cancer screening studies in the UK, such as UKLS and ECLS, when making future recommendations for lung cancer.

5

Wales have National Cancer Standards, including standards for lung cancer, which were originally introduced in 2005 as a means to demonstrate best practice in care and treatment⁶⁴.

The Welsh Government should carry out a public consultation on the current National Cancer Standards for Wales, and commit to updating them based on the recommendations provided.

7

The *Together for Health* annual report for 2015⁵⁰ announced the establishment of a cancer innovation pathway programme, with the first flagship programme dedicated to lung cancer. The programme aims to learn from existing and new improvement projects in order to reduce the inequality of care and outcomes.

The Welsh Government should commit to delivering against the recommendation to introduce a flagship innovation pathway for lung cancer, and publish a timeline of when the results of the pathway will be published.

9

Wales has made substantial steps to ensure that almost all patients are discussed at MDT level (99.6%), however access to specialist nurses still varies from 39.1% to 99% across the country¹⁰.

The Welsh Government should work to ensure there is necessary support at a local level for MDTs, ensuring that their structures are in line with those recommended in Principle 9 of this report. Further to this, it should ensure that all patients have access to a lung cancer clinical nurse involved in all aspects of their care, as recommended in Principle 10.

PREVENTION

AWARENESS

PRESENTATION

REFERRAL

DIAGNOSIS

TREATMENT

2

NHS Wales positively ran a national *Be Clear on Cancer* campaign from July - August 2016⁵², and such efforts need to be continued.

Following the results of the *Be Clear on Cancer* campaign, NHS Wales and Public Health Wales should commit to refreshing this campaign annually at a national level. Local health boards should also outline specific measures to promote this campaign locally or introduce separate initiatives to raise awareness of the signs and symptoms of lung cancer.

4

Both the Welsh Government and the Department of Health promote the use of the NICE urgent referral guidelines⁶³ as a key resource for patients with suspected cases of cancer. However, currently it is difficult to measure whether the guidelines are fully adopted locally and their current effectiveness for lung cancer specifically. Alongside this, there a number of diagnostic pathways across Wales assessing new innovative ways to optimise early diagnosis and referral in response to new evidence from Denmark⁶⁶.

The Welsh Government should assess findings from new cancer diagnostic models being implementing in Wales, such as in Cym Taf, in order to update existing referral guidelines.

6

The UKLCC's survey identified that access to investigative tests and referral are still the greatest delays to rapid diagnosis, with 36% of patients surveyed waiting over one month for a definitive diagnosis after initial suspicion of cancer and 17% waiting over two months. Attempts to rectify delays in diagnosis are underway in Wales through The Outcomes Focused Partner Project which has a specific aim to improve the lung cancer diagnostic pathways⁶⁵.

The Welsh Government should commit to delivering a review of cancer diagnostic services in Wales, as stipulated in the *Together for Health* annual report for 2015, with a focus on lung cancer diagnosis.

8

In Wales, as across the UK, there is still a significant amount of regional variation in access to treatment, which we know impacts overall outcomes. For example, the proportion of NSCLC patients who had surgery across Wales in 2014 varied by over two-fold (8.7-19.6%)¹⁰.

The Welsh Government should work with the National Institute for Health Research and National Lung Cancer Audit to launch a pilot data programme aimed at assessing and addressing local variation for lung cancer treatment.



NORTHERN IRELAND: MEETING THE 25 BY 25 AMBITION

Lung cancer causes more than one in five of all cancer-related deaths, is the biggest cancer killer in Northern Ireland⁶⁶ and presents an average of 1,165 cases a year⁶⁷.

In 2011, there was a renewed focus on cancer services in the publication of the *Service Framework for Cancer Prevention, Treatment and Care*⁶⁶. This set out specific standards of care for different cancer types, including lung, focusing on smoking prevention, appropriate use of CT Scans in suspected cases and radiotherapy. Prevention was also a core focus in *Transforming Your Care*⁶⁸, a review of health and social care services published in 2011, which highlighted that around 340,000 people aged 60 and over smoke, and proposed measures to introduce further controls on tobacco usage⁶⁸. Similarly, in *Making Life Better*, a 10-year public health strategy published in 2014, preventing smoking was a key focus in improving health and wellbeing⁶⁹.

One of the first main assessments of current care was in *Monitoring care of lung cancer patients in Northern Ireland*, published in 2009, which compared the lung cancer care received by patients during 1996 and 2001. The report found positive improvements including patients presenting earlier, use of more complex imaging and increased equality of service access and increased referral rates. However, a significant proportion of patients were still being diagnosed at a late stage, and subsequently survival rates were still poor⁷⁰. As such, the report recommended efforts to promote earlier diagnosis, through better recording of disease stage and increased surgical, radiotherapy or chemotherapy treatment.

Over the last few years the UKLCC has welcomed initial efforts to tackle these identified challenges:

- In 2015, the Public Health Agency (PHA) launched the 'Be Cancer Aware' campaign, created to raise awareness of the signs and symptoms of cancer, with a phase for lung cancer specifically⁷¹
- The publication of the cancer patient experience survey was also welcomed, as it acts as a key way to help improve services and patients' overall experience of care⁷²

Whilst there have been some positive steps identified, gaps in care and services were highlighted in the most recent peer review of lung cancer services, which tracked adherence against Commissioning for Quality and Innovation (CQUIN) measures. Northern Ireland performed well against measures for MDT review and adherence to clinical guidelines and treatment pathways. However, the percentage of lung cancer patients having access to a key worker has decreased from 60% to 40% from 2014 to 2015 and no MDT meeting was recorded as meeting a quorum of 95% or more as recommended⁷³.

In line with priorities to reduce smoking rates, it is encouraging that Northern Ireland has kept this as a focus through promotion of smoking cessation services, and has reported against progress annually. Whilst it was welcomed in the most recent publication by PHA that 21,779 people set a quit date through such services, this in fact represented a decrease of 5,091 (19%) on the same period in 2015⁷⁴.



**ACCESS TO LUNG
CANCER KEY
WORKERS HAS
DROPPED 20%**⁷³



**2,400 AVOIDABLE
DEATHS EACH YEAR
DUE TO SMOKING**⁶⁸



**BIGGEST CANCER
KILLER IN NORTHERN
IRELAND**⁶⁶



**ACCESS TO LUNG
CANCER KEY
WORKER HAS
DECREASED FROM
60% TO 40% FROM
2014 TO 2015**⁷³



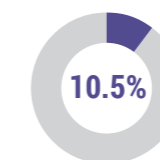
**45% OF LUNG
CANCER CASES
ARE DISCOVERED
WHEN PATIENTS
VISIT ACCIDENT AND
EMERGENCY**⁶⁶



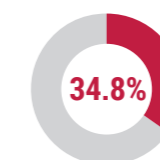
**50.9% OF CASES
DIAGNOSED AT
LATE-STAGE**⁶⁷

Furthermore, and despite efforts to improve diagnosis at an earlier stage, 50.9% of cases from 2010-2014 involved the latest stage of the disease (stage IV)⁶⁷, which results in a far poorer chance of survival than when a diagnosis is made at an earlier stage.

Overall it is difficult to definitively track progress in all areas of care as there has not been a comprehensive assessment of services since 2007, and Northern Ireland has been unable to submit data for the National Lung Cancer Audit. Positively, however, a new audit is underway and is due for publication in 2016.

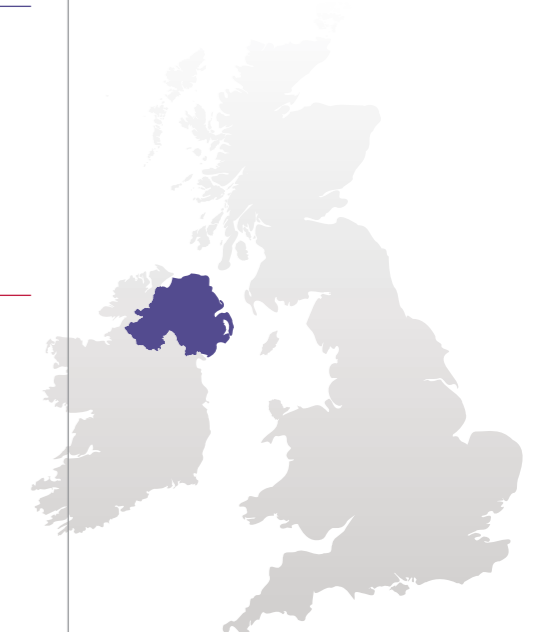


FIVE YEAR SURVIVAL
(2005-2009)⁶⁷



ONE YEAR SURVIVAL
(2010-2013)⁶⁷

Below are the recommendations for Northern Ireland, aimed at combatting poor survival in lung cancer, alongside the UK principles, to meet *The 25 by 25 ambition*. Northern Ireland has identified tackling prevention and encouraging early diagnosis as key priorities. As such, the recommendations below are aimed at building on these initial first steps and setting new ambitions for the future. They are also aimed at creating a renewed focus on giving patients the best chance of survival from the point of seeing their doctor – optimising referral, diagnostic and treatment pathways.



PHASE 1 FUNDAMENTAL STEPS TO MEETING A NEW AMBITION: 2016-2018

RECOMMENDATIONS:

1

Since the publication of the *Service Framework Care Prevention, Treatment and Care and Transforming your Care* in 2011⁶⁶, there has been no formal assessment published of progress against meeting the recommendations set out, despite a review having already been undertaken. Similarly, no progress report for *Monitoring care of lung cancer patients in Northern Ireland* has been published⁷⁰.

The Department of Health should commit to publishing an assessment of the progress made against the recommendations set out in *Service Framework Care Prevention, Treatment and Care and Transforming Your Care* and in line with results from the ongoing audit due for 2016 publication. The Department should then utilise these findings to produce a new framework which is published for public consultation, and sets out specific standards on how to tackle poor survival in lung cancer.

3

The UKLCC welcomed the introduction of the lung cancer *Be Cancer Aware* campaign in 2015. With 45% of lung cancer cases found when a patient attends accident and emergency, where only 13% are deemed fit for surgery⁶⁶, such efforts are crucial in raising awareness of the signs and symptoms of lung cancer and encouraging patients to see their doctor.

The Public Health Agency should commit to annual public awareness campaigns on the signs and symptoms of lung cancer and set a target for doubling the number of patients diagnosed at the earliest stage possible (stage I) in the next five years.

5

The Northern Ireland Cancer Network provide guidance on the red flag criteria in urgent referral guidance for suspected cancer cases, including lung. This is based on the NICE referral guidelines from 2005, which were subsequently updated in 2015⁷⁵.

The Northern Ireland Cancer Network should work with the National Cancer Registry to conduct a national audit to assess cancer referral services in Northern Ireland, providing targeted recommendations on how the pathway can be improved and whether the current guidance needs to be updated based on the most up-to-date iteration of the NICE urgent referral guidance.

7

The collection of data by the Northern Ireland Cancer Registry is fundamental for improving regional variation in care and treatment for those with lung cancer across Northern Ireland.

Local health bodies should work in co-ordination with the Department of Health and Northern Ireland Cancer Registry to develop local targets aimed at raising overall quality of care and reducing regional variation.



PREVENTION

AWARENESS

PRESENTATION

REFERRAL

DIAGNOSIS

TREATMENT

2

Estimates suggest that there are 2,400 avoidable deaths⁶⁸ each year due to smoking, a large proportion of which are due to lung cancer. Whilst it is essential to ensure treating those who already have it, reducing smoking is key to preventing it from arising in the first place.

As part of the Department of Health's annual reporting of smoking quit rates each year, they should include a comprehensive assessment of the current barriers to improving quit smoking services.

4

Although there are currently screening programmes for breast, bowel and cervical cancer, there are no such plans for the introduction of a lung programme or studies to assess the effectiveness of introducing one in the future. Given early diagnosis was identified as a key way to improve survival in the UKLCC survey and over half of HCPs interviewed felt it could significantly improve survival, screening is an initiative which should be given consideration in future decisions on national screening programmes.

The Public Health Agency should work with the HSC Research and Development division of the department to fund a local pilot for lung cancer screening in Northern Ireland. This pilot should consider current evidence on local programmes for lung cancer screening across the UK, including from the Southern Health and Social Care Trust and local trials such as UKLS and ELCS. Following results from the trial, the Public Health Agency should then reassess the effectiveness of introducing a national programme following the decision from the UK National Screening Committee.

6

We know that once a patient presents, it is vital to ensure that they are diagnosed and commence the optimal treatment for them as soon as possible. However, we know from the UKLCC survey that this pathway is not always optimised. Further, the 2015 patient experience showed that whilst it was positive that 65% of lung cancer patients didn't have to see their GP more than twice before being referred to hospital, this is the third lowest percentage of all cancer types assessed, and almost a third worse than breast cancer (94%)⁷².

The Northern Ireland Department of Health should work with the Northern Ireland Cancer Network to set up a working group to develop a standardised lung cancer pathway aimed at optimising diagnostic, referral and treatment pathways.

8

*Transforming Your Care*⁶⁸ noted the importance of an effective MDT, with access to lung cancer clinical nurses also identified by patients in the UKLCC survey as one of the most important factors in ensuring they have a positive experience of care. Currently 69% of lung cancer patients are assigned to a clinical nurse specialist⁷², compared to 94% in breast cancer. In a census of clinical nurse specialists from 2014, the number of CNS posts for lung cancer have stayed the same since 2011⁷⁶. As such, more needs to be done to ensure that lung cancer MDTs are delivering the same quality and experience of care in comparison to the other most common cancer types.

The Department of Health in Northern Ireland should work with local trusts to ensure their MDT structures and processes are in line with current standards, immediately prioritising the elements highlighted in Principle 9 of this report. The Department should ensure that all patients have access to a lung cancer clinical nurse involved in all aspects of their care, as recommended in Principle 10.

CONCLUSION

We can clearly see from this report that across the UK significant steps have already been made to improve long-term survival for lung cancer patients, all contributing to the progress against meeting the UKLCC's founding ambition 10 years ago to double five-year survival rates. However, the lung cancer community has a mandate, founded in the needs of patients, to be more ambitious to pursue the very best chance of patient survival, bridging the survival gap between other cancers, and to meet The 25 by 25 ambition.

The UKLCC survey which aimed to identify what the key factors were in meeting this ambition. There was clear consensus from both primary and secondary care professionals that the most significant factor in improving survival was improving early diagnosis rates and optimising referral and treatment pathways. However, the surveys also identified that there is still a significant gap in patient knowledge of the signs and symptoms, with only 25% of patients going to see their doctor because they recognised their symptoms as those of lung cancer and 51% of GPs identifying that patients not knowing when to see their doctor was the biggest barrier to early diagnosis. As well as this, once patients are identified they still face significant waiting times to be referred and receive treatment, with 43% of patients waiting over one month for initiation of treatment was a diagnosis was confirmed.

Positively it is encouraging that UK governments have clearly identified this as an area in need of improvement, with all nations having invested in public awareness campaigns on the signs and symptoms of lung cancer, either as part of wider respiratory campaign or as a dedicated campaign itself. Parallel with this are a number of initiatives to optimise care pathways and improve survival, such as the ACE programme in England and Wales which looks to optimise and speed up diagnostics to ensure that people are diagnosed as soon as possible.

It is imperative that actions are taken to maintain this positive momentum and address the other key areas of improvement identified within this report, including building local evidence to support a lung cancer screening programme in anticipation of the NELSON trial results and tackling regional inequalities in treatment and care and under prioritisation of MDTs across the UK – which we know from existing evidence, still occurs.

This report is aimed not only to identify the immediate steps which need to be taken now, but to set a vision for the future for lung cancer survival up until 2025.

As an organisation whose members are health care professionals working directly within lung cancer services, as well as wider patient and industry groups, we are all too aware of the competing pressures currently facing health organisations across the UK.

However, it would be wrong to respond to these pressures simply by curtailing our ambition. By setting a long-term vision for lung cancer survival, underpinned by tailored initiatives for each UK nation, this report provides a transformative and attainable plan for lung cancer outcomes so that, year on year, patients diagnosed with lung cancer are living longer.

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